Link

The magazine for people with Spina Bifida and/or Hydrocephalus

ASSOCIATION SPINA BIFIDA AND HYDROCEPHALUS

February/March 1998
Issue No 174 Price 80p

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Headteacher retires

DETERMINATION and a fighting spirit have helped one woman lead the way in overcoming prejudice in all aspects of her life, but particularly in her career.

Looking back over her milestones as a teacher and then head teacher, Faith Seward says by far the biggest battles have been overcoming people's attitudes, rather than any physical barrier.

But the day of her retirement was made extra special by allowing one of her more fantastic ambitions to be realised. Staff at Carr Infants School in York, where Faith had been head for 23 years, arranged for the pupils to present her with a crown so she could become May Queen for her final day in school.

Faith explained: "Every year on May Day we asked the children to vote for a May Queen and every year I told them I'd hoped they'd vote for me as I'd always wanted to be May Queen. It's a joke I have with the children. But on the day of my retirement they crowned me the Queen of Hearts and all the children presented me with gifts they had made."

After doing well academically at school in the 1950s, Faith wanted a career. She wanted to be a doctor, but was told that she would not be physically fit enough. For the same reason, she was also put off from becoming a dentist, speech therapist and hospital social worker.

But she did gain a place at a Church-run teaching college in York. "The Minister of Education questioned whether I was fit enough to be a teacher, but the principal said she would take me anyway and see how I got on – I must have impressed her during the interview."

Faith left with a Certificate in Education and went into secondary school teaching, including five years in Peterborough. "I remember there were lots of challenges especially as, at 4' 10", I was the smallest person in the school."

She returned to York when her father became ill and did supply teaching for a year. Attempts at securing a permanent job, however, proved more difficult. "Prejudice has been my biggest hurdle, not by people who know me, but by having a label hung around my neck by people who don't know me. When I came back from Peterborough and was applying for jobs, I received a letter from one head teacher saying he wouldn't interview me because I was disabled! I was very downcast but I am a very stubborn person."

Faith eventually got a supply job at a primary school in Wetherby. She was taken on permanently when a vacancy arose. During this time she took a year off to complete a Diploma for the Education of Backward Children at Leeds University and later went on to take a BA through the Open University.

She then became deputy head for three years at a primary school in Yorkshire, before applying for the headship at Carr Infants School. She believes she was the first person with spina bifida to be appointed as a head teacher.

During the 1970s, Faith attended several Women of the Year lunches in London and, in 1981, she was awarded the MBE for 'services to the handicapped', based on the work she had done for disabled people in York, mainly in connection with Yorkshire North ASBAH, for which she has been secretary for 30 years.

Contents

ASBAH is a registered charity

E-mail: postmaster@asbah.demon.co.uk Find us on the Web – http://www.asbah.demon.co.uk/

Cover: Faith Seward MBE fought against prejudice throughout her career. She recently retired after 23 years as a headteacher. Story this page. Photo courtesy of: Yorkshire Evening Press.

STAFF NEWS ... STAFF NEWS ... STAFF NEWS ... STAFF

National Centre

● Full-time specialist adviser (education), Peter Walker, retires on 8 April. A feature looking back on his career appears on pages 7-8 of this issue of *Link*. Interviews for a part-time replacement, based in Peterborough, were due to take place in February. Ways of using the remaining hours are being discussed.

South East Region

● Caroline Berkley, specialist adviser (medical) now works part-time instead of full-time. She now works on Mondays and Tuesdays, and Wednesday mornings.

Gillian Yaz has been appointed as specialist adviser (medical) for the latter part of the week, starting on 19 January.

Both Caroline and Gillian are based at South East Regional Office. Gillian continues her ASBAH adviser role for North East London on Mondays, Tuesdays and Wednesday mornings, working from home.

North Region & North West

● Geraldine Binstead has decided to give up her post as specialist adviser (medical) for the north of England but continues her role as part-time ASBAH adviser for North Yorkshire & York, Hartlepool, Redcar & Cleveland, Middlesbrough and Stockton-on-Tees.

Interviews to find a replacement specialist adviser (medical) for ASBAH North were due to take place in February.

● MARGARET Steenson is the new secretary at Northern Ireland Region office in Belfast.

The former appeals administrator of more than 11 years at NICOD – a charity concerned with orthopaedic development – wanted to work for ASBAH as she likes helping others, and was looking for full-time employment and a new challenge.

NICOD provides training centres and accommodation for people with a wide range of disabiities, including spina bifida and / or hydrocephalus.

Margaret met her husband at NICOD and the couple have been married for 10 years. William now works as a care assistant at a nursing home for elderly people with Alzeimers Disease. He still likes to fund-raise for charity, however, and will be running the Los Angeles Marathon for NICOD this year.

In her spare time, Margaret enjoys reading, knitting, the cinema, the theatre and eating out.

The East Belfast resident is a volunteer at her local church and the Girls Brigade and helps out some evenings and weekends at the nursing home where her husband works. She also assists with the care of her husband's sister who has learning disabilities.

See pages 7 & 8 for a report looking back at Peter Walker's career

● FOUNDER *Your Voice In ASBAH* member, Jon Burke has taken up the new role of co-ordinator of ASBAH's user-group forum.

Jon is based at our Northern Region Office for the part-time job, which has been funded by the National Lottery Charities Board. He will be spending a large amount of time travelling round the country, developing local and regional *YVIA* groups, in conjunction with local associations and ASBAH advisers.

"There seem to be generally three main reasons why people with spina bifida and / or hydrocephalus get involved with *YVIA*. Many people have not had much awareness of others with spina bifida in their area and they are eager to make new contacts," he says.

"We also find that there are a lot of shared interests between members. This could be an issue related to ASBAH or something more relevant to the wider disability scene. There is also a growing interest in the training that *YVIA* will be offering."

Jon was founder chair of the Electronic Village Hall in Dewsbury, an Information Technology training organisation for disabled people.

In addition to working 20 hours a week for ASBAH he works part-time for Voluntary Action-Leeds, supporting disability organisations in community care planning and consultation initiatives. He is also doing a part-time degree in politics and history at Huddersfield University.

For more information on his role in ASBAH, or for help in establishing a user-group in your area, contact Jon at the Northern Region Office on 0113-2556767.

Battle against neurosurgery closure

PLANS to close a children's neurosurgical service in south west London have led to a group of parents rallying round their consultants who are trying to get the decision reversed.

Children will no longer be treated at the specialist neurosurgical Atkinson Morley's Hospital from 1 April, if managers who run the NHS South Thames Region get their way.

The closure, revealed just before Christmas by consultants at Atkinson Morley's in Wimbledon has been condemned by Mrs Gill Farrington, whose 15-year-old daughter Kirsty is a patient there for her hydrocephalus.

Mrs Farrington said: "It will mean that, instead of being able to travel quickly to Atkinson Morley's from home, we shall have to travel a long way, fighting through London traffic, to get to King's College Hospital in Camberwell.

"We all know what that means if there are problems with shunts. The shunt needs to be assessed very quickly, and any delays could be dangerous."

Mrs Farrington, who lives in Epsom, has joined the hastily-formed Atkinson Morley's Hospital Action Group, which has launched a petition against the closure and organised a demonstration outside Atkinson Morley's on 27 January.

The consultants, led by neurosurgeon Henry Marsh, say that – if the closure goes ahead – the whole of Greater London and South East England, with a population of over 12 million, will be left with only two paediatric neurosurgical units

In a statement, they said: "Nowhere else in the United Kingdom would there be such a restricted level of provision of acute neurosurgical services to such a large population. In the UK, such an arrangement would be an unprecedented experiment."

The consultants claim the decision was taken after NHS managers called in five paediatric neuroscience specialists from outside London to give professional advice. The basis for closing the Atkinson Morley's service was that it was 'clinically unsatisfactory'.

The consultants said the decision was based on the suggestion that paediatricians were not on site at Atkinson Morley's – yet the arrangement by which they travelled from St George's Hospital was entirely workable, and paediatricians throughout the region supported the service. They added that the decision leaves in doubt the future of adult services at Atkinson Morley's.

Senior staff from ASBAH met Mr Marsh at Atkinson Morley's on 3 February to discuss the closure.

- *Parents wishing to keep in touch with the situation are invited to phone Mrs Farrington on 0181-393 6013.*

Lift on audio cassette tape

ASBAH's *Lift* magazine, which goes out free four times a year to people with SBAH, will be available as a cassette tape from the next issue (February). This is a trial to test demand and is being done with the help of Alan Twyford, chair of YVIA, and his wife Margaret.

People who prefer this format to the printed page should contact ASBAH Publicity as soon as possible. ***Write to: 42 Park Road, Peterborough, PE1 2UQ, or tel: 01733-555988.***

Officers & Staff

Concern over government plans to reduce the number of statemented children

ASBAH has joined a chorus of concern that the government's Green Paper on the future of special educational needs provision in England could result in loss of legal protection for children who most need it.

In a submission sent to the Department for Education in January, ASBAH argues that the main touchstone as to whether a child should have a statement is whether the necessary resources will be deployed without one.

Proposals outlined in the Green Paper *Excellence for all children: meeting special educational needs* to reduce from almost 3% to 2% the number of children who are statemented might result in upwards of 80,000 pupils losing their legal rights to provision which meets their needs.

National, as opposed to local, criteria should be set to ensure consistency of treatment in the statementing process in order to scotch a prevailing belief that support depends on where families live.

"It should be recognised that the 2% of children who may need statements was a notional figure in the Warnock Report, and statements must always be the result of an identified specific need, rather than to meet a statistical requirement.

"Legal rights to provision must be safeguarded at all stages."

Executive director Andrew Russell told *Link* that it would be a nonsense to imagine that children with the severest educational needs would not require the legal protection of a statement, even if they found themselves in the most superbly run schools.

In our submission, ASBAH urged government to ensure that the new Teacher Training Agency established competencies in teaching children with special needs, including physical disabilities. The qualifications of SEN co-ordinators in mainstream schools should also be beefed up.

It was essential to ensure that children are not "abandoned to schools" which have insufficient information and ineffective training in the strategies required to overcome the specific learning difficulties posed by hydrocephalus and spina bifida.

Clear policies should be identified by schools on working with children with emotional and behavioural difficulties, a trend which is becoming increasingly apparent among secondary school children with hydrocephalus. Those policies should aim to keep children at school and be adequately funded.

ASBAH does not go overboard on seeking mainstream education for all. It says the interests of the child must remain paramount, and recognises that not all mainstream schools will be suitable for all children with disabilities and special educational needs.

● The Green Paper proposals for reducing the number of statements issued was marked $^0/_{10}$ by the Independent Panel for Special Education Advice, who commented that what the Green Paper identifies as "bureaucratic procedures" are in reality guarantees in law that children will have their needs met.

RADAR said: "Reducing the number of statements will make it harder for many disabled children to gain access to mainstream schools, which can be reluctant to take children with special educational needs because of fears about the cost."

Launching the Green Paper, Secretary of State David Blunkett said: "Schools identify almost one child in five as having some sort of special educational need. That is why provision for children with special educational needs has to be part and parcel of our whole approach to raising standards for all children."

Children who are in special schools should not necessarily remain there throughout their education, he added.

● ***Trying to get on in Further Education! – story on page 10.***

GLYN Haywood and Geoff Walker raised £200 for Sheffield ASBAH by completing the Great Northern Half Marathon – from Newcastle to South Shields. They are pictured with Glyn's 14-year-old daughter Hannah, of Bramley, Rotherham, who is a member of Sheffield ASBAH.

Peter Walker retires

PETER Walker, our national education adviser, is to retire in April after seven and a half years with ASBAH.

He is coming to the end of a distinguished and colourful career, which has included a spell as a missionary in the Belgian Congo (from which he and his family had to flee for their lives during the 1960 civil war which followed independence) and the headship of three schools.

His motto in sorting out differences between parents and local education authorities has always been co-operation not confrontation. And it has helped him find the right school and adequate resources for hundreds of children.

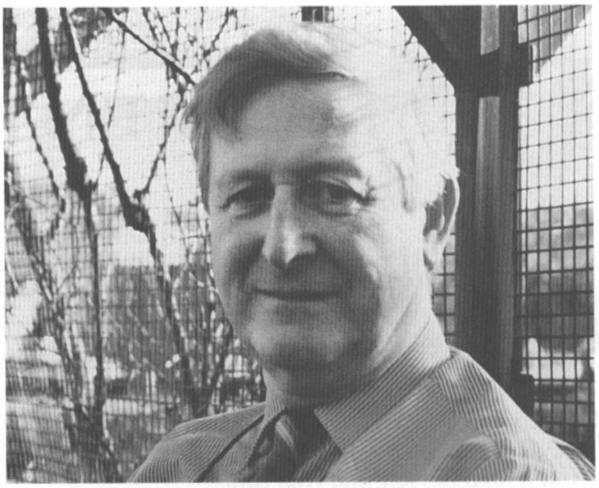
In his retirement, Peter plans to spend more time with his family and to work more as a lay member of the Special Educational Needs Tribunal.

He will be missed by parents, youngsters and staff alike when he retires on 8 April.

Before joining ASBAH, Peter spent 30 years in teaching. After two years at a London theological college, he travelled to Brussels where he studied and gained the equivalent of a Belgian Teaching Certificate.

He then spent several years in the Belgian Congo as a missionary. But, in 1960, civil war broke out, just after the African country gained independence, and he and his young family were forced to flee for their lives.

"We arrived back in England with three children absolutely penniless with only the clothes we were wearing," Peter recalls. "We were homeless and had to rely on friends for accommodation."



Peter Walker, ASBAH's specialist adviser (education), retires in April

With the help of a loan from the local church and friends they put a deposit on a small terraced house and Peter got a teaching post and worked after school, giving home tuition for children with learning difficulties.

continued at bottom of page 8

Help & Advice

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

London, Surrey, Kent, West and East Sussex

ASBAH South East, 209 Crescent Road, New Barnet, Herts EN4 8SB. Tel: (0181) 449 0475. Fax: (0181) 440 6168. Regional Co-ordinator: Jo Francis.

Lincolnshire, Cambridgeshire, Leicestershire, Nottinghamshire, Northamptonshire, Norfolk, Suffolk, Essex, Hertfordshire, Bedfordshire

ASBAH East, ASBAH House, 42 Park Road, Peterborough PE1 2UQ. Tel: (01733) 555988. Regional Co-ordinator: Mary Malcolm.

Northern Ireland

ASBAH Northern Ireland, Graham House, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH. Tel: (01232) 798878. Fax: (01232) 797071. Regional Co-ordinator: Margaret Young.

Northumberland, Durham, Cleveland, North Yorkshire, South Yorkshire, West Yorkshire, Tyne & Wear, Humberside

ASBAH North, ASBAH House North, 64 Bagley Lane, Farsley LS28 5LY. Tel: (0113) 255 6767. Fax: (0113) 236 3747. Regional Co-ordinator: Joan Pheasant NNC.

Rest of England and Wales

ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ. Tel: (01733) 555988. Fax: (01733) 555985.

ASBAH welcomes and appreciates the support of its commercial partners.

***Larkhall Natural Health** gives us 10p from the sale of each container of Cantassium Folic Acid tablets. These can be obtained in chemists and health food shops.*

***AlphaMed Ltd** makes a donation for every prescription order received, as a result of ASBAH's introduction, for continence and medical equipment supplies. Tel services floor, 01733-555988, for introductory Freepost envelope. Prescriptions for drugs or medicines should not be sent to AlphaMed.*

Assessment granted to 14-year-old with Benign Intracranial Hypertension

PARENTS WIN TRIBUNAL

Lee Halcox

PARENTS of 14-year-old Lee Halcox convinced a Special Educational Needs Tribunal that their son urgently required a statutory assessment – overturning a decision by the local education authority (LEA) that he did not need one.

Del and Janice Halcox appealed to the tribunal because they believed Lee had not had the opportunity of showing his potential due to frequent absence from school.

Lee has Benign Intracranial Hypertension (BIH), now called Idiopathic Intracranial Hypertension, resulting in frequent hospital visits, persistent headaches and generally feeling unwell. His condition is controlled by the use of a shunt and painkillers.

His parents felt there were significant gaps in his education because he did not have an individual education plan. Although Lee scored an overall 122 in an IQ test, his maths result fell far short of an average 14-year-old.

Essex LEA told the tribunal that it believed that such a plan was unnecessary because Lee's needs were a result of his medical condition, not learning difficulties. The LEA maintained that an individual timetable, reviewed and monitored half-termly, was adequate to address his educational needs.

Since Lee was diagnosed as having BIH in 1994, he has not attended school on a regular basis. He now attends a home tuition centre fairly regularly for nine hours per week and was, at the time of the tribunal, receiving no tuition at home.

Mrs Halcox, from Pitsea in Essex, said: "We applied for a statement of Lee's special educational needs but were refused on two occasions, so we decided to go to the tribunal.

"We argued that Lee's medical difficulties continue to impede his access to the curriculum, and that he is unable to take part in particular classroom activities and participate in aspects of school life, despite intensive interventions and support programmes being implemented.

"We also told the tribunal that there is clear evidence that Lee is experiencing serious and long-term emotional and behavioural difficulties directly associated with his medical condition."

In making their case, they received evidence on Lee's medical condition from Dr Robert Surtees, senior lecturer in Paediatric Neurology, at Great Ormond Street Hospital, and Dr Sharief, consultant neonatal and respiratory paediatrician, at Basildon Hospital.

These two doctors' opinions differed from Essex LEA's educational psychologist – only brought in after the parents announced they were going to appeal against the LEA's decision – who said Lee's headaches were 'stress-related.'

A letter from Fiona Rowe, an expert in BIH who wrote an article on the rare condition for the Winter '96/'97 *Hydrocephalus Network News*, was also used as evidence in support of Lee Halcox.

Support and encouragement was also given by Peter Walker, ASBAH's specialist adviser (education), who prepared all the paperwork for the case, and Essex ASBAH adviser, Diane Smith, who represented them at the tribunal.

The tribunal ruled that a statutory assessment was necessary to fully investigate and identify Lee's needs. It said: "We conclude that a full statutory assessment is the only way forward for Lee. We add that this is long overdue and should be expedited without further delay as Lee is already at Year 10 and his immediate future education is crucial."

Peter Walker retires

from page 7

In 1965, he was appointed deputy head of a school in Lincolnshire and after one term he became the head.

In 1972, he took time out to study at Nottingham University.

He was then appointed head of a school in Coventry and whilst there was elected chairman of the Coventry North Eastern Community Education Project and became engaged in parental involvement within schools.

"I have always been interested in parental involvement in school as it is the parents who know most about their children," he said. "I feel there should be good liaison between teachers and parents."

He then became head of a school in Sheffield which was one of six schools in the city to be remodelled and created into a 'Resource School', allowing 20 children with physical disabilities and medical conditions to be integrated into each school.

Whilst there he was funded by the then Department of Education Science to engage in research at Sheffield University on parental involvement in schools.

In 1984, Peter was elected Fellow of the College of Preceptors for his outstanding contribution to education.

146 years of voluntary service to ASBAH

Photo by courtesty of The News, Portsmouth

HERE are 12 out of the 14 ladies who, between them, notched up 146 years of voluntary service at ASBAH's chain of charity shops on the Solent. Thanking them for their loyal service, ASBAH executive director Andrew Russell presented them with long-service certificates, and this was followed by a buffet lunch at the Racecourse Snooker Club, Paulsgrave, Portsmouth. ASBAH's national shops co-ordinator, Margaret Gillmore, said: "It has been a joy to work with such a happy, dedicated group of helpers. ASBAH appreciates all the hard work and time given voluntarily by all the ladies and gentlemen that run the shops."

From left to right, starting at the back are: Gloria Hudson, Elizabeth Bates, Vera Lewis, Olga Softly, Ann Reynolds, Audrey Pullen, Silla Lewis, Lorna Link, Betty Nunn. Front row, from left to right: Elsie Downham, Margaret Reay and Betty Thompson. The two long-servers not pictured are Margaret Hatch & Doreen Adams.

Anal plug now available on prescription

A NEW anal plug, which was highlighted in the Aug/Sept *Link*, will soon be available on prescription thanks to lobbying by ASBAH. Many people on benefits will qualify for free prescriptions.

The Conveen Anal Plug – which can help all types of faecal incontinence – was developed by Coloplast. ASBAH was involved in one of three trials, and persuaded 50 young people with spina bifida to try out the product.

Julie Llewelyn, a nurse who specialises in continence management for ASBAH, commented: "Compliance varied considerably but for those who used it successfully their lives were changed.

"They have no more fears of soiling during the school day and they are able to swim, confident in the knowledge that no unfortunate accidents will occur. They can also go on long journeys without worrying about embarrassing leaks."

At £2.20 each, however, the plugs are quite expensive. So ASBAH asked successful triallists to write to the Drug Tariff Section of the Department of Health to request that the plug be made available on prescription.

Mrs Llewelyn added: "I was thrilled when I then heard from Coloplast that it would be available on prescription from 1 March 1998 due to them receiving so many letters from ASBAH service-users."

Although it looks small when unwrapped, the plug expands into a mushroom-like shape to prevent leakage. Coloplast says it is comfortable to wear and easy to remove and can be worn anywhere for up to 12 hours.

The anal plug is available in two sizes and it is recommended that you try both to find the size that works best for you.

For more information contact Julie Llewelyn on 01733-555988, or for a trial pack, contact Coloplast on freephone 0800-220622.

If you're a student, what do you think of further education?

WE WOULD like to hear from students with learning difficulties and physical disabilities in further education (or their parents or guardians) who feel they are being let down by the system.

The Tomlinson committee of inquiry, which reported last year after three years work, found clear evidence that several disadvantaged groups were being excluded from further education – particularly adults with mental health difficulties, young people with emotional and behavioural difficulties and people of all ages with profound and multiple disabilities.

ASBAH suspects that little has happened since then to change people's perceptions and that opportunities to participate fully, with all necessary back-up, remain few and far between.

We want to take up grievances in order to try and help students who feel they are being excluded from further education – through discrimination in the selection process, perhaps, or failure to provide effective support on campus. This could be at a specialist college, in a mainstream FE college or at a sixth form college.

We would like to hear from you if you have tried to use your college's complaints procedure in order to rectify a grievance. Were you successful? Did the college take you seriously? Did you get a satisfactory or an unsatisfactory result?

The Further Education Funding Council, which set up the Tomlinson inquiry, promised to ask mainstream FE colleges whether they could provide the support required to match the needs of individual students with learning difficulties before agreeing to fund a specialist placement. Is that procedure working now?

The Tomlinson Report recognised that there should be lifelong access – for all – to further education so that everyone can seek to increase their learning experiences, boost their skills levels, and obtain additional qualifications.

Access to a rich and varied further education experience remains particularly important for many students with special educational needs if they are to live fulfilled and dignified lives.

Please help put ASBAH more clearly in the picture by letting us know what is happening to you, or your sons or daughters, in further education.

Letters, phone calls or faxes to: Services Department, ASBAH, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, fax 01733-555985. We shall get back to you as quickly as possible. Is FE a rich and varied experience for you?

On their bikes for ASBAH

SEVEN employees and their boss got on their bikes and cycled 73 miles in a day to raise money for ASBAH.

Most of the group had spent only a little time in the saddle prior to the event but all managed to complete the distance within nine hours.

The Keighley to Darlington ride raised a magnificent £630 for ASBAH as all those participating collected sponsorship from family, friends and company directors.

The cyclists, all employed by Darlington-based kitchen manufacturer Magnet, were: Nigel Meier, Bob Nash, Paul Harrison, Kevin Harrison (manager), Gavin Elliott, Richard Walls, Paul Sheen and Lee Fawcett.

It was Mr Elliott who kindly suggested that ASBAH should benefit as his son has spina bifida.

WANTED: men who catheterise

MEN who are carrying out intermittent catheterisation are being recruited for a research project which starts this spring. The project involves an evaluation of all the currently available hydrophilic coated catheters – in all about six types.

Hydrophilic coated catheters are very similar to standard plastic catheters, but they have a special coating which becomes very slippery when moistened with water. This may make catheterising easier by reducing friction.

The project will be carried out by the Continence Products Evaluation Network and is funded by the Medical Devices Agency of the Department of Health.

Volunteers do need not be using hydrophilic coated catheters, but they do need to be carrying out intermittent catheterisation.

Those taking part will receive the products to be tested, easy-to-follow guidelines and questionnaires, a book token as a 'thank-you' and a copy of the evaluation report.

Continence Products Evaluation Network, 5th Floor, South Wing, St Pancras Hospital, London NW1 OPE, tel: 0171-530 3487, fax 0171-530 3980. E-mail: office@cpe.ucl.ac.uk

See page 12 for Paul Darke's views on ASBAH's involvement with *EastEnders*

Trafalgar Square – use of Square transformed. Architects: Foster and Partners. Project: World Squares for All

World Squares for all?

A PLAN to transform a historic part of central London, making it more pedestrian-friendly, has come under fire from ASBAH's mobility adviser Tim Leech.

Tim wrote to City of Westminster Council, saying he believed the needs of people with disabilities have been misjudged in *World Squares for All* – a project aiming to reduce traffic and make public access easier to world-famous sights in and around Trafalgar Square, Parliament Square, Whitehall and from St James's Park to the River Thames.

Tim goes further by saying the plans could deny disabled people access to the statue of what could be regarded as their icon – Lord Nelson – who, he says, is one of the few heroes in history not primarily remembered for his disability.

"I vehemently question whether these plans, which have been drawn up by professional consultants with the backing of central government and the Heritage Lottery Fund, are workable.

"I don't think they have considered parking. They say it will be accessible for disabled people because there will be wider pavements and less traffic, but those people who depend on the car and cannot walk very far will be cut off from their cultural heritage because they cannot park close by.

"I would have liked to have seen improved accessibility to the Underground and more consideration for accessible buses."

Tim added: "The plans may mean less hassle for wheelchair-users, but anyone who can only walk 400 yards and who doesn't have an Orange Badge will have real difficulty enjoying the sights.

"I don't see that giving priority to buses solves the problem because travelling by bus may involve long journeys, which would be inconvenient for people with many types of disability.

"Families with young children with disruptive behavioural patterns may also find travelling on public transport difficult."

Kevin Gleeson, senior planning officer at City of Westminster Council, said there was still a considerable way to go before *World Squares for All* was finalised. "We've just been through the public consultation exercise, presenting two strategies for improvements throughout the whole area. The brief for the project is quite wide-ranging but one of the study objectives is to improve access to people with disabilities and we don't feel we've neglected that objective."

Mr Gleeson said improvements to the area included raised road surfaces to slow down traffic; tactile paving; potential for additional seating and refreshments; more pedestrian crossings and wider pavements.

In answer to Tim's main criticisms, Mr Gleeson said: "London Underground is trying to address accessibility to its stations, and Westminster Station will include lifts as part of the Jubilee Line extension works, but all this takes quite a long time.

"We are giving more priority to buses than private vehicles but there are only three areas which would be closed to all traffic – Horseguards Road, the north side of Trafalgar Square and the south side of Parliament Square. Vehicles will be allowed everywhere else, although in some situations it will be buses only."

He added that the area could not be changed overnight and a lot more refinement and detail needed to be worked out.

The master-plan study was commissioned by organisations including the Government Office for London (GOL), the Department for Culture, Media and Sport, Westminster City Council, English Heritage and London Transport.

The project team consulted 160 groups and mounted two public exhibitions in November. A summary of public comments was presented to the City of Westminster's environment and planning committee in January. The views of this committee go to central government, which will decide on the way forward.

Bridge bloomer

A STEEPLY stepped footbridge has been given the go-ahead as part of a National Trail even though it was opposed by disability groups, including ASBAH.

Tim Leech, ASBAH's mobility adviser, told the Countryside Commission – which is funding the bridge – that the design went against the spirit and the letter of the Disability Discrimination Act.

Bloomers Hole Bridge, near Buscot in Oxfordshire, will form part of the Thames Path National Trail.

The Countryside Commission rejected a ramped bridge design on the grounds that the ramps would intrude too far into environmentally-sensitive water meadows.

Tim wrote to the Countryside Commission, saying: "The bridge being stepped, not ramped, will deny access to disabled people, whether their modes of transport be wheelchair, scooter or trike etc. Even where a mode of transport is not needed, steps can be classed as obstacles to people with hydrocephalus."

Peter Brown, group engineer, bridges, at Oxfordshire County Council, which gave planning permission for the bridge in January, said: "We received a number of comments from disabled people saying the bridge was inaccessible, which we appreciate. But the general feeling of local people was that they wanted to retain the water meadows. They weren't happy with the idea of a bridge at all, but would accept a small one without ramps."

Hugh Crawley, of the Ramblers' Association's Oxfordshire Group, said: "We believe the countryside should be accessible to all, but, in this case, we were in the very painful position of being in opposition to disability groups.

"Our feeling was it is better to have this bridge put in, which could be modified in the future, than no bridge at all. I'd imagine the whole of this section of the trail is inaccessible to all but the most determined wheelchair-user as it's across bumpy meadow, so I feel it would be better to look at this section of the trail to make it feasible for the majority of disabled people and then change the bridge."

30th anniversary

LEICESTERSHIRE ASBAH celebrated its 30th anniversary at Leicester City Football Club in November, *writes LASBAH committee member Carole Armour*.

Seventy members, their families and friends enjoyed a buffet meal and entertainment. The evening offered an opportunity to renew some old friendships, with some exiles returning especially for the evening.

The anniversary cake, donated by a local company, was cut by the chairperson, Mrs Barbara Harding. A draw was also held, raising funds for LASBAH.

AWEAR, which is working to ensure that a national network of clothing services is set up to help disabled people find solutions to their clothing problems, has a new address and a new director. Sid Jurka has taken over from Lyn Purcell and is based at:

Nottinghamshire International Clothing Centre, Knightsbridge Way, Annesley Road, Hucknall, Nottingham NG15 8AY.

Tel/fax: 0115-953 04439.

New job for Link writer Paul Darke

PAUL Darke has been appointed co-ordinator of the West Midlands Disability Arts Forum to foster and promote disability arts within the region of Shropshire, Staffordshire, Herefordshire, Worcestershire, Warwickshire and the West Midlands.

"We welcome contact with all potential and striving-to-be disability artists," he says.

Disability art, Paul explained, is any kind of art form – from written to visual and multi-media – which depicts the experience of a disabled person in society.

"My job is to organise exhibitions, promote individuals, give advice and support for individuals and groups, and find sources of funding," he says.

"Most Arts Councils have a Disability Arts Forum but if yours doesn't, let me know and we can help set one up in your area."

If you'd like to discuss any aspect of his job, contact: Paul Darke, Co-ordinator, West Midlands Disability Arts Forum, The Custard Factory, Unit 334, Gibb Street, Digbeth, Birmingham B9 4AA. Tel: 0121-242 2248.

Paul's job has been funded by the National Lottery Charities Board and West Midlands Art.

- *THE WINNER of the film competition in the Oct/Nov* Link *was Sandra Vaughan, of Turfhill, Rochdale, Lancs. She answered correctly questions set by Paul Darke, winning a signed copy of* Framed: Interrogating Disability in the Media, *which Paul reviewed in the same issue. The correct answers are: 1. Daniel Day-Lewis won an Oscar for playing the cerebral palsied Christy Brown in* My Left Foot; *2. Dustin Hoffman won an Oscar for playing a man with autism in* Rain Man; *3. Tom Hanks won an Oscar for playing the man with a learning disability in* Forrest Gump.

CONTINENCE CAMPAIGN

Reports come in from ASBAH'S front line

DETAILS are emerging of how service-users are challenging cuts in their continence supplies by NHS trusts in financial straits. But, with no national standards imposed on local NHS health trusts, the challenges are throwing up an often bewildering range of responses.

A swift challenge to a trust on the south coast, which has told inquirers that it cannot start issuing supplies to new patients until April, produced the desired response – supply of continence pads to a little girl with spina bifida and hydrocephalus, who had her third birthday last September.

But, further west, another family are having to endure acrimonious letters from their trust after complaining to the chief executive over the head of their health visitor about the supply of pads to their teenage son.

In the first case, the parents were told that their three-year-old daughter would not be considered for free supply of continence pads until April this year – because shortage of money had forced the introduction of a waiting list. There were 80 people on the waiting list.

The family, with a professional background, have never been content to let other professionals make all the decisions about their child's health care.

"We had problems early on with our daughter's bowel management. Our last trust told us that, because incontinence in a baby was a social problem faced by all families, we should come back when she was four or five," said the mother.

"They did not accept we had a problem and that we should be referred to a consultant. It was ridiculous: my daughter had constipation and they would not refer even to a dietitician."

When the mother heard the latest worrying news about the waiting list, she asked her health visitor how her three-year-old could get on the list. With neuropathic bladders and bowels, problems hardly ever go away as a result of potty training.

The health visitor filled out a "totally inadequate" form for her daughter, which did not address the family's basic concerns. The mother then contacted the manager of the service and obtained what was needed for her daughter.

"It is helpful if you are assertive and appear to know what you are talking about. We have told we have been awarded the maximum number available but that, if we want something better like Huggie's pull-ups, we shall have to pay the difference."

In the second case, the family was told that they would be wasting taxpayers' money if they persisted to ask their NHS trust for pads for their teenage son and did not settle him down instead to a routine of intermittent catherisation. They were also told that their son would be visited every six months by two members of staff to reassess his needs, which they argue will basically never change.

"The situation started getting unpleasant when we exercised our rights under the patients' charter and complained to the chief executive over the health visitor's head. But the fact that our phone calls were not getting answered really gave us no choice," said the mother.

She said the trust did not seem to distinguish in their assessments between the needs of sedentary 90-year-olds and those of teenagers, with busy social lives and high expectations.

The family, who say catheterisation is not the answer to their sons's needs, say they have now been assured that an adequate number of quality continence pads will be provided for their son, providing they collect them from their local health centre.

Help highlight the accessible toilets

PEOPLE willing to write down the location of every accessible loo they know are needed by the compiler of a new comprehensive atlas guide of accessible toilets.

The editor of *Is There An Accessible Loo?* wants to hear from any individuals or groups able to help with the project during 1998 – the year in which information on accessible toilets will be collected and checked.

The atlas guide for wheelchair users, to be published in 2000, will include accessible loos throughout England – including motorway service stations, garages along trunk and minor roads, in towns, cities, pubs, eating places, places of worship, national parks, gardens, tourist attractions, travel centres and out of town shopping centres.

If you are interested in helping collect and check information in the guide, please write to: Diana Twitchin, 10 Stilecroft Gardens, North Wembley HA0 3HE. Tel: 0181-904 8321. Fax: 0181-9048321. E-mail: AccLooProj@aol.com

Should ASBAH have co-operat

NO says *Link* columnist Paul Darke

I WAS rung up by a few friends with spina bifida and hydrocephalus when the *EastEnders* story was running who were amazed at the line the narrative was taking.

At first, I even thought that Bianca and Ricky would not have an abortion and that they would change their minds at the last moment – I wasn't worried. I should have been: they had an abortion.

I forgot for a moment the programme's role in reinforcing social norms, however dubious they may be. The position of the soap opera series in British culture is more significant than any other broadcast programmes; equally, it is a significantly large piece in the jigsaw that is cultural social engineering (getting 'the people' to do 'the right thing').

As such, *EastEnders* got it right; society in its practices (legal, medical, cultural, political, religious, charitable and moral) wishes, and actively seeks, to eradicate certain types of people from it: that is, the congenitally disabled be they people with spina bifida, hydrocephalus, Downs Syndrome, et al, through abortion, screening and euthanasia. We are only a few years from such norms being applied to those with acquired disabilities via widespread legalised euthanasia (the elderly, the severely impaired through accidents, etc).

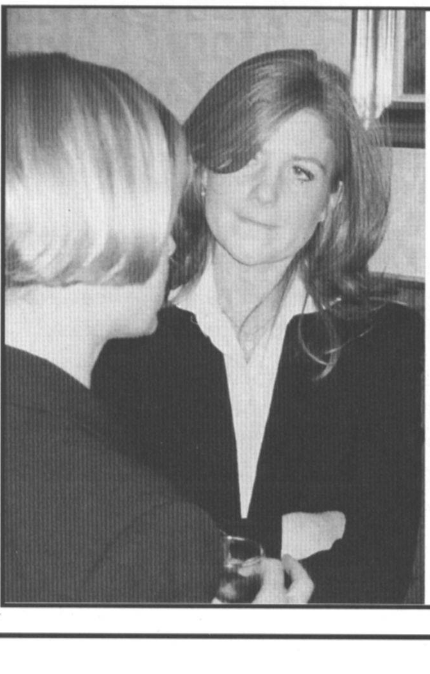
In cultural forms such as *EastEnders* it is not a simple question of it being negative or positive, it is a question of a key form of social engineering confirming and reinforcing society in the practices and behaviours which it deems to be appropriate. One cannot criticise *EastEnders* in any simplistic manner for doing what it always does in the way that it does it; it is pointless and somewhat naive.

The problem for me, and for most other people with spina bifida and hydrocephalus, was in the way in which ASBAH was co-opted in to the arena to defend the programme and its involvement, both in the general media and in the last issue of *Link*. I believe ASBAH made a strategic mistake in working with *EastEnders* given the logic that the plot was going to follow; it should have withdrawn public support for it once it was clear what was going to happen.

The reasoning that the narrative followed a realistic conclusion is, I am afraid, something of a slippery argument. ASBAH is, in the main, run for and with people with the impairment of its title; thus, in one foul swoop, ASBAH denigrated its social grouping, and its members and their families, in the interests of those who will have no significant involvement with it, and at the expense of those of us living with spina bifida and hydrocephalus.

I am not criticising those people who, in real life, follow the actions of Bianca and Ricky – the social pressure they are under to do so is immense: as epitomised by the *EastEnders* plot line – but it would have been positive if, upon its broadcast, ASBAH had come out arguing that, as its members have shown, living with spina bifida is no big thing excepting in our social disablement educationally, structurally, institutionally and environmentally.

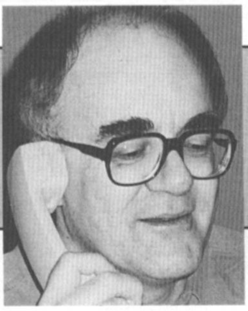
I hope that ASBAH will now contribute to a film, a documentary or some other document, made by people with spina bifida and hydrocephalus, which allows us to represent ourselves in all the glorious forms of living that we, as we are, live. Give up supporting those whose function is our dysfunction.



Bianca with us at House of Lords

Patsy Palmer, who plays Bianca in EastEnders *(left), joined ASBAH at a reception held in the House of Lords in December to promote the full fortification of basic flours with folic acid. The event was hosted by Lord Ashley, and sponsored by Larkhall Natural Health, makers of Cantassium Micro Folic Acid tablets. Over 100 MPs have signed Peterborough MP Helen Brinton's motion calling for compulsory fortification in order to improve the folic acid status of women who do not take folic acid supplements.*

ed with *EastEnders*?



YES says ASBAH publicist Tony Britton

WE co-operated with the *EastEnders's* storyline because we wanted to be sure they got it right. They did – in almost all respects.

The acting and direction were superb. The storyline was true to life; scenes like those on the programme are played out in real life every day of the week.

The results are as harrowing for the parents involved as for poor Bianca and Ricky.

And, in many cases, doctors do make a mess of the way they break the news to the parents that the mother is carrying a child with a severe disability.

Time after time, parents contact the ASBAH to say that – in their grief for the loss of the healthy child they will not be having – they cannot remember what they have been told by the doctor. Or they just were not given any useful information at all.

Considerable thought and discussion took place when ASBAH was approached earlier this year by *EastEnders*, who had decided to include in their plot a storyline featuring a pregnancy involving a birth impairment.

Later it emerged that more than one specialised disability charity had been approached by the BBC, and *EastEnders* judged that ASBAH had provided the fullest and more specific information. So spina bifida and hydrocephalus were selected over other disabilities.

We were told that the storyline would revolve round Bianca and Ricky, and their decision to terminate a much-wanted 20-week pregnancy after a diagnosis of severe spina bifida and hydrocephalus was made.

As a result of information supplied by us, the programme will include in future episodes scenes about how the vitamin, folic acid, can help prevent such pregnancies taking place in the first place.

ASBAH asked if the baby could have been born, to give the opportunity of showing positive aspects of life for a child with a disability. But this was not negotiable: the storyline was to be built round a couple faced with a pregnancy when the baby has a birth impairment, and their decision to choose termination of the pregnancy.

ASBAH never had any editorial control of the storyline.

We believe that the public exposure of the impact of a neural tube pregnancy on a young couple is an important piece of education for the public. Approximately 1,000 such terminations occur in the UK each year, and every year ASBAH provides support through this time to hundreds of parents and family members, at their request, some of whom keep in touch with us for many years afterwards.

We never advise women to terminate their pregnancies. Our policy is clear: termination is legal and ASBAH will not condemn parents who choose this course. However, we are careful to give good, unbiased information to explain the conditions of spina bifida and hydrocephalus, and the opportunities for many children with these disabilities to have a good quality of life and to contribute to society.

The parents are left to make their own decision whether to allow the pregnancy to proceed or not and we feel we must respect whichever decision they make.

Comments have been made that, as a matter of principle, ASBAH should not have co-operated with *EastEnders* on an elective termination of pregnancy storyline because such co-operation might be interpreted as supporting an underlying message that a baby with a severe disability should not be brought into the world. Such a message would indeed be offensive to disabled people, and could be ill-advised if it led to a reinforcement of public prejudice. Although we understand this viewpoint, we do not believe this was the result.

The situation was that *EastEnders* were going to feature a termination, whether or not ASBAH assisted with accurate information.

Furthermore, provided that the script and direction were responsible, and portray the sadness and grief of the situation, we believe that our decision to co-operate with *EastEnders* was correct. The programme represented the baby as a much-loved little girl whose loss is deeply mourned. This is indeed the emotion of many parents who go through the experience.

We also had to ask ourselves whether ASBAH could really expect the producers to adopt an overtly moralistic or didactic line, and ignore the fact that today 10 out of 11 neural tube defect pregnancies are terminated by decision of the mother, following ante-natal diagnosis.

Our decision to work with *EastEnders* was made after much deliberation, but the fact that many millions of viewers will learn something about spina bifida, the distress of deciding to have an abortion, and about folic acid, led us on balance to work with the programme.

Mum in a mill

SINGLE mum Lynda Howard had been gi
pite care to disabled children in Oxfordsl
years when, in 1991, she saw the Anneka
programme on Romanian orphanages. F
on, Mrs Howard's priorities suddenly cha
21-month battle to adopt Alexandra, a fo
with severe hydrocephalus, began. LIZ C
spoke to Mrs Howard to find out why she
help a single child a thousand miles awa

THE SHOCKING image flashed up on TV for just a few minutes of a four-year-old with her enlarged head wrapped in badges at a Romanian orphanage. It was enough to start one woman on a 21-month battle to bring the child to England for medical attention and the love and security of a family.

Why Lynda Howard wrote to the British doctor, who told viewers of the Anneka Rice programme that Alexandra's severe hydrocephalus would never have developed if she had been born over here, when the rest of the nation switched off their sympathy when they switched off the TV, is perhaps not too difficult to understand.

But to then travel to Romania to meet the child and to doggedly persist in adoption when faced with red tape in Romania and Britain – and hostility from the Romanian newspapers which derided Alexandra as a 'monster' – is pretty incredible.

But the story becomes more believable when you get to know the woman and her experience in caring for disabled children.

"I'd been doing respite care for children for 10 years and was used to dealing with life-threatening conditions. I have looked after children with a wide range of disabilities and some with limited life expectancy. I ended up doing it full time – every day of the week. Last year, I cared for seven children.

"One of the children I looked after – six years ago – evolved into shared care. Sonya lived with me for half the week. She had severe hydrocephalus and was quite a one-off in this country because she was not given a shunt until she was four. It was then decided she would survive the anaesthetic but was still quite frail. She lived only another 18 months after the operation.

"When I remembered how much Sonya suffered, with constant vomiting and headaches, I realised how much more Alexandra would suffer without the availability of painkillers. I had learnt quite a lot from Sonya, so it seemed a shame not to use that to help Alexandra.

"I am quite confident about doing the hands-on care – the tube feeds, giving injections, putting up drips. Losing a child is much more difficult, and when I brought Alexandra over here, she was only expected to live for another 18 months. It's no good having death in the front of your mind as it means you can't get on with life. You have to mentally accept it and then put it to one side.

"If Alexandra's ill for a long time though, the thoughts creep in and you have to pull yourself up. It's the difference you've made to her life that counts. It's easier for me than for real parents as I deliberately set out to adopt Alexandra. I had a choice: I could have walked away but I also could have turned her life around and that's incredible.

"At the time, people asked me how I could justify raising several thousand pounds for one child when the same amount would have helped a larger number of children. Every child ought to have the right to medical treatment and the love of a family. If the money had been spread across more children they would have each been helped in a small way, for a short time.

"Alexandra was featured on the programme for just a few minutes but long enough for her to make a tremendous impact. Her head was covered in bandages due to pressure sores. I remember her sunken eyes and the pressure sores. The doctor from one of the hospitals in England who was visiting the orphanage with the TV programme commented that, if Alexandra had been over here, her quality of life would have been so much different.

"I was ironing while the programme was on because I wasn't sure whether I wanted to watch. But when Alexandra was shown, my daughter, who was watching, said: *You ought to get her out, you could look after her.*

"We discussed it briefly that night and the next day I rang the programme and got in touch with someone who knew the doctor. I wrote to him at the hospital saying that this was what I was offering – that we could give the medical care she needed here and also the terminal care.

"The doctor wrote back saying he was thrilled that I was able to help. I also wrote to the charity involved which hoped to get Alexandra out of Romania. In the end, neither they nor the doctor could get her out. It became politically sensitive and I had to go it alone."

Alexandra, then aged four, was one of the most severely disabled child at the orphanage. She had been neglected and physically and [illegible]otion
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From Romania to Oxfordshire: Lynda Howard with her adopted daughter Alexandra, now aged nine

Photos: Alison Littlejohn 01865-300920

the person has someone to live with in the Britain. One of the conditions is that there has to be a cure for the person benefiting from this type of visa. In Alexandra's case, her hydrocephalus would only be controlled by treatment by the insertion of a shunt.

"We didn't fall into the right categories. It was horrendously difficult. One or two people in the British government and one or two MPs in Romania were supportive but others were quite obstructive. The Home Office was dreadful.

"The Romanians regarded me as an Englishwoman who was irritating the authorities by wanting to adopt a child whose 'head was larger than her body and her eyes sunk like the setting sun.' They felt that me adopting Alexandra would damage Romania's image in the West. They couldn't believe that I would want to do such a thing and that there was no shame in being disabled.

"It was my sheer determination and pigheadedness which got us through and because one of the doctors who was supporting me didn't tell me to give up."

Mrs Howard made three trips to Romania over the 21 months. By the time of her second visit, Alexandra had been admitted to hospital to have surgery for a shunt to be inserted. The shunt had been donated by a charity.

"I arrived just as the neurosurgeon was operating. She had been wheeled in her pram into theatre and was cut in four places – her head, neck, chest and abdomen. Soon afterwards, one of the holes burst open and there was a 2-3 inch gap in her neck and they wouldn't stitch her up.

"The neurosurgeon turned out to be very supportive and one of the few people to have compassion for Alexandra. He said: *If I had known she was to go to England, I would never have done the operation.* He had to take the shunt out again. Although awful for her, the operation proved that treatment in Romanian hadn't worked, giving us added reason to get a Medical Treatment Visa.

"I was able to give Alexandra one-to-one care for some of that time in two different hospitals. It was during this time that I witnessed the harshness and brutality Alexandra encountered and saw the way her disability was exploited. I also became aware of the attitudes towards Alexandra and disabled children which, in some way, explained the way she was treated.

"I spoke to several Romanians who, though they could see Alexandra cry and scream, did not believe she had any normal human feeling.

"In one of the hospitals, word went round that a 'monster child' was there and staff used her as a freak show and then this funny English woman came along and we became a double freak show. They questioned me about how I could love such a child – they thought it was impossible.

"At this time she had been many weeks squashed into the pram with her knees bent to her chest and was not able to stretch them. Once I lifted Alexandra from the pram to lie on an empty bed. In the night I was woken by a nurse shouting and pointing at Alexandra and the pram. Through actions I explained Alexandra's legs caused pain and tears. I was clearly understood. The nurse got hold of Alexandra's ankle and yanked her leg down as far as possible. Alexandra woke screaming in pain, the nurse continued to

continued on page 18

Mum in a million, from page 17

Lynda Howard and Alexandra at home in Oxfordshire

shout holding the ankle, then started to pick up Alexandra to put her in the pram but did not hold her head, which is large and heavy. I managed to grab Alexandra's head as she was pushed roughly into the pram."

During her short life of four years, Alexandra had been been damaged physically and emotionally. It was not until some time after she had settled into Mrs Howard's home that she smiled or laughed. Now she has quite an expressive face and shakes her head for 'No' and raises her eyebrows for 'Yes'.

"I came home from my second visit, knowing Alexandra was very ill and might die, and I got in touch with everyone I could think of. I even wrote to Princess Anne. If I was refused by one person, I'd go to someone else.

"Then suddenly the Home Office caved in – probably because they knew I wasn't going to go away. They gave us the visa."

At the time of Mrs Howard's third and final visit – only three weeks after returning home from the second – she still had to find Alexandra's mother to gain her consent to the adoption plan and Alexandra's birth certificate. The mother was found more easily than expected, but quite by chance.

"We tried to get Alexandra transferred to a charity to build her up for the journey to Britain, but the orphanage director refused to allow this. He also refused to tell me who Alexandra's mother was. Then, out of the blue, he dropped the mother's name and address into a conversation he was having with someone from the charity.

"We found her mother, who agreed to go with us to the police to get a passport for Alexandra. If you can get a passport, that really swings it for you in Romania.

"At first the police refused to issue a passport, then there was an all mighty row. Though uneducated, Alexandra's mother bravely told the police: *I say she can go to England. This woman can look after her – do you want to look after her?* I had great admiration for her. I think it had been very difficult for her to come to terms with Alexandra's problems."

Alexandra was sedated for the flight but coped with it very well. Mr Richard Kerr, a neurosurgeon in Oxford, had written to the Home Office agreeing to treat Alexandra, but first she was taken to Mrs Howard's home to build her up before surgery. She had a shunt inserted two months later.

"Alexandra was only expected to live for 18 months but she's surprised us and certainly might continue to do so."

LYNDA Howard's fighting spirit was tested again last year when she was at first refused the school of her choice for Romanian-born Alexandra, now aged nine.

A Special Educational Needs Tribunal at first rejected her appeal that her daughter should go to Penhurst, a special school run by the National Children's Home, which is dedicated to the education of profoundly and multiply-handicapped children.

Oxfordshire Local Education Authority (LEA) favoured another special school, which teaches children with widely different physical and learning abilities, some of whom Mrs Howard believed could frighten Alexandra. There was also no sick room in the school for Alexandra to lie down should she have a headache.

Some months after her appeal had been rejected, Mrs Howard learned from ASBAH education adviser Peter Walker that parents have the right for a review of a tribunal decision.

Although Mrs Howard overstepped a 28-day deadline to ask for a review, another opportunity to do so arose when Alexandra's Statement of Educational Needs was amended to give full-time nursing cover. She was helped by a solicitor who is experienced in educational matters – backing which she believes was crucial in persuading the LEA to back down.

Within five minutes of the second hearing, the LEA offered funding for a part-time place at Penhurst, plus one-way transport costs.

Mrs Howard said: "This is a partial victory for us as it means Alexandra can attend Penhurst five mornings a week, which is enough for her for the time being.

"Alexandra is a fighter and deserves Penhurst. She makes the most of every opportunity and is very alert and responsive."

HYDROCEPHALUS NETWORK NEWS

ASBAH, 42 Park Road, Peterborough PE1 2UQ
Tel: 01733 555988 Fax: 01733 555985
Internet Web Site: http://www.asbah.demon.co.uk/
Reg Charity Number 249338

Spring '98

Developing skills and building confidence

A Northern Ireland perspective

by Lorna Johnston
specialist adviser (education),
Northern Ireland

THE main problem for teachers and others (including parents and ASBAH advisers) is that hydrocephalus is such a complex condition that it is sometimes hard to figure out what is the most important learning activity to focus on to begin with.

Over the last two years, I have learned that the starting point varies from child to child, although some learning experiences are important for all (just as they are for children who do not have hydrocephalus). Most of the children I have worked with have been of primary school age.

In order to try to understand how to go about helping some of these children, I have found it useful to imagine that the 'self' can be made up of different sorts of learning needs. According to this 'picture' I have imagined a child being at a given point of development in a range of different activities within five main areas: **physical** (including sensory perception); **'procedural'** (eg mechanical reading and computation); **social/ communicative, emotional,** and **creative**. I have separated out the areas in order to identify the sorts of experiences which might help the child to make progress in that area, but for the child to make progress, it is not enough to concentrate on just one area of development as progress in one affects progress in another. In this article, I will be concentrating on the 'physical' area, but I have also done work where the main focus has been 'emotional' or 'social/communicative' (for example, work on language and reading).

PETER Walker, who retires as ASBAH's specialist adviser (education) on 8 April, said Lorna Johnston's article would make a useful practical contribution for parents and teachers when developing the various skills of children with hydrocephalus.

- *A report, looking back at Peter's career, appears on page 7&8 of this issue of* Link *(Feb/Mar '98).*

I started with the idea that toddlers naturally want to explore their 'universe' and so, if a particular child does not seem curious, it could perhaps be because he or she does not feel 'safe' enough to explore. Therefore, the initial question was on the 'physical' area and what sort of things might be contributing to a child's lack of confidence. There may have been many aspects of this that I have missed. I concentrated, to begin with, on visual perception and thinking skills using some inter-lockable plastic cubes called Multilink. Other

continued on page 2 & 3

HNN contacts

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Medical/Continence (South East Region): 0181-449 0475 Caroline Berkley (Mon, Tues & Wed am). Gillian Yaz (Wed pm, Thur & Fri).

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User-group forum co-ordinator (England & Wales): Jon Burke 0113-255 6767.

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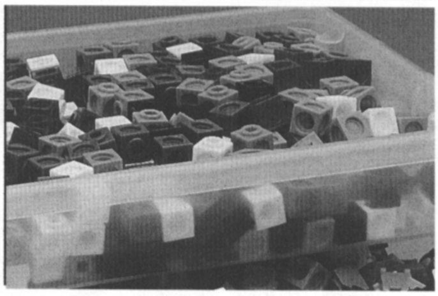
ASBAH's Hon Consultant on Hydrocephalus: Dr Roger Bayston MMedSci FRCPath, contact through ASBAH's Services Dept at ASBAH House.

Developing skills and confidence, from p 1

activities to boost visual perception have included 'thinking skills' work-sheets, produced by Oxfordshire County Council; a 'talk and read' activity; and encouraging children to estimate then check distances/lengths and capacities of objects, (eg how many cups of water would be needed to fill a bowl of a certain size). The particular activity which has been tried has depended on the age of the child and the level of understanding he/she already has about these things.

These activities link the 'physical' area to the 'procedural' area, as we build up 'pictures' of the world through our understanding of how to look for similarities and differences between things. We also need to learn about how things are shaped; how they can be changed or moved; and how they fit together. This ability could be needed, for instance, to figure out how different door handles operate; or make sure a sweater is the right way out; or organise boxes and tins on a shelf in the grocery cupboard. It is also needed for an understanding of most of the Northern Ireland maths curriculum, both at the physical level of measurement and shape, and at a more abstract level when children are expected to be able, for example, to identify patterns and relationships in number.

Many children with hydrocephalus have a 'weakness' in at least one hand. Two of the children I have worked with have been unable to use both hands to work Multilink as one hand was so weak. Children, aged 3-4 years, have also found it difficult to click the cubes together, but have eventually managed to click two together at a time. (I have not attempted this with children of under three and a half). Of the rest, all have eventually been able to work with Multilink, and I have had many reports (both from parents and teachers) that hand-control has improved – for example, 'colouring in' for the younger ones, and handwriting for the older ones. I believe this in itself can contribute to a growing sense of self-confidence, (which also brings in the 'emotional' area, and lays the foundation for the 'creative' area).



Multilink

The activities with Multilink have also provided the opportunity for the parents (and me) to see which 'movements', if any, the child has difficulty with, and therefore needs help to understand. For instance, one six-year-old had difficulty understanding how to rotate a vertical row of Multilink to make it 'lie down' on top of a horizontal row. Others, aged 7-9 years, had a problem in figuring out how to position a cube so that it would be 'behind' a 2 x 3 block of Multilink.

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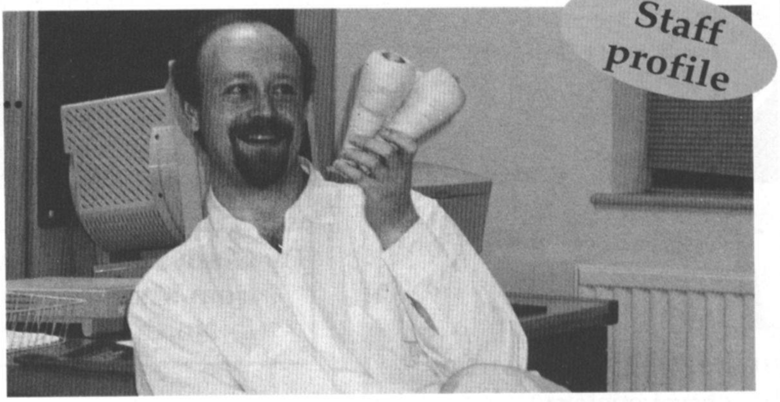
SPECIALIST ADVISER (MOBILITY) TIM LEECH ...



KNOWS his parsnips, onions and other fruit and veg simply because he enjoys eating historic varieties of fresh food rather than the intensely grown fodder most of us pluck off the supermarket shelf.

He enjoys finding tastes and food experiences which have been lost over the centuries and which can be regained and passed on to others.

"I like to add a bit of interest to a fairly repetitive thing, eating. You might as well enjoy it. I have grown some lovely artichokes and parsnips, and I was very pleased with some carrots – a vegetable which I previously never enjoyed."

A member of the Henry Doubleday Seed Bank, a collector of old cookery books and an archaeologist interested in the way buildings have changed over the centuries to reflect changing eating habits, Tim was recently asked to write a book on the history and archaeology of British cooking.

The Henry Doubleday Seed Bank gave him half a dozen seeds of a mediaeval broad bean called Martock, once grown in the Bishop of Wells' wall garden, and a climbing bean originally grown by the Cherokee Indians. The idea is to build up your stock of seed until you have enough to sow, collect, eat and pass some on to other enthusiasts.

"I am particularly interested in rare varieties of tomatoes," he says. "I grow historic stuff more than anything else. I plant it and let it go. I'm not really interested in organic methods, but I don't put anything on them because I don't like putting poisons on the things I eat, and because I'm lazy and a skinflint."

Developing skills and confidence, from p 2

These activities are also designed to help children predict, by learning the things which need to be taken into account in order to predict sensibly. This involves eye movements. The children are taught how to scan and check horizontally for information – in figuring out how to continue a two-colour pattern of Multilink, or in 'matching' an object in a row with a target object.

This ability also helps them, for example, to count an 'untidy' array of objects on a page, and is one of the pre-reading skills they need. It may also contribute to good spelling: one child has made a significant gain in a standardised spelling test.

Linked to these is an ability to focus on one object, then another, and scan backwards and forwards to check for similarities and differences in the details. Again, when they have learned how to do these things, it seems to give them a 'good feeling' about themselves: perhaps because they have been able to decide for themselves what the answer would be rather than trying to remember what someone told them the answer was.

Confidence-building is really the key to all successful learning experiences, and there is still much more to be found out about what helps these children build up confidence. That process can be 'hurried along' if we can share our observations through a medium such as this magazine.

● **Multilink is available from educational supplier NES Arnold (tel: 0115-971 7700), and is featured in its *Primary Mathematics* catalogue. Bearing in mind that 100 cubes are enough for each child, Lorna suggests parents get together and buy a larger quantity as it works out a lot cheaper when you buy 1000 (£69.95 with handbook; £61.95 without handbook). Prices exclude VAT.**

True story

By Gladys Scrimshaw, RGN from Knaresborough, North Yorkshire

I GET increasingly concerned that many doctors still do not seem to understand the hydrocephalus shunt system.

Our son Stephen would have been 30 this year. He was born in 1967 with spina bifida and, as a result, he developed hydrocephalus when he was five weeks old. His hydrocephalus was controlled by a Spitz Holter valve.

We were immensely grateful for the wonderful way he was looked after in those early weeks. The surgeons, doctors and staff did miracles with him and we were so proud to bring him home.

I had a very sympathetic GP but, apart from that, I felt I was not given any support at all during the immediate and traumatic days after his birth.

As a nurse, it seemed I was expected to know just what to do with this child. I had never been a mother before and people seemed to forget that. Yes, I had looked after babies with hydrocephalus during my general training but I did not know anything about the shunt system. Experience was going to teach me a lot.

My husband and I had no real idea of the enormous responsibility we were taking on when we brought Stephen home for the first time. We could never have envisaged any of the problems which were going to come to us and to him at that time.

It was a responsibility that we were determined to carry out because we both loved him so very much. He developed into a very loving personality with a lovely sense of humour. He was generally a happy little boy but he had many days when he was not well at all.

The next years were not without trauma as he had to undergo numerous operations. On two occasions, at the ages of nine and 14, the valve draining the cerebro-spinal fluid from the brain became blocked and it meant immediate emergency surgery.

On every occasion, he came back bouncing with new life. He seemed to accept his condition with great courage and fortitude and never complained of his disability. He was totally dependent on people around him for all aspects of his daily living. He spent most of his day in his wheelchair.

Whilst Stephen was at school, we felt we had great support – from the school, run by Barnardos, from ASBAH and the medical staff at Sheffield Children's Hospital.

However, this support declined when Stephen became an adult. Yet, as approached his 21st birthday, his medical problems became much greater. He had started having fits when he was 14 but these were fairly well controlled by drugs. As well as this, he was now only functioning on one kidney. He was also prone to chest infections and urinary tract infections. His scoliosis was becoming worse.


Stephen, Scrimshaw aged 16

In 1989, he was admitted to hospital four times in three weeks because he was constantly fitting. I was almost referred to as 'an over-anxious mother' and one doctor decided Stephen brought on the fits himself which I found extremely hard to believe.

I felt his shunt was not working properly, but each time I was told it was fine. I accepted what the doctors said, but I wasn't convinced they were right. Each time Stephen came home, he presented the same symptoms.

The pressure during those weeks was almost too much to bear at times. Once, he was

continued at top of page 5

sent home with a kidney infection. I then had the responsibility of doing bladder wash-outs via his catheter. Another time, I was asked to give him a course of injections. I had little or no support from the district nurses – we never saw them. I am sure I must have saved them a lot of money but, then, all the responsibility was placed on my shoulders.

At the beginning of January 1990, Stephen seemed to be losing interest in his surroundings. He hadn't really shown much interest over the Christmas celebrations and these were something which he always enjoyed. We called a doctor, who happened to be relatively new to the practise. He diagnosed a chest infection and prescribed antibiotics.

Stephen did not make any significant improvement, so we called the doctor at least twice during the next few days. I was now convinced that if something wasn't done quickly, Stephen was going to die in front of my eyes. I was really worried.

We were told he now didn't have a chest infection but yet there was to us no doubt that something was very wrong with him. Trying to convince the doctor of this was becoming hard work. Stephen couldn't sit up, he couldn't even hold a cup. He really did look awful!

My husband and I were almost at the end of our tether and it was having a devastating effect on our other three children.

We felt that Stephen should be admitted to hospital. We were convinced that there was a problem with his valve. Was it blocked, I asked the doctor? He said that he couldn't see any neurological signs. They were obvious to me but I was only a nurse and, once again, was probably regarded as the over-anxious mother. The doctor left, saying he would make an urgent appointment with the neurosurgical consultant, but we would have to wait for that. We were left devastated and almost in a state of shock with our 'dying' son who was in urgent need of medical attention.

I could not stand it any longer and decided to contact the consultant myself via his secretary. Her advice was to take him straight away to hospital.

Stephen then had to undergo the most traumatic journey in the back of our car – he should really have had an ambulance. It was not fair to have to transport someone we loved, who was so ill, like that – but it seemed to be the only way to get him there.

When we arrived at the hospital, Stephen was immediately scanned and was in theatre within an hour.

The next day he was in intensive care with bronchopneumonia, fighting for his life – yet the day before he had no signs of a chest infection!

The shunt system was found to be not working at all, so I was right! This was successfully corrected but it was too late. His condition deteriorated rapidly and he lost his fight for life two weeks later at the age of 22.

We don't want to blame anyone for what happened but we did feel let down in a way by the medical profession. I feel that this might have been prevented if there was a clearer understanding of the problems of the shunt system.

Once the problem was isolated, everything that could possibly be done for him was done and he was well cared for during his final days, but it was too late.

I believe that some of the mistakes which we made were probably due to a lack of experience. The shunt system in the treatment of hydrocephalus has now been in use for over 30 years, so why is it that some doctors still do not seem to understand it?

Not all Stephen's life was traumatic, we had many joys with him and our lives have been enriched by having known him. But I would not want anybody to have to go through what we went through in his last week.

What's in the Feb / Mar Link

Link is ASBAH's main magazine. Subscription details from National Centre.

Council tax discount available to some carers

CARERS who look after someone who is over 18, who is not their spouse or partner, for a minimum of 35 hours a week, can claim substantial reductions in their Council Tax bill.

The specific requirements to give you entitlement to the discounts are:

1. You must look after some one who receives the higher rate of Disability Living Allowance (DLA) care component or higher rate attendance allowance.
2. You must care for that person for a minimum of 35 hours per week;
3. That person is *not* your spouse or partner;
4. The person you are caring for is over 18;
5. That person lives with you.

Council Tax bills are based on two adults living at an address. Certain people are 'not counted' when councils work out Council Tax bills. Those 'not counted' include people who are severely mentally impaired and carers.

- If no-one is 'counted' as living as an address you can get a 50% discount.
- If only one person is 'counted' as living at an address you can get a 25% discount.
- If two or more people are 'counted' then you will not qualify for a discount.

To claim the Carers Discount you need to meet the above criteria. The discount is available to anyone, whatever their income or savings.

- If there is more than one person who cares for at least 35 hours per week you can get more than one Carers Discount. However, each carer will have to show the local authority that s/he cares separately for at least 35 hours per week. (Note that there are 168 hours in a week!).
- Carers who receive the Invalid Care Allowance have already proved that they care for a person for over 35 hours per week.
- The Carers Discount can be backdated to when the Council Tax was first introduced (April 1993).

To claim for your Carers Discount contact your local Council Tax department. If your council refuses your claim you can appeal to the Valuation Tribunal. Details can be obtained from your local authority.

Address change for equipment company

CYCLONE, the company specialising in mobility and fitness equipment, is now known as Cyclone Mobility and Fitness Ltd and is now based at: *Unit 1, Meadow Lane Industrial Estate, Ellesmere Port, South Wirral L65 4TY. Tel: 0151-355 4393.*

Cyclone still sells the *Advantage* and *Enigma* wheelchairs, the *Tracker* hand cycle and the *Versatrainer* – a single unit fitness piece of equipment for wheelchair-users.

Clyclone Mobility and Fitness Equipment's Freepost address is: Freepost NWW3068, Ellesmere Port, South Wirral L66 1BR. Freephone: 0500-434493.

Clothes with easy dressing features

CLOTHES with easy dressing features are contained in the new Special Collection catalogue.

Garments with elasticated waists, long-fronted zip fastening, stretch fabrics for ease of movement and roomy armholes are some of the features, designed to make life easier for people of all ages with dressing difficulties.

Special Collection has worked closely with the Disabled Living Foundation in the design and the selection of its products, which include leisurewear, dresses, knitwear, outerwear, lingerie and footwear. Each item is fully illustrated.

Brochure from: JD Williams and Company Ltd, The Special Collection, 53 Dale Street, Manchester M60 6ES. Tel: 0161-236 5511 (enquiries) or 0161-236 9911 (orderphone).

HN NEWS letters

OUR son is 17 years old in July and I have been receiving your newsletter for 16 years in which I have read many interesting articles.

We felt we needed to write to 'boast' about our son. Chris was diagnosed with hydrocephalus at five weeks old and had a Spitz Holter valve inserted, which was revised three days later.

When he was discharged from hospital, we knew our problems were just beginning. He had a severe left-sided weakness and over the years he suffered other problems – ear, nose and throat, vision impairment and poor immune system, to mention but a few.

We had wonderful support from our local Child Development Centre which he attended on a weekly basis until school age. He received physiotherapy, occupational therapy and visual assessments. He was behind his peers for many years.

We are not sure when he caught up but, despite setbacks and 10 operations and being visually impaired, he has been a fighter, crossed every hurdle and *never* complained.

But this year sums it all up, when on what must be the proudest day of our lives, he achieved two Cs and seven Bs in his GCSEs. He even got a C in Technology which he finds extremely difficult due to hand-eye co-ordination difficulties.

He has now gone on to study 'A' levels, so if there is anybody out there who feels like we did 16 and a half years ago, please be reassured. With determination and professional support, it *can* be done.

Liz and John Lawson
Northallerton
North Yorkshire

Make the most of your experience

AN INFORMATION pack is now available which aims to help people with disabilities make the most of the skills they have developed as part of their life experience when applying for jobs.

Make Your Experience Count is a result of a project funded by the National Lottery Charities Board.

It is available free to unemployed disabled people, £10 for non-profit organisations and £20 to others.

For a copy of the pack, or for more information, contact: Liz Cornell at the Learning from Experience Trust (LET), Anglia Polytechnic University, Victoria Road South, Chelmsford CM1 1LL. Tel/fax: 01245-348 779.

KEEP on sending us your *True Stories*, but we would particularly like to hear from readers who have a positive or amusing story to tell!

Perhaps you have achieved something that you are really proud of, or you have taken up a new pastime or sport which you would like to tell other *HNN* readers about? We would like to hear from you!

Please write to: Rosemary Batchelor, Co-ordinator, Hydrocephalus Network, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

A READER from the West Midlands would like people with hydrocephalus who have full-time jobs to write in with their experiences.

We will publish as many of your letters as possible. This will mean that job experiences can be shared and/or encouragement given to those who are currently unemployed or are having difficulty keeping a full-time job going.

Please send your letters to: Rosemary Bachelor, Co-ordinator, Hydrocephalus Network , ASBAH, 42 Park Road, Peterborough PE1 2UQ.

True story

by Jane Procter from Kendal, Cumbria

MY son James is 14 years old. He had a shunt inserted when he was three months old. Until last November he had had no trouble at all with his shunt.

On the Saturday, he went out on his bike. His back became so painful that he had to sit down. On the Sunday, he had a painful back and a headache. On the Monday, he came home from school in the morning feeling very unwell. I did not associate any of this with his shunt because no one had ever mentioned that a malfunctioning shunt can cause a painful back.

By the Thursday, he was worse. He had a 'wushing' sound in his ear, the same side as his shunt and he was suddenly sick for no apparent reason. I was quite sure he had a blocked shunt as he had no high temperature.

At 8am, I telephoned the specialist hospital, where James first had his shunt fitted 14 years ago. I explained that James had all the symptoms of a blocked shunt and asked if I could bring him down to be checked. The journey from our home to this hospital takes about two hours. The hospital would not let us do that. We had to see our GP first.

Eventually, at 12pm , we managed to see our GP. He didn't think James's shunt was the problem, but he referred us to a local hospital for a scan.

Time was going on and James was feeling very unwell. No-one could interpret the scan because they had no other scan to compare it against and they did not know what ventricle size was normal for James.

14-year-old James Procter

Anyway, he was admitted and given a bed and all the necessary forms were filled in. At 5pm they decided he should go to the specialist hospital. We arrived at 7pm. After many tests it was decided that James could go home the following morning.

The following morning James was much worse with a severe headache, painful back and persistent vomiting. At last, someone agreed that James had a blocked shunt. The diagnosis came too late for morning surgery, so poor James had to suffer until 7pm.

His old shunt, which had lasted for 14 years, had stretched so much that nothing could get through it. That is why his symptoms happened gradually.

The operation lasted about an hour. James recovered in about half an hour. The results were amazing. No headache and no back pain. The following morning James was playing computer games.

Once again, mother's instinct was right.

Most readers' subscriptions to* Hydrocephalus Network News (HNN) *are due in May, but if you are not sure when your subscription is due, please phone Lynn Thomas in ASBAH's Services Department on 01733-555988.

Annual subscription rates (four issues a year) are: £2.00 (UK); £5.00 European and overseas suface mail and £10.00 by airmail.

SPINAbilities book review

AN IMPRESSIVE book for and about young people with spina bifida, produced in the United States of America, has generally received the thumbs-up from professionals on both sides of the Atlantic.

In this article, *Link* editor LIZ CAWTHORNE goes into more detail.

DIRECT answers to just about every question I imagine you could ever asked about yourself, your personal needs and relationships with others are contained in a positive and easy-to-read book called *SPINAbilities*.

Produced in the USA, *SPINAbilities* is subtitled *A Young Person's Guide to Spina Bifida* but it is much more than this. Its contents are as bright and young in attitude as its rainbow-coloured front cover. The opening chapter briefly explains what spina bifida and some associated problems are and their effects. Later chapters give practical tips and suggestions on how to become more independent – conceding that learning to take care of yourself is no mean feat but well worth all the extra time and effort that is required.

For example, there are illustrations on special ways to dress, transfer techniques to get in and out of bed and suggestions of special equipment which can make using the bath, shower or toilet easier.

There are chapters on the type of mobility aids you may need, how the bladder and bowel work and ways of keeping them healthy, and *Caring For Your Largest Organ* – how and why you should look after your skin, so avoiding pressure sores.

A later section on relationships looks at overcoming possible problems with sisters, brothers, parents, friends, and girlfriends/boyfriends.

It gives tips on how to gain the skills needed to make friends and to join in a conversation with other young people. It also explains why some brothers and sisters find it difficult to get on and each, in their own way, feel that 'life's not fair'.

The book pulls no punches when it comes to answering questions about more intimate relationships. If you can ignore the American phraseology, the relevance of the questions ring out as loud and clear for young people over here as they do for their counterparts in the States. For example, the book asks: *What if I'm with my date and I pass gas, or have a bowel or bladder accident? What if my friends are all having sex? If I can't have an erection, how do I have sexual intercourse? How can I avoid a bladder or bowel accident during intercourse?*

Part Three – *Growing Up* – gives some tips on overcoming problems with your attention-span, memory and recalling information – to help with school and college work. In the chapter, *Tools and Techniques,* there are some good ideas about organising yourself ready for each school day. There are also some useful suggestions about storing information so that you can remember it more easily. Then there are tips on how best to stay 'tuned in' to the job you're supposed to be doing.

Pay-day is the name of a chapter on preparing for the world of work – developing skills, gaining experiences, knowing your rights, taking advantage of training and learning about your job interests.

The final section is about staying healthy in body and mind. It explains how to deal with feelings such as anger, sadness, loneliness, frustration/resentment. Then there are tips on eating wisely and taking regular exercise and why these two things are important to everyone.

Included is an illustrated programme of simple stretching techniques – designed to be used as a cool-down after aerobic exercise or weight training. Various types of aerobic exercises suitable people with limited moblity are suggested.

SPINAbilities is edited by Marlene Lutkenhoff and Sonya G Oppenheimer. Marlene Lutkenhoff is a clinical nurse specialist in the field of parent/child nursing and the service co-ordinator for the spina bifida clinic at University Affiliated Cincinnati Center for Developmental Disorders.

Sonya Oppenheimer is a developmental paediatrician and director of the Department of Pediatrics at the Cincinnati Center for Developmental Disorders and Professor of Pediatrics at the University of Cincinnati.

***SPINAbilities* is available to *Link* readers at a special price of $13.95, plus shipping and handling charges of $11 for one book, $13 for two books. Additional copies will require higher shipping and handling charges.**

Please send your order, with a credit card number, to:
Information & Referral Dept, Spina Bifida Association of America,
4590 MacArthur Boulevard, NW, Suite 250,
Washington, DC 20007-4226.

A full list of publications from the Spina Bifida Association of America is also available from the same address.

DATES FOR YOUR DIARY

Saturday 28 February

ASBAH Study Day for families, Worcester College of Higher Education, 9.30am-4pm. Topics include introduction to spina bifida and hydrocephalus, implications for learning and behaviour of children with hydrocephalus, continence management, with choice of workshops. £12 per adult; couples £20. ***Geraldine Long, tel: 01789-763090. or Jenny Green, tel: 01926-511206.***

Saturday 7 March

South East Region ASBAH study day, 'Going for it!' (issues around independent living), Christchurch Forum, Trafalgar Road, Greenwich, London SE10. £5 per person. For young people with spina bifida and/or hydrocephalus, and family members. ***ASBAH South East, 209 Crescent Road, New Barnet, Herts EN4 8SB, tel: 0181-449 0475.***

Monday 9 March

ASBAH South Beds Support Group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, 01582-605749.*

16–20 March

'Looking Good, Feeling Good!', residential course organised by Cornwall ASBAH for 12 young people with spina bifida and/or hydrocephalus, Churchtown Centre, Lanlivery, Bodmin, Cornwall. Funded by National Lottery Charities Board; free to participants. ***Lynne Young, Pen-Cherry, 5 Keast Close, Indian Queens, St Columb, Cornwall, tel: 01726-861062.***

Saturday 21 March

ASBAH Study Day on spina bifida and hydrocephalus. Speakers include: Mr Taufiq Sattar FRCS, specialist registrar in neurosurgery, Booth Hall Children's Hospital, Manchester; Mary White, specialist continence adviser and Lorna Johnston, specialist adviser (education/hydrocephalus), ASBAH (Northern Ireland). 9am-4.30pm. Park Dean School, St Martin's Road, Oldham, Manchester. All day £7.50; morning or afternoon only £6.50. Closing date for bookings: 10 March. ***Details: Jean Black, tel: 0161-476 0059.***

Saturday 21 March

Cornwall ASBAH study day. ***Lynne Young, tel: 01726-861062.***

Sunday 5 April

ASBAH Family Day, an introduction to alternative therapy for children, aged 7-12 and their parents/guardians. Meldreth Manor School, Royston, Herts. Cost: children free; adults £5.00 each. Sponsored by BBC Children In Need Appeal. Closing date for applications: 1 March '98. ***Details: Lynn Thomas, ASBAH services dept, 01733-555988.***

17–19 April

Adventure Training Weekend for young people with spina bifida and/or hydrocephalus, aged 11-17 inclusive, organised by national ASBAH, Low Mill Residential Young People, Askrigg, Leyburn, North Yorkshire. Activities include abseiling, archery, climbing, pony trekking, orienteering, gorge walking, high ropes course, caving. ***Cost: £30 per participant. Details: Rebecca Sewell, tel: 01733-555988.***

Monday 20 April

ASBAH South Beds Support Group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, 01582-605749.*

Monday 11 May

ASBAH South Beds Support Group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, 01582-605749.*

Saturday 16 May

'The Forgotten Parent', a study day for fathers/stepfathers of children/young people with spina bifida and/or hydrocephalus. Post-Graduate Education Centre, City Hospital, Nottingham. 10am–3.30pm. £10 per person, including buffet lunch. Book by 1 April. ***Lynn Thomas, ASBAH House, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, fax 01733-555986.***

Wednesday 20 May

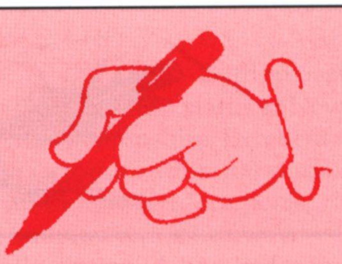
'Changes in Disability Benefits: what might they mean for parents and prospective parents with disabilities?' Seminar organised by the Maternity Alliance Disability Working Group, ASBAH House, 42 Park Road, Peterborough. 11am-3pm. £20, including sandwich lunch (free to parents not funded by an organisation). Sign language intepretation. The venue is accessible to people using wheelchairs. Speakers: a disabled parent, representatives from ASBAH and Scope. *Maternity Alliance, 5th Floor, 45 Beech Street, London EC2P 2LX, tel: 0171-588 8583, fax: 0181-588 8584. E-mail: ma@pro-net.co.uk*

5 – 7 June

'Having Fun, Feeling Great!' National ASBAH activities and workshop weekend for people aged 18 and over, Plas Menai, Portdinorwic, North Wales. Activities include sailing, kayaking, speedboat, climbing, abseiling. £50 per participant. ***Mrs Jill Bartlett, 4 Ta'ir Felin, Felinheli, Gwynedd, North Wales LL56 4JF.***

Monday 8 June

ASBAH South Beds Support Group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, 01582-605749.*



Dave's diary

JANUARY found me (and family) up north visiting my grandparents. We were polishing off another meal when the conversation turned to the Year 2000 and how would we celebrate it? Where would we go?

It seems bizarre to be less than two years (OK, three if you want to be picky!) from the New Millennium. By 2000 AD, I thought we'd be a united world, with people regularly holidaying on the moon, or driving our atomic-powered flying cars to work in Europe's capitals.

These days my hopes are more down to earth: All I want for the Millennium is to visit my nation's capital and get a little co-operation and help from Londoners when I get there. Shouldn't be too difficult, after all we've become a caring, sharing people since Princess Diana's funeral. Yeah right! And pigs will land at Heathrow! While I was out laying down flowers, some jobsworth was busy dropping a thirty quid parking fine on my Orange-Badge covered car.

After that little incident in London, I'd sooner spend Jan 1, 2000 AD in Outer Mongolia than our beloved capital. Well, the travel and parking's so much easier! OK, I'm exaggerating (slightly!), but you'll find more Orange Badge parking spaces in Outer Mongolia than central London, which just doesn't recognise the scheme. How disabled people live and work there I'd love to know. How do they stay mobile? I just can't do without my Orange Badge.

I do know London councils have a problem with finding suitable places for parking (disabled or otherwise). But then, so do I. And I know which one of us has the clout to make spaces for OB users available. The problem is that the Orange Badge scheme allows regions to either do their own thing or opt out completely of what's supposed to be a national scheme. It's weird. Without being less or more disabled, you go from the scheme not being recognised in much of London, to people being given extra time on yellow lines in Scotland. (And people say the Scots are mean?).

Seriously, it strikes me that the OBS has the same limitation as many other actions for disabled people – organisations are required to provide help, but only if they want to. Is it just me that sees the contradiction there?

To be the greatest benefit to disabled people, the scheme must be given teeth and imposed (by government or Europe, whichever has more clout by the Millennium) on the traffic controllers of our towns and cities.

At present the only toughening up done seems to have been aimed against the scheme's users. Now we are all required to carry our pictures in the badge. I suppose it stops fraud, but I reckon having my ugly mug looking out the windscreen all the time must scare off quite a few car thieves too!

Thinking about another work of art, as a nation we are planning to celebrate the New Millennium with the creation of the Millennium Dome. I'm sorry, but with the best will in the world it still looks like an upturned soup dish to me. Not that I'll ever be able to park close enough to get a proper look!

Had I been asked, I'd have said a better way to commemorate the Millennium is to provide proper disabled parking in London, via the Orange Badge Scheme, and open up the capital's Millennium celebrations to all the people.

David Fulford-Brown

DIARY DATES
Northern Ireland

Thursdays, until Easter

Keep Fit and Healthy Lifestyle, Joss Cardwell Centre, Belfast, 7.30-9.30pm. *Linda Maxwell, tel: 01232-761814.*

Wednesdays, 'til Easter

Survival Cookery, Ballymena, morning sessions. *Linda Maxwell, tel: 01232-761814.*

Thursday 5 March

Playday for parents of younger children with SBAH, Bannville Hotel, Banbridge, Northern Ireland. *Linda Maxwell, tel: 01232-761814.*

25–26 April

'Girl Talk', residential weekend for 18-25-year-olds with SBAH, Balmoral Hotel, Belfast. *Linda Maxwell, tel: 01232-761814.*

Thursday 27 August

Training Day for Classroom Assistants, Northern Ireland. Details to be confirmed. *Linda Maxwell, tel: 01232-761814.*

Letters

We invite letters for publication. Send them please to: *Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.* The Editor reserves the right to edit letters for publication, so keep them as short as possible.

WE read with interest the item on discounted AA membership for Orange Badge holders in the Oct/Nov *Link* and my husband applied.

When the application form arrived, we were disappointed to find he was only entitled to a discount if he paid by direct debit.

Having had a bad experience of a direct debit payment with another organisation, we now prefer not to get involved in payments of which we are not in control. We prefer to pay by cheque, which we find is much simpler.

It doesn't seem fair that Orange Badge holders can only make this saving on AA membership by paying by direct debit.

Lucy and Roger Elliott
Pinner, Essex

MY name is Jan and I 'd like a pen-friend who lives near Hastings. I'm 14 years old and live in South Germany. I have spina bifida and hydrocephlus but I lead quite an active life. I take part in all the lessons of our local comprehensive school. My hobbies are reading, collecting stamps and model trains.

This year, my class is going on a study trip to the south of England. That's why I would prefer to have a pen-pal who lives near Hastings as there might be a chance to see you!

Please write to: Jan Hanisch
Heinrich-Langenbach-Str 7a
D-76593 Gernsbach
Germany

OUR 16-year-old son Damien has spina bifida and is looking for a friendly family to stay with for one or two weeks this summer.

Would any British youngster with spina bifida like to stay with us at our home in Grenoble and then (or before) have Damien to stay at his/her home?

Francoise Rouyer
26 route du Peuil
38640 CLAIX
France
Tel: 04-76 98 67 70

I WOULD like pen-pals, aged between 40 and 55 years old, male or female, who are single and who have hydrocephalus and the same kind of spina bifida as I have, which is meningocele.

Miss M Ormsby
25 St Paul's Court,
Oswaldwistle
Lancs BB5 3HP

MY husband is able-bodied and we have two children, Ronald, aged five, and Susan, aged two.

I would like to contact other couples in which one or both of the partners has spina bifida so that I can get to know more people with the same disability as myself and share experiences.

Karen Hall
4 Mardale Close, Kempston
Bedfordshire MK 42 8JS

I HAVE spina bifida and have an able-bodied son, who is 12 years old. I would like to pass on my experiences to other females who would like to have a child, but are afraid to.

Sue Flaherty
Albuquerque, New Mexico
email: sbf@wizrealm.com

I SAW your article about Dr Sandler's book Living with Spina Bifida (*Link* No 172) and I promptly ordered the book.

I am writing to recommend the book to all parents of children with spina bifida. It was a light in a dark tunnel.

The book is written in a caring, easy to understand manner. It is split into different age-groups and is full of information, answering questions you did not realise you even had. It is clear that Dr Sandler cares about the children he treats beyond the care of a doctor. He not only feels for the children but feels for the parents also.

I have looked in lots of book shops for such a book for quite a while and at last I have found it. Congratulations to Dr Sandler and thank you ASBAH for bringing the book to our attention.

Mrs A Bate
Dudley, West Midlands

Editor's note: We have received inquiries about how people may obtain Living with Spina Bifida, *the new 262-page book by Dr Adrian Sandler, published by the University of North Carolina Press in hard-cover ($45) and paperback ($19.95).*

Most booksellers in Britain will obtain it on special order. Orders can also be placed through the publisher's London sales office at Trevor Brown Associates, tel: 0171-388 8500, fax 0171-388 5950, but there is usually a 10% surcharge on US prices and postage will be extra. Visa and MasterCard orders can also be taken at UNC Press, Order Dept, PO Box 2288, Chapel Hill, NC 27515-2288, USA, but add $4 shipping for one book, $1.50 for each additional book.

HOLIDAY ACCOMMODATION

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

WEYMOUTH BAY– Fully equipped, wheelchair-accessible caravan – sleeps five; on Haven Holiday Park, full use of all facilities – heated indoor & outdoor pools, bars, children's club & full entertainment programme. Three miles from Weymouth. *Details from: Margaret Humphreys, tel: 01494-714270 (Bucks & E Berks ASBAH).*

FRANCE – Ile d'Oleron, near La Rochelle – Mobile home for wheelchair-users. Fully adapted (shower etc), sleeps six, near beach, disabled owner. *Brochure from M Mardle, Fricourt, Filey Road, Old Heath Road, Southminster, Essex CM0 7BS. Tel. 01621-772447.*

SELSEY, WEST SUSSEX (SASBAH) – Fully equipped, purpose-designed for wheelchair access, mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. *Details from Mrs B Nunn, tel. 01903-763473.*

Mar y Sol – Tenerife – Wheelchair accessible apartments. Heated pool with hoist. Restaurant, poolside bar, equipment hire. Sunshine guaranteed all year round. Ring today for cheapest prices. *Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX, tel: 01753-685718.*

Algarve – Portugal – Wheelchair-friendly luxury villas with swimming pools, or small friendly hotels with adapted rooms. *Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX, tel: 01753-685718.*

FOR SALE

BEC Sterling Senior in perfect condition, front-carrier basket. £1,400 ono. Can deliver. Gerrard McCarthy, tel: 01483-487445.

ADJUSTAMATIC bed as new, 3ft 6in wide with built-in massage system to ease pain. Helps to ease a wide range of problems. Comes with two new mattresses – one firm, one medium. Was £2,400, now a bargain at £1,100. Tel: 01827-282633.

NAISH HOLIDAY VILLAGE, NEW MILTON – Clifftop park with "excellent" status at New Milton, Hampshire. Excellent site facilities within 100 yards, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible log cabin accommodation, Sleeps six, well-furnished. Free club membership.

GRANGE COURT HOLIDAY VILLAGE – Park with "good" status at Goodrington Sands, Devon. Excellent site facilities within short walk, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible, mobile home. Sleeps 4-6, well appointed. Free club membership. (Purchased with funds from the National Lottery).

MILLENDREATH HOLIDAY VILLAGE – Excellent seaside site with good facilities, just outside Looe in Cornwall. Restaurant, clubhouse, indoor pool. Fully-equipped, and fully wheelchair accessible, two-bedroom chalet accommodation. Sleeps six – well-furnished and comfortable. Free club membership.

Details: Mr P Cash, tel: 01425-672055 – Bournemouth Spina Bifida Association, registered charity number 261914.

LINK Rates

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Small adverts for the next issue of *LINK* (April) should be submitted by Monday, 9 March. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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