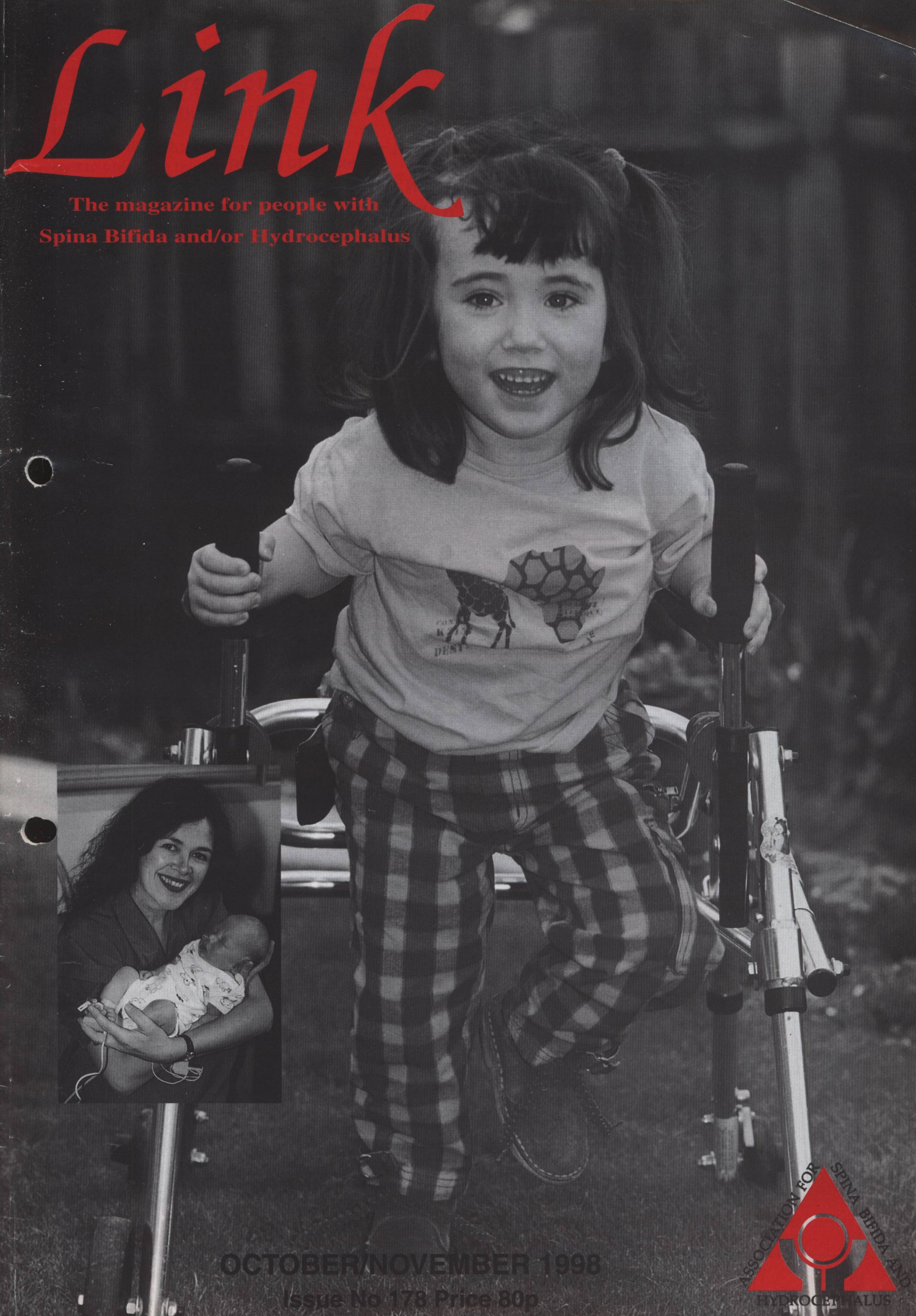
Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



OCTOBER/NOVEMBER 1998

Issue No 178 Price 80p

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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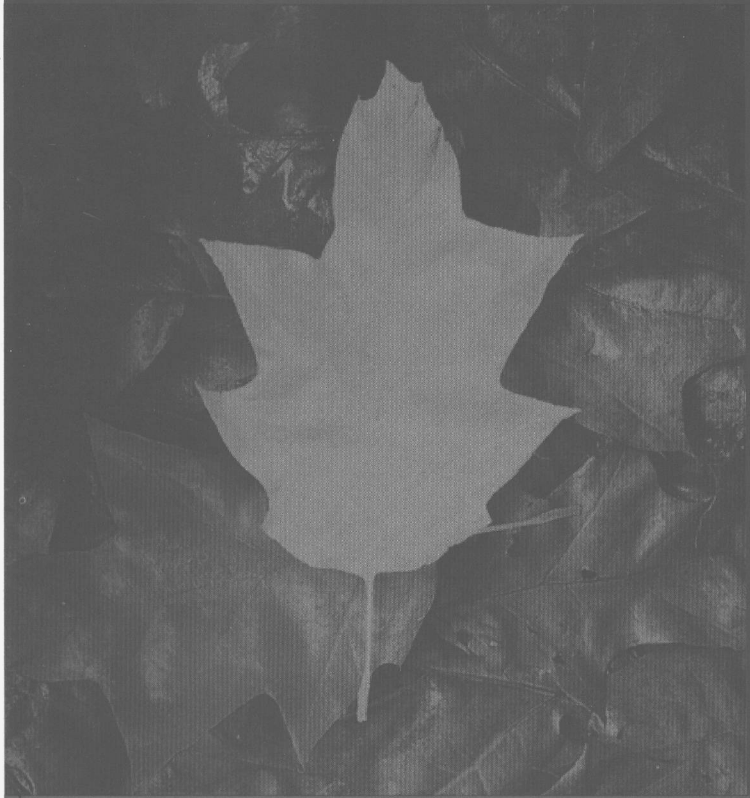

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EastEnders' story – 'worth 500,000 leaflets'

A SPINA BIFIDA storyline continues to unfold on the popular BBC TV soap opera *EastEnders* – after Bianca discovered in mid-September that she was pregnant for the second time.

Bianca and Ricky's decision to terminate their first pregnancy last November after prenatal diagnosis of spina bifida and hydrocephalus attracted major media attention at the time. It also won a BAFTA nomination for the actors involved, Patsy Palmer and Sid Owen.

ASBAH has again been involved as script consultant and has given the BBC all the information needed for a positive portrayal about people with disabilities, their great contribution to society and their right to full participation. But, as with last time, ASBAH has no editorial control over what actually appears on screen.

We also impressed on the BBC the vitally important part that folic acid supplements play in helping to prevent spina bifida. Strong, clear messages about folic acid have been given on screen.

"So far, so good, and the folic acid messages have been worth half a million leaflets in doctors' surgeries," commented ASBAH publicity manager Tony Britton.

Letter from ASBAH's Executive Director

Andrew Russell, Executive Director

Dear Friends

IT HAS been a busy and interesting year so far for ASBAH, with more changes due. I was particularly pleased to attend six regional meetings of local Association members around the country, at which it was good to see many old and new friends and to hear a huge amount of news. ASBAH's five-year strategy was the main topic – ensuring that members know what we're doing and why, and taking on board your comments.

The work of ASBAH's Advisers continues as the core of our work, meaning we get alongside families and individuals when we are needed, to offer our support and the knowledge we have gained from our members and service-users over 32 years.This is the key, important task for which ASBAH was set up. It is as relevant as ever today, and I am extremely proud of our professional team.

We were kept busy making sure that the GMTV Appeal in July was as successful as possible both in raising funds and in raising ASBAH's profile. Among many people who played a part, two in particular illustrated how well our message about people with spina bifida or hydrocephalus can be put across on TV. These were the two Davids.

David Nicholson, as a retired accountant with hydrocephalus, was able to show through his mature comments how someone with this disability can have an interesting and successful career and play a valuable part in an organisation such as ASBAH. David Proud charmed millions of viewers with his positive attitude and a certain sparkle which, at 15 years old, will open doors for him in the future.

continued on page 4

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ASBAH is a registered charity

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

Double cover star (main photo): Four-year-old Gabrielle Gibbons, from Hampshire, who is featured on the cover of ASBAH's 1998 Annual Report and Accounts, see page 9. Inset photo: Bryony Jones and her new baby, see 'Mother's agony' feature, pp 14-16.

STAFF NEWS

- Joanne Grenfell is the new specialist adviser (education) and will work 'in tandem' with Mike Dodd until his retirement on 6 November. *She is based at the Northern Region office on Thursdays, tel: 0113-255 6767.*

Over a career spanning 16 years, Joanne has taught children of all ages – from nursery to 'A' levels.

She will continue with her present job as part-time co-ordinator of a Resource Provision Unit, where she is responsible for integrating children with disabilities – including spina bifida, hydrocephalus and cerebral palsy – into a mainstream junior school. In this job, she works alongside a speech therapist, occupational therapist and physiotherapist, and is involved in training teaching assistants.

Joanne holds a Master's degree in Education from Hull University, and gained a Special Educational Needs qualification from Bradford University. She is acquainted with annual reviews and the statementing process.

Married with two children, aged two and seven, Joanne likes gardening and watching movies. She lives in Huddersfield.

- Lucy Holmes has been appointed part-time adviser for West and South West London, following Deryck Brown's move to Virgin Atlantic, and the re-organisation of adviser patches in London.

Lucy takes up her post in October on completing her Child Branch Nursing Diploma.

She has previously worked as a residential social worker with physically disabled children and, in New Zealand, as a sports instructor teaching disabled people outdoor pursuits.

She has a BA degree in Sports and Recreation Studies: her dissertation was on teaching outdoor pursuits to disabled people. Her interest in caring came about while she was working as a sports instructor in the Lake District and New Zealand.

- SIMON Forshaw is a new assistant housing support worker at the Five Oaks Housing Scheme following the departure of Juanita Vernau.

Simon was a decorator for four years after leaving school, but then became interested in youth work and became a relief housing support worker for homeless people in Leeds and Bradford.

Five Oaks Housing Scheme is jointly run by Bradford Social Services, Sanctuary Housing Association and ASBAH.

Letter from the Executive Director,

from page 3

I was really grateful to both Davids, and delighted with these messages. Thanks, too, to all the staff and members who freely gave their time and efforts to this important opportunity for ASBAH.

An essential part of my job is to put the needs of our members across to the Government, and I have been making sure ASBAH is known to politicians from all parties, and to the new Government in particular. We have been commenting to ministers and Departments on a series of vital policy issues in the fields of health, education and social security, in many cases with the help of our User Forum, Your Voice In ASBAH. The Government has promised change, and we have to make sure that those with spina bifida and hydrocephalus are fully taken into account.

At the end of the year, two people are retiring who have loyally served ASBAH for more years than they care to mention, and whose contributions continue to be immense. This is not the proper occasion for tributes, but I will just say here that Derek Knightbridge and Teresa Cole will leave enormous gaps when they retire, and we are gearing up to make sure that the changes go smoothly.

We have made some changes in our senior management structure, and two new appointments have been made. Our new Finance Director and Company Secretary will be Mr Brian Deffee, an experienced and qualified accountant and company director. To the new post of Assistant Director (Policy and Marketing) we have appointed Mrs Linda Hams, formerly Executive Director of Dogs for the Disabled, a division of Guide Dogs for the Blind. She comes to us with qualifications and experience in industry and marketing, and a track-record in the charity sector. Welcome, very warmly, to both.

Thanks to all of you who have given us encouragement and your support in a year which has been rushing past faster than ever. All of us staff, whether we work in ASBAH House, from home, in a Regional office or an ASBAH shop, appreciate being part of the ASBAH "family."

Best wishes

Andrew Russell

Andrew Russell

MBE for David Holding

PARALYMPIC champion, world champion and world record holder David Holding has been honoured by The Queen with an MBE.

The 30-year-old, from Kettering, Northants, was among those rewarded in The Queen's Birthday Honours List.

His mother Patricia, father Rodney and sister Julie will attend David's investiture at Buckingham Palace on 30 October.

David said: "It's nice to be recognised for my achievements."

In August, he added the Class 55 100 metres world title to his Atlanta Paralympic gold medal at the Disability World Athletics Championships in Birmingham.

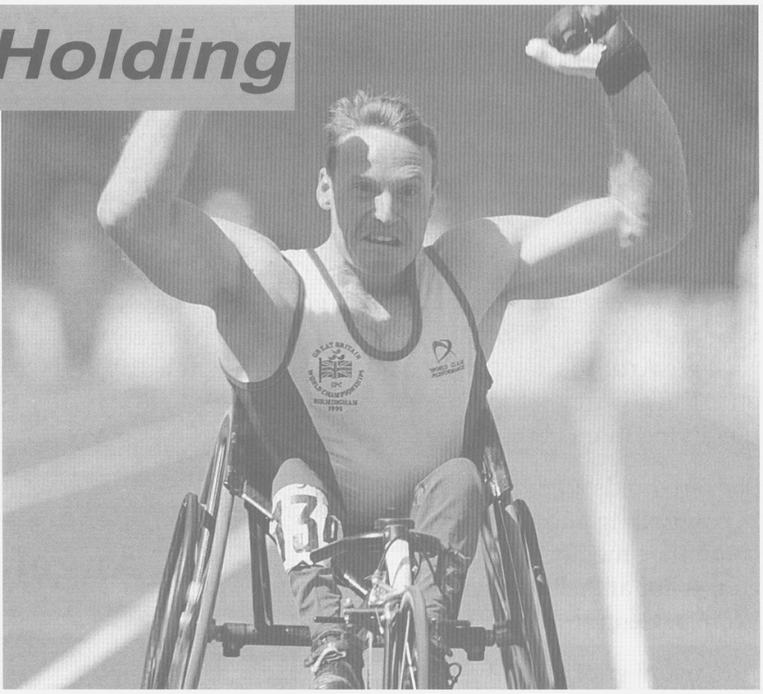


PHOTO: GRAHAM BOOL

David Holding winning the 100 metres at the Disability World Athletics Championships in Birmingham in August

Now he is working towards his current long-term goal – to win another gold medal for the 100 metres in the Year 2000 Paralympics in Sydney, Australia.

David trains every morning before going to work – fortunately, his day as an accountant does not start until 10.30am.

"In wheelchair racing, you have to be a good sprinter as well as having a high level of stamina. You have to like training and like the exercise to get into it. You've got to be really keen on it as racing chairs aren't easy to sit in."

David started racing at school at 14. He entered junior regional athletics championships, organised by BSAD – now Disability England – and got through to national competitions.

He gave up racing for a year after leaving school but then noticed how wheelchair racing was becoming more popular, so started training again.

So what is David's advice to youngsters just starting out or wanting to improve? Join a weekend organised by the British Wheelchair Racing Association. Free first year's membership with newsletter, coaching at weekends and you can even be loaned a chair. *Details from: Rick Cassell, 31 Bostocks Lane, Sandiacre, Nottingham NG10 5NL.*

Fact*file*: David Holding

- **Gold medal 100m (Class 55), Atlanta Paralympics 1998.**
- **World record holder 100m.**
- **Four times London Marathon winner.**
- **Silver medal 800m, Commonweath Games, Canada, 1994.**
- **British record holder in marathon, half marathon, 10k and 5k.**
- **British record holder in 100m, 200m, 400m, 800m & 1500m track events.**

Officers & Staff

STAFF NEWS EXTRA ... STAFF NEWS EXTRA ...

● Shirley Kearns is Northern Region's new specialist adviser (occupational therapy) following Rose Hinchliffe's move to St James's Hospital.

Shirley has just completed a three-year research project on Juvenile Chronic Arthritis, having worked as an OT in a variety of settings since qualifying more than 20 years ago.

She also holds a graduate diploma in counselling and is a management committee member of and counsellor at the Wakefield Well Woman Centre.

As a member of the Religious Society of Friends (Quakers), she co-convenes the Children's Committee in Huddersfield, occasionally taking the Children's Meeting (Sunday School).

During a career break, ending in 1987, Shirley worked for the York-based Family Fund as a visiting social worker.

Shirley is married to a senior social worker and has four children.

She is based at Northern Region office on Mondays and Wednesdays, tel: 0113-255 6767.

Goodbye to Jill and Rea

● JILL WHITMORE, one of our receptionists at ASBAH House, has left to train as a rehabilitation worker for people with visual impairments.

Jill, who is arguably less well known than her guide dog Rea, will work towards a Diploma in Higher Education at the Guide Dogs for the Blind School of Vision and Rehabilitation in Hindhead, Surrey.

Jill has worked for ASBAH for more than seven years. She has raised £1,350 for ASBAH in two major sponsored walks in consecutive years.

CHANGES have been made to the areas covered by three advisers in order to provide a service for people in Worcestershire.

● Warwickshire, Coventry and Solihull (postcodes CV, B37 and B90-95) are covered by Jenny Green, tel: 01926-511206.

● Staffordshire (except south, below Wombourne), Walsall, Wolverhampton and Sutton Coldfield (postcodes WS, WV and B72-79) are covered by Liz Henshall, tel: 01538-753006.

● Birmingham, Dudley, Halesowen, Sandwell, Worcestershire and south Staffs (below Wombourne), postcodes B (except 37, 72-79 and 90-95) are covered by Geraldine Long, tel: 01789-763090.

Angela's 20-year milestone

● SEEING the people she has known grow up from babies to independent living in adulthood, has been major source of job satisfaction for our longest serving adviser.

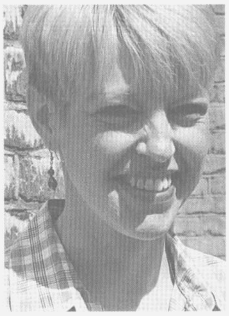
Angela Lansley, whose 20 years' service was marked with a presentation at our Northern Region centre, covers Merseyside and South Lancashire full-time.

When she joined ASBAH in 1978, advisers were called social workers and her patch was St Helens in Merseyside.

Angela said: "Being an ASBAH adviser is a wonderful job. I have made many good friends out of the people I work with."

Angela has competed an MA which looked at disabled people's input into ASBAH. Her research was entitled 'From Royals to Rights' to see whether ASBAH had moved on from having a disabled person presenting a posy to a member of the Royal family to a rights-based organisation.

Angela said: "*Your Voice In ASBAH* is an able and articulate group and I was interested to see how you could encourage less able people to play a role."



● STEPHANIE Etchells has taken up the new role of data and information development worker at national centre.

Stephanie's job is to review and update all records, and improve information collection, analysis and communication.

The fulfilment of these tasks will enable us to make more effective use of all the information given by staff reports and so on.

The 20-hour-a-week post is being funded for three years by a grant from the Department of Health.

Stephanie, a mother-of-two, was formerly employed doing similar work by travel firm Thomas Cook.

● NORTHERN REGION'S specialist adviser (medical), Sue Ingham, has left to take up a full-time post at the Army Apprentice College in Harrogate.

While a replacement for Sue is being found, medical support for those in the North will be available from national office on 01733-555988.

● JOHN RICHARDS, Beds & Herts adviser, has returned to work after recovering from a car accident.

Occulta experiences

A self-help group has been formed in Leicestershire, co-ordinated by ASBAH adviser Cathy Harrell, which is proving useful to three women, who found out they had spina bifida occulta – the so-called 'hidden spina bifida' – late in life. Editor LIZ CAWTHORNE met them and now tells their stories.

Meeting of the Leics Spina Bifida Occulta Group and their children. Left to right: Cathy Harrell, ASBAH adviser, Val, Michelle and Claire.

"WHEN I found out I had spina bifida occulta, I was so shell-shocked, I had to talk to somebody, so I rang ASBAH," said Val, a member of the Leics SBO Support Group.

But she only found out ASBAH's phone number when she happened to walk passed a stall at a car boot sale which was being run by the local ASBAH group.

"My spina bifida occulta was diagnosed, unknown to me, when I was 16. I only found out, by accident, when I was 38, after reading my GP's notes which had been left open while I was being treated for an ear infection.

"I was amazed that I had the condition. It was a great shock to me."

The dramatic revelation meant Val could start putting together everything she had ever wondered about in her medical history.

At school, she had had difficulty doing PE. She was born with a deformed foot and a thinner left leg. She had two operations on her foot when she was 19, but nobody told her what might have caused it.

But the real tragedy for Val, now

continued on page 8

SB OCCULTA WAS A THEME OF THIS YEAR'S SPINA BIFIDA WEEK, 14–20 SEPTEMBER

Help & Advice

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

Greater London, Berks, Hants, Kent, Surrey, 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.

Bedfordshire, Cambridgeshire, Derbyshire, Essex, Hertfordshire, Lincolnshire, Leics, Northants, Nottinghamshire, Norfolk, Suffolk

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.

Cleveland, Cumbria, Durham, Greater Manchester, Humberside, Lancs, Merseyside, Northumberland, Tyne & Wear, North Yorks, South Yorks, West Yorks

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.*

Val's experience, from p 7

aged 45, not knowing she had SBO, came when she and her husband tried for a family.

Her first baby was born prematurely due to having anencephaly – the most severe and fatal form of neural tube defect in which the brain does not form properly or is absent.

She later had an ectopic pregnancy – where the foetus is formed outside the womb – which nearly killed her.

Fortunately, Val went on to have a test tube baby with no problems – Natalie is now four and a half. But Val is angry that nothing was said about her SBO by medical staff at the time of her earlier pregnancies.

In recent years, Val has found she has to pass water quite often, mainly at the night. In the day-time, she can only pass a little urine even when her bladder feels full. "I seem to only be able to 'go' properly at night – I may have to go three or four times," she says.

Val is often physically exhausted at the end of the day and has a weakness in her right leg. She also has scoliosis – curvature of the back.

Due to her leg problems, Val has recently been referred to a neurologist.

Occulta experiences

MICHELLE, another member of the Leicestershire Spina Bifida Occulta Support Group, now has to use sticks and a wheelchair to help her get about.

Michelle remembers that she was a clumsy child who was always falling downstairs and whose toes have always curled over. From the age of 13, she had other problems, such as urinary tract infections and kidney infections. Later, when she was pregnant, she was treated for kidney scarring.

During her pregnancy for her second child, Michelle suffered continuous urinary tract infections and needed a special support to carry the extra weight.

After the birth of her second child, at the age of 24, she was referred to a back specialist. His assistant examined the lower part of her back and said: "I think you've got a form of spina bifida."

An x-ray confirmed she had spina bifida occulta. Michelle said: "I was told I'd got SBO but there was nothing to worry about and that there was no pain with it.

"But the pain has got worse and it's now terrible and I have to take painkillers which have their own side effects."

Two years ago, she got a second opinion but this resulted in her undergoing a rigorous three-week physiotherapy programme. This left her in a worse state than before with pins and needles in her legs, complete loss of bladder function and loss of feeling in her right leg.

Due to the numbness in her leg, multiple sclerosis was suspected so, at the age of 27, she was referred a neurologist.

"I had an MRI scan which dismissed MS but confirmed the spina bifida occulta. Doctors told me the feeling in my leg would come back."

Eighteen months later, Michelle is still without feeling in her leg. She also suffers from constipation and bladder problems.

She now needs a wheelchair to go out with her husband and two children on family holidays.

The uncertainty of her condition wears her down. "One week I'm in a wheelchair, the next week I'm not," she said.

CLAIRE, a mother-of-three, discovered she had spina bifida occulta just over two years ago when she was 25.

She said: "I was born with a dislocated hip and a slightly deformed foot. Whilst at school, I had recurrent back pain and I remember my parents bought me Start-Rite shoes which were built up for me.

"On leaving school, I tried various jobs, like shelf stacking, but all of them hurt my back, so I gave up."

At first, Claire's GP said the back pain was due to her having children. Then he diagnosed possible arthritis, and she underwent X-rays which showed spina bifida occulta. An MRI scan showed she had problems but these were not considered severe enough.

Another wrong diagnosis was made when she told her GP she suffered from constipation – she was told she had irritable bowel syndrome.

Claire said: "The main symptoms I have these days are pins and needles, which leads to numbness in my left leg, tingling in my arms, and bowel and bladder disturbance. You can stick pins in my lower left leg and foot, and usually I can't feel them."

As well as the pain and discomfort, Claire is not fit enough to hold down a job, yet is having difficulty claiming Disability Living Allowance (DLA).

She said: "When I applied for DLA, I was refused, so I went for a job as an industrial cleaner, working three hours a night, five nights a week. After one week, I was in agony."

Claire was advised by her GP to resign from the job, but he did not mention the spina bifida occulta in the letter he wrote in support of her resignation.

Claire said: "It's important to have a diagnosis for your own peace of mind, so you can claim any benefits you are entitled to, and from a hereditary point of view – it is important for my daughters to know that their mother has spina bifida."

Now Claire is on her second attempt at claiming DLA and this time, since having an MRI scan, her GP has acknowledged spina bifida occulta on her forms.

"Hopefully, it will be just a matter of time before other areas of the system acknowledge spina bifida occulta as a disability," she said.

Empowerment champion to retire after 17 years

AFTER 17 years with ASBAH, first as fieldwork manager and latterly as assistant director (services), Teresa Cole will be retiring shortly after Christmas.

At every stage of her career and from her vantage point, Teresa has been able to assess if national and international policies on disability have been mere weasel words or whether they have had a real impact for the better on the lives of disabled people.

Teresa, also vice-president of the International Federation for Hydrocephalus and Spina Bifida, has penned these thoughts for *Link* magazine.

Teresa Cole

Seventeen years ago, I left a job I enjoyed but one which was very stressful, and moved to a village outside London to fit in with my husband's job. I decided to look for a post that would be interesting, quiet and non-stressful. I chose ASBAH!!!

In the UK, we have had so many hopes raised and then dashed in recent years as many parts of the country fail to deliver the goods on educational, social and benefits reforms for disabled people.

The stop-start progress on civil rights for disabled people has been typical of the halting pace. But empowerment has gathered pace in the last 17 years, and ASBAH's work within this area with YVIA, in which I have been closely involved, has both reflected the spirit of the times and led the way in many aspects of user-involvement.

The DDA with all its shortcomings is one indication that attitudes in Government are changing and the recent announcement of a Disability Rights Commission is an encouraging sign that change is being driven more proactively.

Statementing for special educational needs and the relevant Education Acts were big steps towards making sure that disabled children realised their potential. Sad to relate that, even in this area today, there are still struggles to obtain classroom and therapy support, and full access.

The benefits system continues as a big, confusing maze of new names, lengthy forms to fill, concern and uncertainty. Consider yourself lucky if you have someone like an ASBAH Adviser to show you the way through.

One of the most far reaching changes for the better has been in the type of accommodation considered appropriate for disabled people. When I joined ASBAH, the large, residential establishment was much in favour.

These have now largely been closed and they will not be missed. In their place, we see a much wider choice of places to live – small group homes, one-person flats and so on. People with disabilities can make choices which give them the level of independence they prefer; the individual has become the focus, not the requirements of an amorphous bureaucracy.

At the heart of user-involvement/ empowerment, we must not lose sight of the fact that choice can be frightening to users and providers alike. The fear and anxiety of losing control, of failure, of exposing one's vulnerability require a recognition of the differing, even conflicting, interests involved.

Empowerment should involve responsible attitudes and behaviour on all sides, developing ways of negotiating from different strengths and perspectives, of supporting people as they gain (or regain) control, of providing advocacy for those who cannot speak for themselves and the validation of people's abilities and experiences.

Loss of dignity – either because people are denied a full role in deciding their own future or because they just do not have enough to live on – must become a thing of the past as we approach the Millennium.

It has been a privilege to be part of the growth of ASBAH over the last 17 years. I have made many friends among staff and the families and individuals with whom I have come into contact. I will miss their friendship and support.

I know also that ASBAH will continue to be a leader in good practice. I will follow its fortunes with interest, whatever I do in the future.

Link cover star

HAPPY Gabrielle Gibbons, aged four, is our double cover star – of this issue of *Link* and the 1998 ASBAH Annual Report and Accounts.

She attends The Cedar School in Southampton for children with physical disabilities and a local playgroup where she meets non-disabled children from her local neighbourhood in Woodley, Hampshire.

She loves going horse riding every week at the Fortune Riding Centre in the New Forest and enjoys swimming lessons. Her mother, Pauline, joked: "Gabrielle has a busier social life than us!"

Ward closure would wound ASBAH families

PLANS to close a hospital children's ward in Cornwall, where the NHS is in financial difficulties, could affect the quality of support given to disabled people in the west of England's most isolated county.

If the Rainbow ward at the West Cornwall Hospital, Penzance, is shut to ease the cash crisis, west Cornwall families wanting to visit children recovering after major operations at Treliske Hospital in Truro will have much further to travel.

"Beds in the Rainbow ward are used regularly by children recuperating after major operations at Treliske, the county's only general hospital. Closure of the Rainbow will make life very difficult for families because of the long distance involved," said Lynne Young, ASBAH adviser in Cornwall.

Mrs Young, a member of the county's Community Health Council, was in the thick of a fight which in August, resulted in Health Secretary Frank Dobson rejecting the local health authority's plan to axe four cottage hospitals in Cornwall.

On 13 August, the Health Secretary travelled to Cornwall to announce that he refused to allow the closure of four cottage hospitals in Fowey, Saltash, St Ives and Penzance. The closures were part of a strategy drawn up 11 months ago by Cornwall & Isles of Scilly Health Authority to reduce a £4m deficit.

Mr Dobson said of the hospitals: "I believe the people of Cornwall need them, particularly because of the huge distances that need to be travelled. . . (they) are crucial to the health and healthcare of the people living in the county, and that is why I have decided they have got to be kept."

But he did not give details of any new money to be spent on Cornish healthcare and the proposal to close the Rainbow ward soon emerged. The health authority pointed to the fact that it did not have permanent paediatric consultant cover as recommended by the royal colleges, but campaigners urging it to be kept argue that cover can be arranged from Treliske.

Other hospital bed cutting plans are in the pipeline, as are probabilities that the Penrice Maternity Unit in St Austell will go and improvements to cancer, heart and kidney care at Treliske will be delayed. Two NHS Trusts – Cornish Healthcare and Trecare – are also likely to be merged to achieve management savings.

ASBAH adviser Lynne Young said: "The whole focus of the original strategy was Treliske, Treliske and Treliske again, where, in fact – with the help of a public appeal called the Joey Appeal – they have just started building new children's facilities.

"But I had to complain at architect design stage that no account had been taken of the needs of children in wheelchairs, or indeed of parents in wheelchairs who stay with children overnight, before anything was done about it. These facilities are now included."

Continence and wheelchair services reviewed

LITMUS test NHS reviews – on continence and wheelchair services – are being steered by Health Minister Paul Boateng.

On 2 September, he ordered the setting up of an incontinence working party with a firm brief to publish new guidance on continence services by Spring next year.

Mr Boateng said: "Good continence services are a vital component of the National Health Service. They play an important part in enabling people to lead independent lives. I want to ensure that the NHS provides a modern continence service that lets people have access to high quality, prompt and readily available assistance."

In June, he promised to complete a review of the £50m wheelchair services initiative, also by the Spring of next year. The scheme allowed the NHS to provide powered indoor/outdoor wheelchairs for severely disabled people and set up a wheelchair voucher scheme – allowing users to put the cost of an NHS wheelchair towards a higher quality chair of their choice.

Spending on the wheelchair voucher scheme fell abysmally below expectations in its first year. By December last year, health authorities had spent just £225,000 of the £7m ring-fenced funding available.

ASBAH executive director Andrew Russell commented: "The results of these two reviews will be litmus tests of the way the Government behaves towards severely disabled people.

"In both cases, we need reassurance that these services will be taken seriously as essential elements of the NHS and that good continence services and wheelchair provision are recognised as being important to the every day health needs of citizens."

▲ ***ASBAH's own annual snapshot survey of NHS continence supplies was due to be published at the end of September. Last year, it revealed a worrying trend among some NHS trusts of cutting services to pre-school age children.***

Mike Dodd to retire

THERE have probably been a few fireworks in the career of one of our most respected specialist advisers, who retires the day after Bonfire Night – his 60th birthday.

With masses of experience as a special educational needs teacher, headteacher, local education authority and Church of England education adviser, OFSTED inspector, independent training consultant and sixth form college governor – together with a fabulous sense of humour – Mike Dodd will be missed by both staff and parents.

Since joining Northern Region, three years ago, as specialist adviser (education), Mike has been impressed by the general quality of ASBAH advisers – their knowledge and ability to learn, and to put what they learn into practice.

He has also gained a great deal of admiration and respect for both parents and children.

"I have thoroughly enjoyed my time here," he says.

He has gained a lot of pleasure in helping families to win their cases against local education authorities (LEAs) at the Special Educational Needs Tribunal. But the real satisfaction has been getting disputes sorted out before they go to tribunal by networking with his LEA contacts.

Mike said: "The interesting thing about special education is that it will always be at the cutting edge of education. As soon as one need is met, another need arises. There are children integrated today who you wouldn't have thought would be integrated 10 years ago."

He is worried, however, that the current Government's emphasis on excellence in schools will lead to schools not fulfilling or ignoring special educational needs.

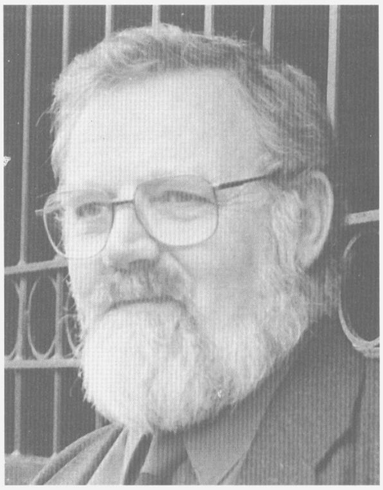
But he does not believe this will result in a big comeback for special schools as this is not what most parents want and, in his opinion, would be a more expensive option than mainstream integration.

"In fact, there is now more demand for integration into neighbourhood schools, rather than resourced primary schools, as children want to go to school with their friends which means that teachers don't have the back-up or information about the disabilities. I have gone in to train teachers about hydrocephalus and I think, increasingly, there will be a need to do this."

He added: "Similar demands are now being made in further and higher education which we have not had to fight for in the past and which we will have to do more of in future."

Demands include improved physical access, teacher information, resources and support, and more positive attitudes about disability.

He said: "Attitudes are the hardest things of all to change, but this is mainly due to the teacher's fear of letting children with special educational needs down in their education. Most teachers are highly conscientious and my job has been to persuade them that they can make a difference."



When he retires, Mike will continue as a recently-ordained unpaid curate at St John the Evangelist Church at Golcar, Huddersfield, where he works alongside the vicar doing the normal job of a priest, conducting marriages, baptisms and funerals. "I received a bash on the head from God after staying away from the Church for 30 years," he says.

And he looks forward to spending more time as a 'professional' grandfather and more time on holiday in Brittany and Tenerife. He will also be able to 'garden properly' and, in his wife Jill's words, 'become a house husband' while she continues to work as a MENCAP day centre manager.

Mum battles on for son's education

A MOTHER is still fighting for her son to get an appropriate primary education – even though her complaint against an authority over her son's nursery education was upheld by the Ombudsman.

With the help of Mike Dodd, ASBAH's specialist adviser (education), Karen Spencer appealed to the Local Government Ombudsman about Sefton Metropolitan Borough Council when a two-month delay in writing her son's statement and a further delay in issuing it, resulted in Jack losing four months of nursery education.

Jack's statement was just one of a backlog of 100, which council officers said had accumulated since the introduction of the Code of Practice. The Code of Practice says that councils should normally issue a statement of a child's special educational needs within 26 weeks of the start of the formal assessment process.

In May, the Ombudsman concluded that Mrs Spencer, from Southport, had sustained injustice in consequence of maladministration and should be paid compensation in recognition of the delay and the stress caused by the delay. The council was told to pay

continued on page 12

Find out in the next issue how much money was raised for ASBAH in GMTV's Get Up & Give appeal

Mum battles on, from p 11

Jack Spencer, whose mum is battling for him to go to his local primary school

£50 for each month of the delay, as well as a further £150 in respect of the time and trouble caused to Mrs Spencer in pursuing Jack's case.

In addition, the council was advised to review its approach to children with special educational needs, both in terms of the staff required to deal with the administrative workload and in terms of funding for the provision required by statements.

However, despite the Ombudsman concluding in favour of the Spencer family, they had still not received compensation in September. Even worse, Mrs Spencer had been forced to start a fresh battle to ensure that Jack could attend his local primary school.

In September, Mrs Spencer said: "Jack started primary school today yet has still not been issued with a statement. Even though the council has agreed for him to go to our local primary school, they have refused to pay for any adaptions which means nothing was in place on his first day.

"The school governors have agreed to pay for four ramps and toilet facilities, but when I saw that a single ramp costs £1,000, I felt guilty as this is more than is raised at a single school fete.

"But then, I thought, why should I be grateful when all I am trying to do is ensure my son is educated at his local school?

"So, we are still battling on but, despite all the heartache, I'm not going to give up now. I would like to thank Mike Dodd who helped with the wording of our letters and told us who to complain to."

She added: "When we started with our complaint about Jack's nursery education, at the beginning of 1997, we took two tacks – the Ombudsman and Department of Education. We did it to frighten Sefton but, since then, there have been so many phone calls and letters. I could have given up but I was determined. They treat it like a job but to you it's the future of your child and it's so important."

Mike Dodd commented: "This was an important decision by the Ombudsman and very satisfying for me as an ASBAH adviser.

"If a council has slipped up in legal terms, sometimes just threatening to go to the Ombudsman is enough to push a council into action."

H&SB conference in 1999 is down-under

PERTH, Australia, is next year's venue of the Eleventh International Conference on Hydrocephalus and Spina Bifida.

The conference theme will be *A future with purpose – A future with choice*. There will be guest speakers from overseas and Australia. Medical issues as well as those to do with family and every day life will be covered.

The conference creates a opportunity for people with spina bifida and/or hydrocephalus to come together, with spouses, family, carers, policy makers and planners, local authorities, researchers, doctors, medical staff, academia and anyone interested in the management of the condition and care of individuals, and plan *A future with purpose – A future with choice.*

The conference runs from 23-26 September 1999 at The Sheraton Perth Hotel – a five-star property offering luxurious rooms, 24-hour room service, first class restaurants and bars, plus heated pool and gymnasium.

Prices range from $12 to $175 per night and cater for single, family or shared accommodation.

So delegates have the opportunity to mix and network in a relaxed and social atmosphere, an interesting and entertaining social programme is being designed. The conference opens with a welcome reception on Thursday 23 September 1999, involving a meal and entertainment on a cruise up the Swan River by night.

Delegates and accompanying persons will find spectacular touring opportunities in Western Australia, ranging from the majestic forests of the south-west to the unspoilt rugged beauty of the north. A range of pre- and post-conference tours, to suit a variety of budgets and tastes, will be featured in the conference registration brochure.

For those wishing to have an extended holiday in Perth, the Spina Bifida Association of Western Australia has secured some very affordable accommodation for all its delegates and visitors for the week following the conference.

Contact: 11th International Conference on Hydrocephalus & Spina Bifida, Secretariat, Petrie International, PO Box 568, Kalamunda WA 6076. Tel: (intl 61) 08 9257 2088. Fax: (intl 61) 08 9257 2099. email: petrconf@iinet.net.au

Beauty therapists asked to get in touch

A BEAUTY therapy student is keen to hear from anyone else doing this work from a wheelchair, to exchange information/tips.

- ***Kristie Crawford can be contacted on 0151-280 8143 or you can leave a message on the ansaphone of her ASBAH adviser, Angela Lansley, on 0151-733 8392.***

AGM reports

MAKING your voice heard by the Government on a wide variety of issues that could shape the future of disabled adults and children, was the most enduring message of a wide-ranging talk by Philippa Russell OBE, Director of the Council for Disabled Children.

In her talk at our AGM, *Getting A Life: Social Inclusion and Public Policy*, Mrs Russell began by describing the twists and turns in the life of her son, Simon, who has hydrocephalus and has recently been diagnosed as having Benign Intracranial Hypertension.

This has included her son getting a mortgage from a building society which was, at first, surprised to discover that someone with learning difficulties could have their own home.

"In some ways, life for disabled people has never been better but also, in many ways, it has never been worse," said Mrs Russell.

She mentioned the Benefits Integrity Project – her son Simon was one of those quizzed about his disability in relation to receiving Disability Living Allowance.

On a more positive note, the Disability Discrimination Act (DDA), section on Access to Goods and Services, she said, could have easily been left in mothballs. But promises for this section to be heard in the first year of the new Government, and the promise of a Disability Rights Commission, never materialised until they were forced back on the agenda by disabled people.

Mrs Russell appealed to everyone to get the new pack on the DDA and comment on it – even if you do not feel you can answer all the questions.

"In David Blunkett's words, the number of responses to consultation that land on a Secretary of State's desk directly determine how important it is," she said.

At local level, it was again up to individuals to ensure that the DDA Goods & Services section was implemented by checking that access to buildings was done in a way that disabled people wanted.

Christmas is coming ...

ASBAH has extended its range of Christmas goods. We will have the range of personalised Christmas cards that we have done for the last two years. Prices start from £54 for 50 cards, and 35% of every order value comes to ASBAH.

We also have a supply of Fundraising Direct Christmas catalogues for the purchase of cards, gift wrap, decorations, calendars, toys and gifts. Prices are very competitive (cards start from £1.99 for 24), and 25% of every order value comes to ASBAH.

● ***Copies of the personalised Christmas card leaflet and/or catalogue from Elissa Lowder, Appeals Department, on 01733 555988.***

MEMBERS voted to fill seven vacancies that had arisen on ASBAH's Executive Committee from eight nominations.

Those who were voted on to Executive Committee were: Michael Booth, Godfrey Bowles, Edward Evans, Eileen McCabe, Eric Prentice, Tim Robinson and Brenda Sharp.

AT OUR annual meeting, during the presentation by a Charity Commission representative, members raised the question of whether members of executive committees (charity trustees) and people connected with them (family members) can receive benefits, for example grants or services, from the charity of which they are a trustee.

In normal circumstances, they cannot, under charity law. However, recognising that user involvement is desirable, in 1994 ASBAH negotiated a change in the recommended **model constitution** for our local associations.

All local associations that adopted this constitution have the power to benefit trustees (and connected people) provided that, in the making of that particular decision, the trustee is not present and does not participate.

This power is provided for in Section 18, Clause 2 (a) of the draft constitution which the majority of local associations adopted formally in 1994.

● ***If you have any queries on this matter, please send them to the Company Secretary at ASBAH.***

USEFUL Charity Commission publications on Annual Returns include:

- Self-assessments – CC56. To help smaller charities avoid paying an accountant.
- Receipts and Payments Accounts Pack – CC57.
- Accruals Accounts Pack – CC58.

Orderline: 01823-345427.

Landmark income from Computer Sense Ltd will grow

HONORARY Treasurer Charles Ortner described as a landmark the first Deed of Covenant – of more than £44,000 – from Computer Sense Ltd which, he said, would be a source or regular and increasing income from the company.

This would be much valued as most ot ASBAH's sources of income fluctuate, which means they are difficult to predict in any year.

There was a small surplus in income last year, but not enough to invest.

Income and expediture had been close to budget – due to professionalism of staff and effectiveness of fundraisers, said Mr Ortner.

Mr Ortner added his thanks to retiring finance director Derek Knightbridge, who has loyally served ASBAH for 14 and a half years. He said: "My sleep has been easier because I've known our accounts have been in capable hands. I welcome Brian Deffee and hope he will allow me as much sleep."

The terrible words that every

SORRY, YOUR BABY IS

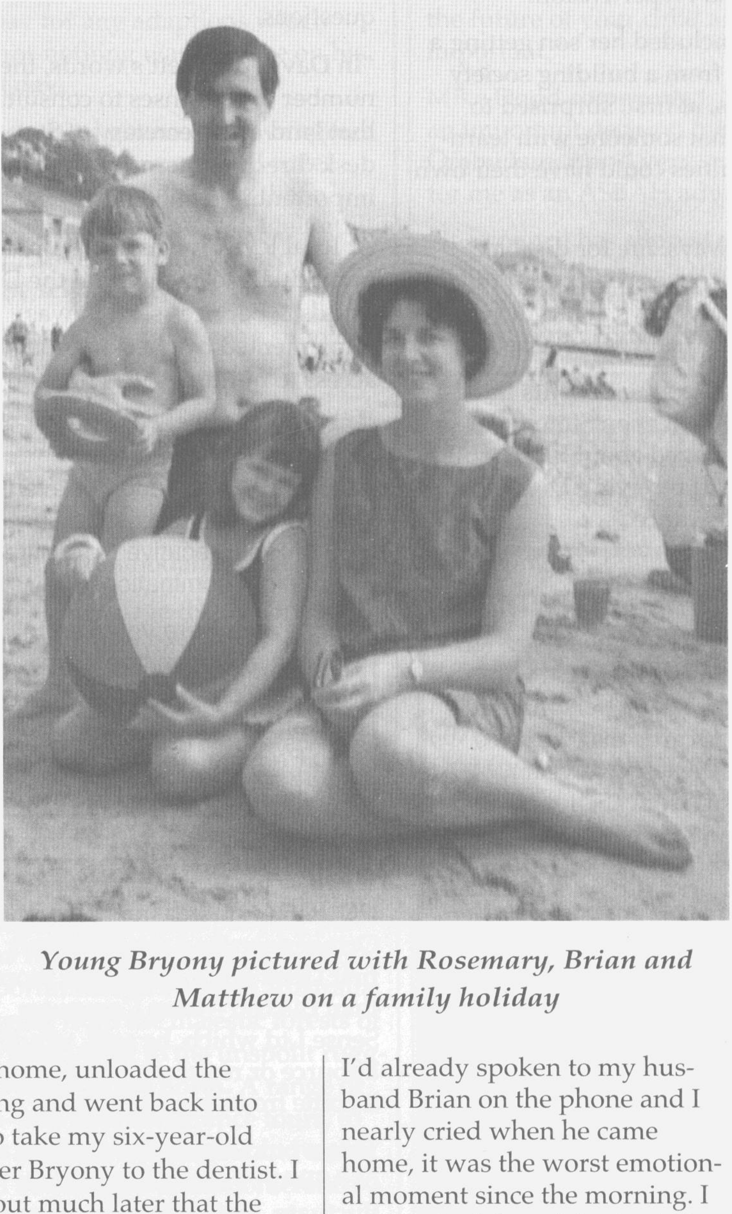
THIRTY years ago, Rosemary Haward endured the agony of giving birth to a baby destined to die. Her daughter, *Birmingham Evening Mail's* women's editor, Bryony Jones, pregnant with her first child, reveals her horror at discovering she too is at high risk of having a baby born with the same fatal condition. *Reprinted courtesy of Birmingham Evening Mail.*

WILLIAM was a nine to five baby; he was born at 9am and died at 5pm. But I had no idea he had a fatal abnormality until a few days before his birth.

I will never forget the doctor's words when, after having an X-ray, he told me: "I'm afraid the baby is abnormal."

He said the head was affected and I must have asked if it would die for he said it would.

I don't remember anything else except that I was thinking all the time: "So this is how it feels to have really bad news, this is how you behave."



Young Bryony pictured with Rosemary, Brian and Matthew on a family holiday

Rosemary's story – 1967

I just sat and stared out of the window, my heart beating very hard and very fast. That afternoon I went shopping, loading up the family's food at Sainsbury's. I had a great desire to shout: "Look, my baby's abnormal and it's going to die." I wanted to tell as many people as possible. I wanted to hurt and shock them as much as I was feeling hurt and shocked, yet I didn't want to meet anyone I knew face to face. I could tell people over the phone but I didn't want to see them.

I loathed the unknown object inside me, still kicking and punching – all my love had turned to a sickly dread. I just wanted it to be taken away, torn out, got rid of. That changed before it was born and I loved it again. I'm glad of that.

I went home, unloaded the shopping and went back into town to take my six-year-old daughter Bryony to the dentist. I found out much later that the dentist had a baby that died too, only a year before. But I sat there, smiling when necessary and said nothing.

I'd already spoken to my husband Brian on the phone and I nearly cried when he came home, it was the worst emotional moment since the morning. I cried in bed that night; I cried every night for several weeks.

The next day I went to see a friend, Helen, as she'd had an
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grunts, the pig noises, the stink of the hissing mask, the grey coldness of the steel bedhead in my clutching hands, the wailing and the heaving, the nurse asked someone for the oxygen cylinder.

Absolute hell

"You're not going to try and revive it, are you?" someone said. "No, it's just for reference," my nurse replied. Still not a comforting word to me.

Muzzy head, then the absolute hell, torture, agony; then wrenching, tearing pain almost beyond the point of feeling.

Then the burning freezing of the knife cutting me, my high screams, a nurse forcing the mask over my face ordering: "Take this, take this," like some dreadful communion and the next second me crying: "Stop it, stop it."

But worst of all was the knowledge that in giving birth I was killing my baby – it could not survive outside my body.

Then with the last bubbling, tumbling, slippery feeling, the baby was born and the lonely, lonely feeling that no miracle had happened.

I lay sobbing without tears while I felt, warm and alive, my baby shoving me gently with its foot. And still no-one spoke, no-one said one word to me. They cut the cord, they wrapped the baby up. I turned over to see it being wheeled out, all covered up in towels and I heard it cry, not a roar of angry protest but a sad bubbling cry, a sigh.

They didn't even tell me it was a boy. They wouldn't tell me what

cont'd at bottom of p16

Birmingham Mail's women's editor, Byrony Jones, with her mum

Bryony's story – 1998

I HAVE always known my mother's third baby died shortly after birth. But I was 15 weeks pregnant before I learned I was at high risk of having a baby with the same fatal condition.

To say I was horror struck was an understatement. Her baby had anencephaly, where most of the brain and skull are absent. It is the most severe form of spina bifida and yet I'd never made the connection. But then, nor had she.

The normal risk of a woman having a baby with a neural tube defect is one in 3,000. My family history meant my risk was between one in 50 and one in 100. I learned this from contacting ASBAH.

Higher dose

I listened to the woman on the end of the phone with increasing panic. My efforts to reduce the risk of a spina bifida baby by taking the recommended daily 0.4mg of folic acid before conceiving and during the first 12 weeks of pregnancy had been insufficient: I should have been taking a much higher dose on prescription, she said.

The woman was very nice and tried to be reassuring – "You could have 49 children before having one with spina bifida" – but I could hardly wait to put the phone down. I wanted to scream.

And when I did, I hugged my tummy tightly, desperate to be close to my unborn child, and I howled, I really howled.

continued at top of p16

Bryony's story – 1998, continued from page 16

Over and over again I wailed: "I didn't know, I didn't know."

My feelings were of guilt and inadequacy, facing the possibility that I faced a similar tragedy to my mother, simply because I didn't know. I already have my own multiple sclerosis to cope with; I couldn't bear the thought of losing what might, at the age of 36, be my one chance to have a child.

I phoned Good Hope Hospital, where I was booked to give birth in September, to ask for a 16-week scan, which the woman from ASBAH said would show up any obvious spinal abnormality.

My obstetrician obliged and a week later my partner and I were looking at an ultrasound scan of our baby, its skull and fishbone-like spine clearly visible. It waved a hand and kicked its legs.

The sonographer grunted: "Looks all right to me, don't know why you're having this scan," which was far more reassuring than if he'd rushed off for a second opinion.

Take comfort

A week later a blood test assessing the risk of me having a baby with spina bifida (and Down's Syndrome) was said to be 'fine.' I was further reassured by the detailed 19-week scan which also failed to show up any obvious signs of abnormality.

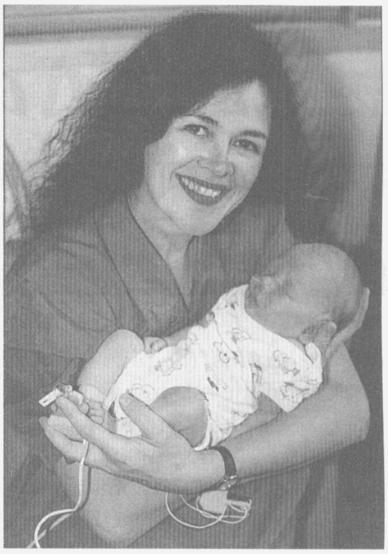
My baby could still be born with an abnormality – screening tests are far from conclusive – but I shall deal with that it it if happens. Meanwhile I take comfort in the knowledge that nearly all babies – 97 per cent – are born healthy.

Pregnancy care has evolved out of all recognition since my mother gave birth to her children.

Women today are offered a range of screening and diagnostic tests which, although potentially adding to the worry of early pregnancy, can enable people to make decisions appropriate for them even before the bump of pregnancy appears.

And should the worst happen, women and their families are today treated with far more compassion and understanding than in the past. If a child is lost before, at, or after birth, parents are given the opportunity to hold their dead baby and to have photographs and hand and foot prints to treasure. Funerals, cremations and memorial services can be held, acknowledging that their baby was a real person who tragically died.

How much more humane than my mother's harrowing experience of birth and death.



Bryony Jones with her new baby, Tristan Jamie, who was born on Sunday 30 August

● ***Bryony gave birth to Tristan Jamie, weighing 6lb 10oz, on Sunday 30 August 1998 at Good Hope Hospital, Sutton Coldfield. Despite having some initial breathing problems, Tristan is healthy. He was born naturally – three days before Bryony had been booked in for a Caesarean Section.***

Rosemary's story – 1967, continued from page 16

was wrong except that it was its head. They didn't tell me what he weighed. They didn't tell me anything and I was too afraid to ask.

I never saw him or held him, which I resent deeply. Back in the 1960s, it was considered best for the mother. I still cry when I think about that.

When I asked at midday if he was still alive, the nurse said: "He's still gasping," and avoided my eyes. Gasping! What an awful picture that conjured up.

I lay in a limbo which should have been so delicious, a haven of achievement and bliss, as it had been for my first two children, born at home.

I was put in a tiny room and outside the window was an enormous fir tree. It was 18 December 1967 and when night came the tree was lit with a hundred coloured Christmas lights. It was very comforting, especially after I was told my baby had died. I kept the blind up all night so I could see it.

When I went home the next day I found that Brian had been unable to tell the children or prepare them for the death of the baby. So I had to tell them.

Perfectly formed

I later learned that William, as we named him, weighed 8lbs and, apart from his head, was perfectly formed. Had he lived he would have been unable to do anything, physically or mentally, and because of that I have always been thankful that he died. But I grieved for the baby he should have been, and I always will.

We wanted William to be cremated, but for some unknown reason "they" wouldn't do it, so he was buried: they never told me where.

My fourth child, Barnaby, was born, after an anxious pregnancy, on 2 April 1969. His name means Son of Consolation.

Tests could help predict walking ability of children with spina bifida

A NEW test on children with spina bifida could lead to accurate predictions being made about how much walking ability they, and others, will have in adulthood.

Some 115 children – all the known children with spina bifida, aged 4-16, who are receiving on-going treatment in Northern Ireland – will have been tested by orthopaedic surgeon Michael Eames by the end of this year.

Mr Eames is continuing the work started three years ago by senior registrar Catherine Duffy at the Gait Analysis Laboratory at Belfast's Musgrave Park Hospital, which looked at how much energy children with spina bifida used while they were walking.

Using new computer software, Mr Eames has developed an additional test to monitor the upper body movements of children with spina bifida when they walk to see if their centre of gravity changes.

There are four stages to the test:

- Talking to the parents and the child to gain a personal history;
- Thoroughly examining the child to see the level of the lesion;
- Placing 28 markers on the child's feet, legs, arms, trunk and head;
- Asking the child to walk three or four times in view of a computer-linked camera which picks up the markers on their body. The computer then works out the child's centre of gravity.

The tests, on 60 children so far, have shown that, contrary to previous thinking, the children's centre of gravity does not move while they are walking. Instead the children expend a great deal of energy to keep their centre of gravity in the same place.

Mr Eames said: "We have seen that the children's upper body movements are more organised than previously thought. Their upper bodies are moving around so much in order to keep their centre of gravity in one place."

Like his predecessor, Mr Eames is also conducting an energy utilisation test. For this, a small box housing a computer is worn on a belt by the child. The computer, linked to a mask worn over the child's nose and mouth, measures the amount of oxygen used up as the child walks.

Five-year-old Megan Gilbert, from Holywood, County Down, is tested by orthopaedic surgeon Michael Eames at the Gait Analysis Laboratory in Belfast.

PICTURE REPRODUCED WITH KIND PERMISSION OF BELFAST NEWSPAPERS LTD

Using the two sets of data – the child's centre of gravity when walking and the amount of energy used up – a computer can plot points on a graph and predict a child's future walking ability.

Mr Eames is also using the data to home in on which types of splint regimes and surgery appear to be working.

Although other factors, such as family background and motivation, can determine whether older children are better at walking, or stay walking further into adulthood, Mr Eames says that by far the most important factor for children under nine years old, is the position of the lesion.

He said: "The level of the lesion is most important because the child can only be helped if they have the neurological function which allows the leg muscles to work.

"If we can predict what will happen to a child's walking ability as they grow up, then we can prepare the child and the family for the outcome and offer the most appropriate treatment."

Mr Eames has been supported in the tests by his MD supervisors Dr Richard Baker and orthopaedic surgeons Trevor Taylor and Aidan Cosgrove.

He is also grateful for the help he has received in tracing some children with spina bifida from ASBAH Northern Ireland Region.

More follow-up work will be needed as the children grow older to confirm Mr Eames's computer predictions and to monitor methods of treatment.

● There are other gait analysis laboratories throughout the country working with children with spina bifida including: the Robert Jones & Agnes Hunt Orthopaedic & District Hospital, Oswestry, Shropshire; Alder Hey Children's Hospital, Liverpool; Guy's Hospital, London; and in Oxford, Dundee and Edinburgh.

Living with Spina

The views of people aged

by Priscilla Alderson PhD

Social Science Research Unit

Institute of Education, University of London

A new approach

How is this study different? Most research sees people with spina bifida as patients and is about their illness and treatment. This study is about each individual as a person, and about social rather than medical aspects of their lives. Typical research asks: "What does spina bifida prevent you from doing? How does spina bifida mean that you are different from your friends?" Then the likely mixture of complex factors tends to get lost, and spina bifida can appear to have much greater control over daily life than it actually has. It may be that lack of money or transport limits a person's life much more than having spina bifida does.

Making contact

The study was approved by the Institute of Education ethics committee. ASBAH helped us to approach six adults living in London and five agreed to be interviewed. A leaflets explained the project, its aims, and the rights of the interviewees. They were all interviewed at home. After the interviews, a summary sheet was filled in with

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Disability Publishing and Publishing Disability *by Paul Darke*

THERE are now so many books about disability, by disabled people, on the market that it is becoming increasingly difficult to sort out the good from the bad.

As a rule of thumb, it is always a good idea to steer away from the biographical ones that feature a well-known person or those that are linked to an individual who is currently the subject of a film or documentary. These are usually very medical model or 'triumph over tragedy'-type books which pander to archetypal assumptions about us – the disabled – and disability.

By far the best two books about disability – socially and politically, that is – are Michael Oliver's books: *The Politics of Disablement* (1990) and *Understanding Disability* (1996), published by MacMillan. These are life-changing books that explain and explore the social models of disability with a conviction, balance and clarity that is unsurpassed elsewhere. Although they are academic books, they are accessible and written in a way that is revealing and explanatory without becoming patronising or supercilious. If anyone claims to know about the social model of disability and does not own, let alone have read these texts, they are not to be taken seriously.

Two new books, both available in paperback at under £20, are available on the subject of disability and offer interesting reads – comparatively, as well as on their own. There is the American text, *The Disability Studies Reader*, edited by Lennard J Davis (Routledge, 1997) and a British alternative, *The Disability Reader*, edited by Tom Shakespeare (Cassell, 1998). Davis's introduction to disability is typically American: it assumes that all stateside writing is superior whilst concentrating on equality in a capitalist and normalising context.

Shakespeare's book, on the other hand, offers an introduction to disability from disabled writers in a social context, with a wider range of perspectives on a wider range of issues. Considering that Davis's text does not even mention Michael Oliver's books (see above), I am instantly deterred from preferring his book to Shakespeare's which, in its bibliography, seems to reference every piece of writing ever done by Michael Oliver.

Relating back to the positive letters of support published in the last *Link* about my criticism of *EastEnders*, a very stimulating and enlightening book on the issue of abortion is *Swimming Against the Tide: Feminist Dissent on the Issue of Abortion*, edited by Angela Kennedy (Open Air Books, 1997).

It is surprising that some of the most progressive writing about disability can often be found in books that are seemingly about subjects other than disability (either medical or social model). Another good example of this is Michael Burleigh's *Death and Deliverance* (Cambridge University Press, 1995), subtitled *'Euthanasia' in Germany 1900-1945*. This book is essential reading for all (especially non-disabled) people as we enter the potentially very dark road ahead for disabled people in the 21st Century. As someone clever once said, reading is to the mind what aerobics is to the body. And, boy, do we need to be fit for the battles ahead.

Bifida

between 18 and 33

THIS article reports interviews with five people who have spina bifida. The research is part of a Europe-wide project about pre-natal screening.

The whole project includes large surveys with "experts", doctors, midwives, pregnant women and the general public.

However, little is known about the views of the most directly concerned people, the ones who live with an inherited condition. So **PRISCILLA ALDERSON** and colleagues interviewed five groups of people, who have spina bifida, thalassaemia, cystic fibrosis, sickle cell or Down's Syndrome.

This study aims to find out about the quality of their lives and their views about their family and friends, education and work, hopes and aims, problems, the things they enjoy or want to change, and briefly about screening and genetics. The study is meant to make their views more widely known, in order to inform people who plan, provide and use screening services.

each person so they could decide how they would like to highlight their main points. People's names have been changed in this article.

Interview Findings

Four women and one man were interviewed. They are aged between 18 and 33, the average age is 26. They all went to mainstream school, apart from Richard who went to a special school until he was 12, when he changed to mainstream. Vivian had to fight through the courts to be able to go to mainstream school. Cristel said that doctors and teachers refused to accept that her back was painful and that she could walk only very slowly. She was often in trouble at school for being late for lessons when there was some distance between the classrooms.

They all went on to further education, doing courses in retail, leisure and tourism, sport, health and social care, IT and office skills, and Vivan did A-levels in French, German and English. All the interviewees are now in employment apart from Cristel, who is a single mother to a three-year-old son. The others are a secretary, a recreation assistant, a sales assistant and Vivian has done a range of jobs: promoter of festivals and events, arts administrator, journal editor, marketing manager, journalist, playwright, a consultant on access for disabled people in the arts world, educating professionals about disability, and she is a member of the Direct Action Network of disabled people campaigning to have access on public transport.

Households Three people live with their parents, Vivian lives on her own and Cristel lives with her son. She is determined to prove that she can be independent and care fully for her son. Although she gets on well with her parents and her son's father, she prefers to live in her own flat. They all stress how much they value their independence. Angela feels that the authorities should provide better housing for young people as she can't afford to leave her parents' home.

Main likes Talking about daily life moved beyond medical viewpoints and helped to show how the interviewees value the quality of their lives. The wide range of activities covered dispels myths about disabled people leading boring, restricted lives. Richard loves sports including archery, basketball, aikido and weight lifting and hopes to train for the Olympics. He thinks keeping fit is very important and he can pull himself up and down stairs in his wheelchair. Vivian was the only other person to use a wheelchair and is also very active. Four of the interviewees like travelling abroad. Spending time with friends and family was often mentioned, especially for two of the women who enjoyed being with their nieces. Other activities included helping at Brownies and Rainbows, going to restaurants and the cinema, dancing, reading, computers, music, art and decorating, disability activity days, relaxing at home, watching TV. Vivian very much enjoys working.

What do you find most useful in your life? The main answer was "independence." Three people said they knew their families were there for them when they needed them which was helpful, but they didn't like asking for help unless they really needed it. Vivian said that a great help to her was knowing *when* to ask. Other helpful things were cars, a wheelchair, reflexology, going out with friends and, for Cristel, her son and her flat with no stairs.

Is there anything you would like to change or improve in your life? Two people said there was nothing they would like to change. Angela said she would like to be taller, partly for the convenience of being able to reach things and partly because people's attitudes towards her would be different because, as she is, she looks very young. She would also like bigger feet because it is hard to find fashionable shoes with such small feet. Vivian wishes that she didn't get depressed and Cristel would like to go to college and sort out an education and a good job. She finds it hard to find suitable work as she can't stand up, sit or move for long periods of time.

Is there anything you would like to change about society? Access was often mentioned in answer to this question. Two people said they would change 'everything' about society; New Labour, the NHS, education and social attitudes. Richard thinks that more integration is very important. He is keen to expand opportunities for disabled people at the sports centre where he works. Angela said more should be done to improve housing and Cristel said she would rather work than live on benefits and she feels that more jobs should be accessible to disabled people.

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continued from page 19

Living with Spi

The views of people aged bet

What are your main hopes for the future? Jackie and Angela both like to take one day at a time, although Angela mentioned saving for a holiday and hopes to get her own flat. The other three all want to advance their careers. Richard wants to continue getting fitter, and maybe take part in the Olympics. Vivian would like to earn more money so that she can save and will be able to support herself when she is more disabled. She would also like to have children and has consulted an obstetrician about this as she has a curved spine. Cristel very much wants a career and would like to find a way of working that helps people. "My friends say I'm like a psychiatrist. They phone me up when they have problems."

What are your views on becoming a partner? This question also led to answers which stressed independence. Cristel no longer lives with her boyfriends because she felt that he was looking after her and she couldn't stand that. The others say they feel happy on their own and would only want to have a long-term relationship if they met the right person. No one mentioned spina bifida as a problem with relationships.

What are your views on becoming a parent? Views about parenting are very mixed. Angela feels that she is a very motherly person and would love to adopt a child, but would not go through pregnancy and birth because of her condition. Jackie used to want children but looks after her two nieces and says: "Those two are enough. They come to stay. They're hard work, especially when they're; naughty. You have to keep them busy." Richard is only 18; he would like to have children but isn't too bothered at this time. Vivian is planning to have children now, and Cristel is "very pleased to be a mum."

What do you think about genetic research and gene therapy? There were some positive views on genetic research. Cristel is in favour of research about treatment but would prefer more knowledge about prevention, and better training for health staff about caring for people with spina bifida. It was not until her son was born that tests revealed the cause of her back pain. Jackie feels that screening is a good thing and that they "should test for everything." Richard feels that he does not know enough to comment. Angela and Vivian were more dubious about the benefits of genetic research. Vivian said: "They should be testing for illnesses likes cancer and AIDS, not for disabilities." Angela isn't convinced of the value or promise of the research. She said: "We are all here for a purpose, disabled or not."

The views on gene therapy were far more negative. Angela believes the money could be better spent on practical help and support for people. Richard cannot see it as being much use, however. He thinks that, if he was asked to do research, he would give it a try once and then decide whether to continue rather than just dismissing it. When asked about gene therapy, Vivian replied: "uuurgh, perfect people are already here. Cosmetic surgery – a load of rubbish." She is angry that any disabled people should be under-valued or their lives thought not worthwhile. Cristel said: "I think it's wrong. You shouldn't alter nature because it might make it worse for people in other ways. You don't know the side effects."

What do you think about prenatal screening or testing? Three of the five felt that screening was a good idea because, even if you are not considering an abortion, you can prepare for the child and find out properly about the condition. Cristel said that, although she did not agree with abortion, she thought that everyone should be given the chance to make an informed decision. Angela said that screening should not be about the possibility of abortion. She believes that "parenting is unconditional." Parents should accept their child on any terms but still thinks that screening is a good idea so that the parents can prepare. Richard thinks the funds for screening could be spent on more useful things like rehabilitation. Vivian said she wouldn't have screening tests because she disagrees with abortion: "You can't decide for people who haven't had their lives yet."

Comments

How typical are these five people? They are likely to be unusually confident and outgoing to agree to be interviewed. They talked calmly and openly about personal and potentially painful issues. Some of them raised sensitive topics before the questions were asked about them. This group may be at the most positive end of the spectrum of people with spina bifida. Some have serious disabilities but it seems that personality and attitudes, as well as health or ability, have a strong impact on quality of life. Whereas typical research, by centring on medical topics, may over-emphasise illness, this study centres on social topics and may under-report health problems. We did not try to find a typical group, but have piloted a new more socially-based interview approach which we hope to follow up with a larger group, to see how typical the views of the 40 people in the five groups are. Questions raised by this study, and more details from the interviews, will be discussed in further reports.

Professional and public views of spina bifida are dominated by reports from health staff, who mainly see people with spina bifida

a Bifida

veen 18 and 33

when they are ill. Prenatal counsellors may not know anyone with spina bifida, and they can have over-negative views. The interviewees, even if they are unusual, are an important group, because they challenge general assumptions about spina bifida.

They give a broader picture which balances the present negative one and could help people who plan, provide and use screening services to have more informed understanding. Apart from their direct answers on prenatal screening, the interviewees give indirect answers. When talking vividly about the quality and value of their lives, they questioned assumptions in pre-natal screening that life with spina bifida is better prevented.

This group suggests that they are held back by negative attitudes rather than lack of medical care. They long to see progress in social attitudes, to overcome prejudices and discrimination. Knowing how hurtful discrimination can be may lead them to be more liberal and non-judgemental, as they would like other people to be. They are all in favour of prospective parents being informed, but want their choices to be properly informed by a better understanding of positive sides of living with spina bifida.

Note: ***For details of further reports of this study, please contact: The Social Science Research Unit, Institute of Education, University of London, 18 Woburn Square, London WC1H ONS. Email: p.alderson@ioe.ac.uk***

Acknowledgements

I am very grateful to everyone who agreed to be interviewed for this research, to ASBAH for helping me to contact them, and to the European Commission for funding the research which is directed from Helsinki University.

Tesco's staff fund-raise for ASBAH

STAFF at a branch of Tesco's adopted ASBAH as their charity of the month and raised £884.15.

ASBAH was nominated by Kate Donaldson, whose 15-year-old daughter Georgina is a service-user.

Various fund-raising activities were organised including a car boot sale and a sponsored swim, and collection tins were placed on the tills at the store in Sleaford, Lincolnshire.

Sue Mason, ASBAH adviser for Lincs, said: "We are very grateful to all staff at the Sleaford store for their efforts and to Mrs Donaldson for nominating ASBAH."

PHOTO: Tesco's branch customer services manager, June Barber, (left) presents a cheque to ASBAH adviser Sue Mason, flanked by Georgina Donaldson, Kate Donaldson (back row) and other Sleaford store staff.

DIARY DATES

30 October – 1 November

ASBAH family weekend, Pioneer Centre, Kidderminster, Worcs. Closing date for applications, **21 Sept.** *Lynn Thomas, Services Department, ASBAH, tel: 01733-555988, fax 01733-555985.*

6–7 November

The second All Round Ability Exhibition, organised by Scope and RADAR in partnership with *The Guardian*, London Arena, Docklands. Entrance free to all visitors who pre-register. *Maria Adderley & Associates, tel: 0181-293 5903. Email: adderley@dial.pipex.com*

Monday 9 November

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

Tuesday 10 November

Opportunity '98, national conference for parents with a young child with disabilities and professionals working with these families, "What are the needs of parents with children with multiple disabilities in the first year? How can these needs be met?" Organised by the One Hundred Hours charity. Birmingham City Hospital. *Sheila West, conference co-ordinator, tel/fax 01422 884890.*

Saturday 28 November

Hydrocephalus Study Day, organised by ASBAH Northern Region, The Dolphin Centre, Horsemarket, Darlington, 9.45am–3.30pm Cost: £6 per person. Speakers include: Mr Conor Mallucci MBBS, FRCS, and Carole Sobkowiak, FCSP. *Bookings by 31 October to ASBAH House North, 64 Bagley Lane, Farsley, Leeds LS28 5LY, tel: 0113-255 6767.*

Monday 7 December

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

The impossible *is*

by Christine Helliwell

CHRISTINE HELLIWELL was born with spina bifida in Halifax, during deep snow, in 1947. She wrote her biography hoping that it would encourage other disabled people – and their parents – to help themselves as much as possible. Having this attitude, she says, has helped her cope more easily with difficult situations.

Christine, a member of *Your Voice in ASBAH,* says: "Much can be done and much can be achieved. Whatever you do, never give up. The impossible is possible so do not just sit back and accept things as they are. Get on with living."

This is Part One of her remarkable life story.

SOMETIMES you have to be cruel to be kind. That was certainly true for me. My mother was very firm with me and, at times, I thought, a little hard. But as an adult I now realise it was all for the best.

She was as strict with me as with my sister in seeing that I made my bed, tidied my room and helped with the washing up. Occasionally, I would also go shopping for her. Sometimes a little extra pocket money was offered to the one who made their bed quicker. Usually I lost, but it was a great sense of achievement when I did win.

As soon as I was able to travel on a bus on my own, my mother insisted that I travelled to and from the school clinic on my own. Many people thought it was wrong that a disabled person should travel alone on a bus, but I know my parents were right. Without a strict upbringing, there is no way that I would be as independent as I am now.

My mother used to make me do the exercises I had been taught to do at the clinic. Many parents used to say that they had no time to spend with their disabled child to see that they did the exercises properly.

Christine (back row, on the right) as a Guide, after being presented with her Blue First Class and All Round Cords

My parents never took or fetched me from anywhere that I could manage myself. I know many people thought this was wrong. Some people would have had me in a wheelchair from the day I was born but my parents were making sure that I was going to be as independent as possible.

My father was the breadwinner and worked very hard. I cost them a lot of money because there was no such things as special shoes in those days and the National Health Service had only just started. Social Services and the National Health Service have made life a lot easier. We did not own a car but father would occasionally hire one and take us all away on holiday.

My sister made sure I took part in all games when we played out. She insisted that I joined in the games or she would not take part. A favourite saying of her was: "Christine's playing and bags me be first."

My brother is nearly 20 years younger than myself. I remember taking him to a pantomime and the majority of children in the audience were disabled. My mother had warned him to be careful as these people could easily be knocked down. He was very careful with them but, when he nearly tripped me up, I reminded him what mother had said. He replied: "Oh, you are only my sister, you don't count."

At the age of eight, I joined St Paul's Brownie Group in Halifax. I could only just walk and only got to Brownies due to the fact that two other Brownies called for me and I was able to put my arms on their shoulders. Going to Brownies encouraged me to get on to my feet because I could see what the other children were doing and wanted to do the same.

There was one meeting, in particular, that I shall never forget. The other Brownies used to sit on the window sill of our meeting place and Brown Owl and Tawny Owl used to tell them off for this. I wanted so much to be like the other Brownies that one week I tried to get up onto the window sill and eventually did so. By this time, Brown Owl and Tawny Owl were arriving. The other Brownies quickly jumped down from the window sill but I, being slower than the rest, did not manage to get down before they entered the room. To my surprise, I was not told off. Instead Brown Owl looked at me in amazement and said: "How did you get up there?" Being disabled can help as well as hinder.

possible

Christine Helliwell

We used to have races at Brownies and the prize nearly always used to be a tin of toffees. Of course, I was the slowest runner there but I used to win the races because I stuck my arms out to balance myself, which meant that no one could get past me! I was quite a bit older before I realised why I was winning all the races.

It was not all joy at Brownies. In good weather, we used to walk to the swings to play. The distance was not far for a physically fit child but was quite a long way for me. I used to make myself go but, on numerous occasions, returned home with bleeding feet. Eventually, my feet got used to me walking on them.

Soon after my feet had hardened off, I went on Brownie revels. On these occasions, six or more Brownie packs got together in a large park. Quite a lot of walking was required to get there. My mother and grandmother came with me. On numerous occasions I was asked if I wanted a lift in a car but I insisted that I walked with the other Brownies.

On arrival at the revels, we joined in and played games with members of other Brownie packs. At midday, we ate a packed lunch and drank orange juice.

After this meal, we played more games, then had a sing-song, after which we prepared to come home. Once again, I was offered numerous lifts in cars but I turned them all down. I wanted so much to be like the other Brownies. I had had a thoroughly enjoyable day, but came home absolutely shattered. On entering the living room, I collapsed on the floor and fell asleep, still dressed in my coat.

One of the hardest activities for me at Brownies was skipping backwards. It took me a number of weeks to achieve. I wanted to do this before entering Guides because I wanted to gain a certain badge. Brown Owl was willing to let me do something other than skipping, but both my parents and I were determined for me to achieve my aim – to be able to skip backwards and, eventually, I did it.

At the age of 11, I started Guides like the others and learnt many things. I worked hard for no less than 14 badges including: child nurse, first aid emergency helper, health, cooking, collector, knitter, needlewoman, fireman house orderly, writer, hostess and little house emblem second class. Eventually, I became the Kingfisher patrol leader.

In February 1964, I received the Fortitude Badge for Bravery and, finally, the highest award possible for a Guide who was physically disabled – the Blue First-Class Badge and All Round Blue Cords.

Due to my disability, I had not found a way to attend camp. I wanted to go so much that my captain invited my sister and I to attend a full day at camp.

We set off as early as possible and came back as late as we could. When we arrived, we helped the other Guides prepare the food for dinner, after which we collected wood for the fire. In the evening, we sang songs around the campfire. This one day in camp meant an enormous amount to me. At last, I had experienced something of what camp life was about.

It was chiefly through Brownies, Sunday School and Guides that my religious faith became very strong. During my teens, my faith was at its strongest and it was during this time that I was confirmed.

Life as a child and a teenager was quite hard. As a young child, I was made fun of by other children – either by them mimicking the way I walked, or calling me names. Teenagers quite often just ignored me.

As a teenager, I was conscious of the fact that I could only wear shoes that were specially made for me, not fashionable ones. I knew I could not wear a skirt unless a bodice was attached to it as, if I did, the zip at the back would gradually work round to the front.

Almost everyone finds life hard during their teens but I do believe it is that bit harder for a disabled person. I am sure it is this that deepened my faith.

After finishing Guides, I successfully trained to become a Brownie leader – a Brown Owl. Today, I'm involved with the Trefoil Guild, which helps the Brownie and Guide movement by fundraising, helping out at events and offering to give cover when leaders are sick.

Continence

I went through my 20s and 30s without any bladder or kidney checks, despite the fact that I had always had continence problems. You have to remember that ASBAH did not come into existence until 1966, by which time I was 19, and medical knowledge about the condition was extremely limited.

In the final year of my Open University degree, at the age of 38, I met a young woman who had been left disabled by a road accident. It was this chance meeting that set the ball rolling towards solving my lifelong continence problems.

The woman suggested I saw her consultant and got me an appoint-

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The impossible *is* possible, *from page 23*

ment. Unfortunately, the surgery which had helped my friend, turned out to be unsuitable for me. I remember staff at the hospital being shocked that I had never had a bladder or kidney check in my life and I was found to have a colossal infection, which explained why I had been feeling unwell.

I was referred to a surgeon in Sheffield to try intermittent catherisation. This proved much more appropriate and was made easier after nurses switched from using plastic to silver catheters. And, although intermittent catherisation has not kept me entirely infection-free, it is no understatement to say that this procedure changed my life.

At the age of 39, I could at last go on holidays with able-bodied people and I was not restricted in my choice of holiday destinations to those which accepted disabled people.

I still see the Sheffield surgeon, who has recently helped me again – this time to have the ACE (antegrade continence enema) operation, which is proving very successful.

Holidays

As a young woman, I spent a great holiday in Austria with severely disabled people, and we were each assigned an able-bodied helper. However, it was really important to me to go on holiday with able-bodied people, so that I could forget my disability and get on with dealing with my continence quietly, on my own.

The summer after I was introduced to intermittent catheterisation, I booked into the Dreadnought Hotel in Calendar, travelling there by coach. It was the very first holiday I had spent exclusively with able-bodied people and it felt fantastic.

Christine (right) on holdiay with Catherine Luke, pictured here with Catherine's daughter Elspeth

I had already learned to love Scotland through another friend I had met during my Open University degree course. Catherine Luke had responded to a note I had placed on the noticeboard at Nottingham University, where we were staying for a summer school, asking for someone to give me a lift in their car up and down a long, steep slope which separated the teaching blocks from the halls of residence.

Catherine and I became firm friends and she learned of my daily trips to the university laundry with wet sheets. But, despite this, she and her husband, Warren, invited me to spend a short holiday with their family in Falkirk, Stirlingshire. I have been going there now for 16 years. These holidays have given me tremendous happiness.

But now I can travel anywhere both in this country and abroad. A coach tour I joined to Belgium included a most memorable day in Bruges. Each year, I make regular trips to The Chadwick Hotel, Lytham St Annes, Lancashire, which has superb facilities for disabled visitors.

● ***The final part of this series, based on Christine Helliwell's autobiography, will appear in the Dec/Jan Link.***

Beginning of February

Complete IVF treatment.

2 March

I'm feeling moody and have a sore chest. Phone St Thomas' and am told I might be pregnant! I don't believe them; I think it's PMT.

Go to St Thomas' to give a urine sample for a pregnancy test. When we go back into the office for the result, everyone is nodding at me. The result is positive! I feel really hot and nearly pass out. It is amazing news and, though it's what we've been hoping for, I can't believe it.

Monday 9 March

First routine scan – all looks OK.

23 March

Eight weeks' pregnant and it is confirmed that I am carrying *twins*. I am so happy and shocked. Stuart nearly fell off the chair. My feelings are hard to describe. I just can't believe it.

Thursday 26 March

Having problems with my stomach. Go to my GP, who I haven't told that I am pregnant as I wanted to wait till the crucial three months had passed. I'm gutted that I have to tell them but I'm frantic that my stomach problems are sorted out.

30 March

Week nine. Go for a detailed scan at Guy's Hospital to check for spina bifida. Very daunting but seems OK.

27 April

Another scan to check for spina bifida at Guy's. The consultant checks the back of the necks and size of the heads. Meet my midwives at St Thomas' this week.

12 May

Week 15. Met my obstetrician at St Thomas' – she's wonderful and says she is really pleased to have me (as someone who has spina bifida and is carrying twins). She's done all her homework and got all my notes from Guy's where I go for checks on my legs. I agree to be examined by a junior doctor for his Member of the Royal College of Obstetricians and Gynaecologists exam next week.

The twins' tale

Ann Wright's pregnancy diary

HAVING a daughter was the best thing that ever happened to Ann Wright, and she and her husband Stuart desperately wanted more children.

After seven years of trying, Ann and Stuart resorted to assisted conception in order to have a second child. Throughout these seven years, Ann took the higher dose of folic acid to reduce the chances of her baby being born with spina bifida.

Fortunately, Ann and Stuart had to wait only a year before they were helped by the programme and Ann became pregnant, in February, at the first attempt of having in vitro fertilisation (IVF).

Now the family, from Waterloo, London, have the joy of twins to look forward to on 4 November, and Ann is keen to encourage other disabled couples, who want children, to try and keep trying.

This is Part One of Ann's diary of the pregnancy.

21 May

Interviewed and examined by the young doctor, then his examiner. I am annoyed and regret allowing this as the young doctor tells me I should now think about being sterilised – when I've only just got used to being pregnant! I was not impressed. Stuart is very cross.

I'm hoping for a normal delivery. One of the babies may go into the breech position, so I may need a Caesarean or, if there are any problems, I'd have a Caesarean for both.

25 May

Week 17. Go back for second scan at Guy's which shows that one of the twins is fine; the other is lying down, so they can't see if it's OK. All the measurements are OK but I have to go back again. I'm at the critical stage in the pregnancy when I may have to make a decision. I am concerned that we won't be given enough time to decide as I'm so close to the four-month stage. It is very worrying.

15 June

Week 20. Feel more movement from the twins – ripples and kicks. Stuart and I call them 'tremors'. I'm not getting much sleep. This has been the case right the way through the pregnancy – since around the beginning of June.

25 June

Week 21. Go back to the consultant at Guy's and get the all-clear on the second baby. This news is like a huge weight that has been lifted. It seems we've been waiting for this news for so long.

July

I am generally lacking in energy and suffering from back pain. I rest all the time; I don't want to fight the tiredness. Without my electric scooter, I'd be stuck in the house.

14 July

Week 24. I have a sore throat which, combined with heartburn, makes me feel very unwell. I feel very sick. See obstetrician at St Thomas' and explain what's wrong and that I'm not keeping down any food or drink. I've also had a urine infection for about six weeks. Had antibiotics from GP but these haven't worked. I'm admitted and have a drip put in through which they put antibiotics. Within 24-hours there is an improvement and the drip is taken out.

Friday 17 July

I'm allowed home. I'm told that if I have any problems, including extreme tiredness, I should go back to hospital and they will keep me in.

Thursday 23 July

Week 25. Met doctor at St Thomas' about my back pain. I've already been to my GP as I couldn't wait for my appointment at St Thomas'. I explain which painkillers my GP has given me and these are fine. The pharmacist says I should take one tablet every six hours. I decide not to take them unless I really need them.

Friday 31 July

Week 26. Routine check-up with midwives who take my blood pressure and a urine sample.

6 August

Sick at 3am. Couldn't sleep because my back was killing me. Painkillers didn't work. The pain is probably due to me having a weak back and because one of the babies, I think, is hitting my back. Once or twice, I haven't been able to walk at all.

● **The final part of Ann Wright's *Pregnancy Diary* will be published in the Dec/Jan '99 *Link*.**

● David Fulford-Brown will be back with 'Dave's Diary' in the New Year.

Making it happen in N Ireland

OVER the last year or so, Helen Clarke has encouraged 50 people with spina bifida and/or hydrocephalus to attend a meeting or social event in her role as ASBAH project worker for Northern Ireland.

The aim of her three-year contract is to help adults with the disabilities meet one another, enjoy themselves and enable those who feel confident enough to start a user-forum in Northern Ireland, which will feed viewpoints and ideas into ASBAH. This group will eventually work with the well-established *Your Voice In ASBAH (YVIA)* on the mainland.

Helen commented: "If I got 8 or 10 people committed to forming a user-forum, that would be great, but for the rest of the people I've met, who enjoy socialising, it would still be important for them to continue with their outings as it is so easy to become isolated."

Helen Clarke, ASBAH project worker for Northern Ireland

During her time working for ASBAH, Helen – who herself has spina bifida – has masterminded dozens of social events in five out of the six counties in Northern Ireland, usually meals out or cinema trips. This year, there have been social outings in Belfast, Ballymena, Lisburn, Derry and Cookstown.

Helen started the ball rolling a year and a half ago by writing to service-users in Northern Ireland known to ASBAH advisers and then inviting them to a social event in their area. Helen has met people individually in their homes, when required, so that they could get to know her before deciding to socialise with others.

"The outings to a cinema or restaurant have been a device for getting people to know each other as many feel more comfortable in a social setting. Many of the people I have contacted are very keen on meeting people from all over the province, not just in their own locality.

"I am hoping this will lead to some of them getting involved in the user-group forum, which would have a direct input into the running of ASBAH at regional and national levels."

Some of those who have been socialising with Helen are now 'doing it for themselves.' The group in Belfast organised a half-day event on 10 October, which included a talk by *YVIA* chairman, Alan Twyford, entitled 'Making It Happen.'

Alan spoke about the kinds of activity *YVIA* is involved in on the mainland, discovered what the Northern Ireland groups have been doing and whether the Northern Ireland groups would like to do something similar to *YVIA*.

Alan Twyford, chair of Your Voice In ASBAH

Alan said: "Helen has been getting small, local groups going, which is what we are trying to do over here. There are something like 100 people actively interested in *YVIA* and a steering group of 12-15 who meet regularly."

It is expected that service-users from the rest of the province will also attend this major event at Belfast's Balmoral Hotel.

- *The Autumn issue of* Lift *has more news from Ireland. Adults with spina bifida/hydrocephalus from both sides of the border took part in a project on access which included a trip to the USA! If you're an ASBAH service-user and you're not getting* Lift, *order your free copy today!*

Sales of new racing chair are soaring

By David Proud

A REVOLUTIONARY new racing wheelchair has been developed by a semi-retired wheelchair racer and his business partner, who has also had racing experience making cycles. The new chair is called the Draft Mistral.

Barry Norman and Dan Chambers had three main aims when designing the chair – to make it stronger, lighter and more affordable than any other racing chair on the market.

The result of 12 months of development has produced a chair that is selling rapidly at the rate of around one a week. Sales of the chair are also taking off internationally.

And Tanni Grey, five times Paralympic world champion and London Marathon winner, is currently using a Draft racing wheelchair.

Just released on the market is an every day chair. Both the every day chair and the racing chair are made of aircraft aluminium. Other developments are a hand cycle and a roller system for wheelchair racing.

The basic racing chair is £1,450. Other options are available at an additional cost.

Further information on both chairs from: Barry Norman, at GBL Eastern, on 01480-831212.

HOLIDAY ACCOMMODATION

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

ISLE OF WIGHT ASBAH

Fully-equipped, wheelchair accessible, two-bedroom bungalow. Sleeps six. Clubhouse, indoor heated pool, shop etc. Lovely views, many interesting places to visit. Own transport advisable. *Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983-863658.*

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).*

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.*

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.*

ORLANDO, FLORIDA

House with a heart for disabled travellers! Spacious, luxury, adapted bungalow situated on golf course. Three double bedrooms, two bathrooms (Mangar bathlift installed), Cable TV, free local telephone calls, free Country Club membership. 24-hour 'on-call' management company. 15 mins Orlando Airport. 20 mins Disney. Paraplegic owner. *Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT, tel/fax: 0161-792 3029.*

FOR SALE

Transit van auto white. 37,000 miles. G-reg. Remote control Interbility lift and back door. Extra light power steering. Excellent condition. Price £7,500. Tel: 01751-473943.

Lightweight collapsible wheelchair, Quickie, 14" manual. Good condition. £600 ono. Tel: 01246- 568915 (Chesterfield area).

LINK Rates

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Small adverts for the next issue of *LINK* (December) should be submitted by Friday, 6 November. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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