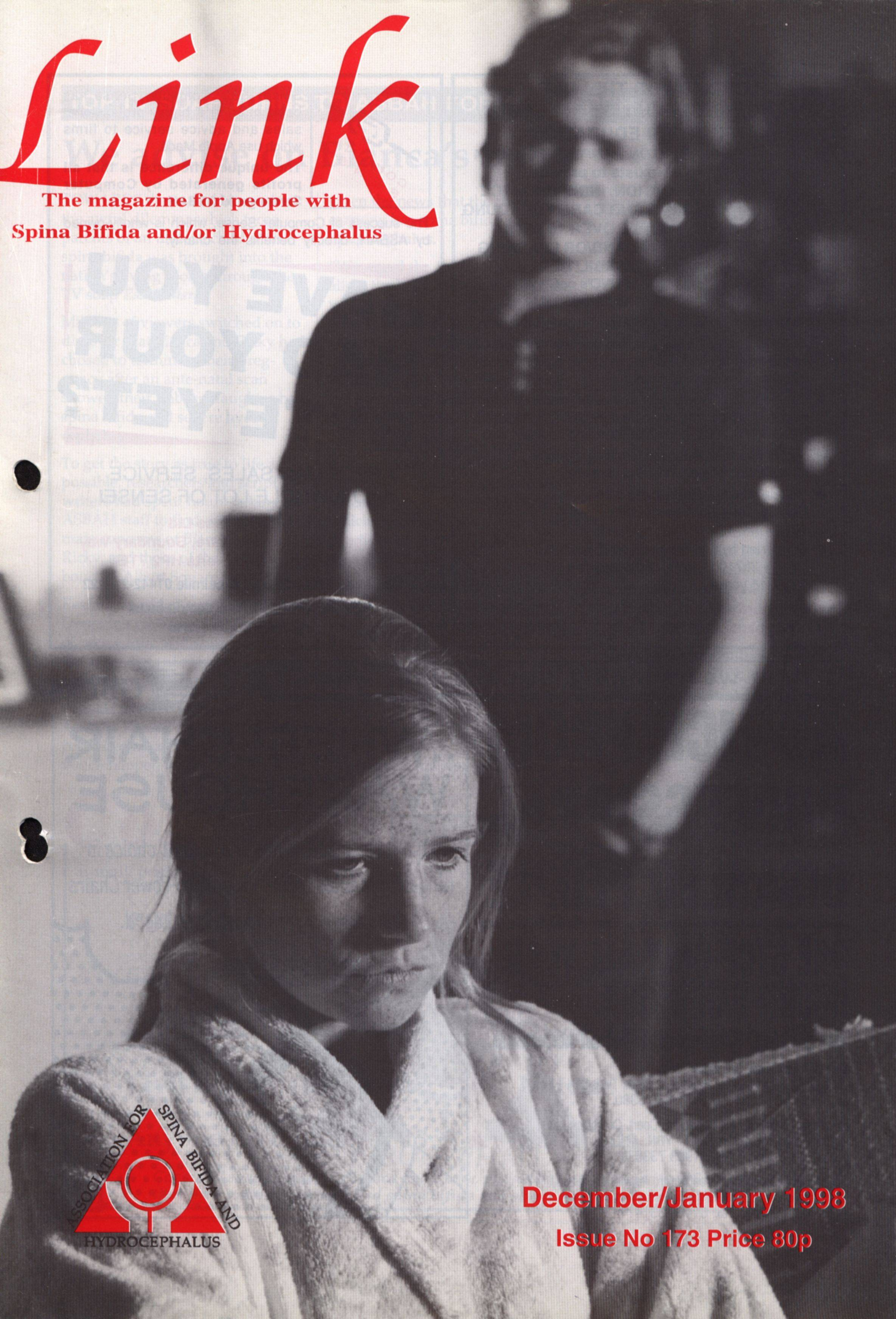
Link

The magazine for people with Spina Bifida and/or Hydrocephalus



December/January 1998

Issue No 173 Price 80p

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..time was running out for Joe, when..

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TOP TV SOAP TURNS TO ASBAH FOR RESEARCH

We advise on Bianca's baby

TOWARDS the end of November, the awful dilemma which faces parents of an unborn child with spina bifida was brought into the nation's living rooms through the TV soap *EastEnders*.

Millions of viewers switched on to discover that Bianca and Ricky had chosen to terminate their pregnancy after an ante-natal scan showed their unborn daughter had spina bifida and severe hydrocephalus.

To get the story as true to life as possible, researchers and script writers had spent hours talking to ASBAH staff to find out what the main concerns of Bianca and Ricky, and those of their neighbours in Albert Square, would be.

EasEnders added a scene during December covering the importance of taking folic acid supplements in the daily diets of women planning to become pregnant.

ASBAH executive director Andrew Russell said: "We were consulted on all possible scenarios which happen when a mother is given the news that the child she is carrying has spina bifida and hydrocephalus.

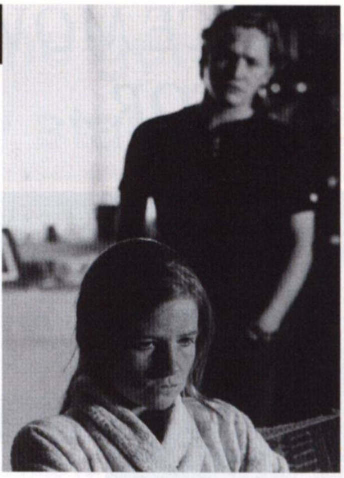
"We urged the *EastEnders* team to allow the baby to be born, but this was non-negotiable as far as they were concerned. Their story was to be built around the agonising dilemma of a couple having to decide whether or not to continue the pregnancy. Nothing we said could have changed that.

"*EastEnders* obviously kept full editorial control. But, as a result of the information we supplied, we succeeded in introducing ideas which represent good professional practice at a very difficult time in many people's lives."

Over 1,000 women, affected by neural tube defect pregnancies, face up to similar news every year in the UK, with termination of pregnancy favoured by over 10 out of every 11. Many mothers and family members phone ASBAH for advice and support at this time – on average 720 a year.

Rosemary Batchelor, our senior adviser on health and policy issues, said: "I spent hours talking through the issues involved with a researcher from *EastEnders*, to help her get the script right and understand what is really important to women and families who have to face up to the situation.

"Our association with *EastEnders*, and its huge viewing audience, gives ASBAH the best opportunity in years to position ourselves as a very responsible – and responsive – national voluntary organisation."



Bianca and Ricky, characters on EastEnders, *whose unborn baby was found to have spina bifida and severe hydrocephalus*

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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/

Cover: TV soap characters Bianca and Ricky, played by Patsy Palmer and Sid Owen, learned that their unborn daughter had spina bifida and severe hydrocephalus. Full story this page.

OFFICE MOVES FOR ...

All change for three regional offices


South-East Region co-ordinator Jo Francis in New Barnet, Herts


Northern Region co-ordinator and START manager Joan Pheasant in Farsley, off Leeds ring road

IN THE past few months, there have been address changes for three out of four of ASBAH's regional offices.

In August, South East Region moved to wheelchair-accessible offices at 209 Crescent Road, New Barnet (as reported in the Oct/Nov *Link*).

In November, Northern Ireland Region moved from Coleraine to Belfast, and Northern Region moved from Ilkley to Farsley, off the Leeds ring road.

The full contact details are:

ASBAH Northern Ireland Region
Graham House
Knockbracken Healthcare Park
Saintfield Road
Belfast BT8 8BH.
Tel: 01232-798878.
Fax: 01232-797071.

ASBAH Northern Region & START
ASBAH House North
64 Bagley Lane
Farsley
LS28 5LY
Tel: 0113-255 6767
Fax: 0113-236 3747

ASBAH South East Region
209 Crescent Road
New Barnet
Herts EN4 8SB.
Tel: 0181-441 9967
0181-449 0475
Fax: 0181-440 6168.

Northern Ireland regional co-ordinator Margaret Young and new regional secretary Margaret Steenson are based at the new Belfast office. There is more space for staff meetings and a small area for an information/resource centre will be created.

In moving to the healthcare park, Northern Ireland Region has joined other statutory and voluntary organisations and so will be raising its profile amongst them. It shares a building – previously part of a psychiatric hospital – with organisations including Action for Dysphasic Adults, the British Epilepsy Association, Disabled Drivers Association and the Downs Syndrome Association.

The Northern Ireland office is wheelchair-accessible and open 9am-5pm, Mon-Fri. An answerphone operates at other times.

The ground floor offices at ASBAH House North, Farsley – where Northern Region and START are now based – have a bus stop outside (with services from Leeds city centre) and seven car parking places. Pudsey train station is a five-minute taxi ride away.

Northern Region co-ordinator and START manager Joan Pheasant, secretary Rachel O'Brien, and occupational therapist Rose Hinchliffe are based there full-time. ASBAH House North is open Mon-Fri, 9.30am-4.30pm.

● WE say a fond farewell to Karen King who left Northern Ireland Region in November.

Karen, who has a 25-year-old daughter with spina bifida, was full-time secretary since the region was formed, six and a half years ago.

She reluctantly decided to leave due to the office move to Belfast which, as a Coleraine resident, she felt would have been too far for her to drive every day.

Karen has also been involved in ASBAH (Coleraine, Ballymoney and District Branch) for 17 years for which she is currently a committee member.

She said: "I have enjoyed my work as regional secretary – it has been a worthwhile and fulfilling job."

● RACHEL O'Brien is the new secretary for Northern Region. Rachel replaces Anna Haig, who left ASBAH in the summer.

Rachel, aged 25, has wanted to work for a charity ever since she left college. Her interests include aerobics, swimming and cricket.

CSL loans scheme gets off to a healthy start

AN APPEAL to ASBAH's supporters to help fund the next phase of expansion of our trading company, Computer Sense Ltd, has got off to a healthy start.

The company, which has ambitious plans to widen its range of products and services by trading in the PC market, has launched a loans scheme in order to increase its working capital.

So far, loans totalling £11,000 have been received by CSL finance director Derek Knightbridge and the books remain open to anyone still considering taking part.

Mr Knightbridge said: "People have recognised the vital part that CSL will play in ASBAH's future success and have been generous. The more funds we can attract through this loans scheme the more attractive will Computer Sense be to suppliers and the banks."

The appeal for loans – in units of £250, repayable if required after two years – has been endorsed by Patrick Daunt, chairman of ASBAH when Computer Sense was launched and now one of our vice-presidents.

In a note of recommendation *(see panel opposite)*, he urges ASBAH's many friends who are able to do so to join him in lending their personal support.

Supporters can choose whether their loans shall be interest-free, or receive 3% interest a year.

The company's move into PCs is essential because many large customers want Computer Sense to supply all their computer needs – not just Apple computers, which the company has specialised in since it started trading in Hemel Hempstead four years ago.

For reasons explained in the loans scheme prospectus, ASBAH can neither lend Computer Sense the money to fund the next stage of its growth nor go to the normal commercial money markets.

***Copies of the prospectus, first issued in August as a supplement to* Link*, are still available. If you would like to be sent one, please contact:* Derek Knightbridge at ASBAH House, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, fax: 01733-555985, e-mail: derek@asbah.demon.co.uk**

I WANT very much to recommend the Computer Sense Loan Scheme.

From the first, I have been confident that this is an excellent way to increase CSL's capital – something essential if CSL, which has already proved itself to be a viable and vigorous enterprise, is to reach its full potential.

And there can be no doubt at all that in the future ASBAH without the help of the income from CSL will have to reduce its services, while with that help there is every hope not only of maintaining but even of extending them.

I have not hesitated to give the Loan Scheme my personal support, and hope that all those of ASBAH's many friends who are able to will want to do the same.

Patrick Daunt
Vice-President and former Chairman of ASBAH.

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Gill Winfield Cert Ed

Time to take action NOW on continence supplies

FED UP with excuses given for not getting adequate continence supplies from your local NHS health trust? Are you being fobbed off with a poor or non-existent service?

Then ASBAH gives you the chance NOW to do something about it.

Look below, and you will see that we have broken down the NHS complaints procedure into simple steps which readers can follow so their grievances get an airing.

To make sure that the NHS managers involved cannot keep your complaint under wraps, we have added one more step.

If your grievance is not resolved to your satisfaction at local level, we say you should pass on the complaint to your MP. Make it easier for the MP by passing on copies of all correspondence. NHS managers hate MPs looking over their shoulders.

ASBAH can even make the job of complaining easier for you. If you are not quite sure how to go about it, contact **Milly Rollinson**, our services manager at **ASBAH, 42 Park Road, Peterborough,** and she will arrange for one of our specialist medical advisers to draft your complaint. Her phone number is **01733-555988.**

But, in order to encourage other people to start complaining, we would also like to hear from readers prepared for details of their complaint to appear in *Link*. Let Milly know if you are prepared to help with publicity.

You have a right to the best possible health service. Sometimes you can only get it by standing up and being counted. Stand up for this right today.

Complaints procedure – continence supplies

Stage	Key Person	Response Time
1. Local Resolution	Complaints Manager NHS Trust (Provider)	Within 4 weeks of receipt of complaint.
	↓	
	Complaints Manager Health Authority (Purchaser)	Within 4 weeks of receipt of complaint.
	↓	Complainant has 4 weeks from receipt of reply to take next step.
If you do not get a satisfactory answer, write to your MP and ASBAH, sending copies of correspondence with Trust/Health Authority.		
2. Independent Review	Convenor (confers with independent lay person)	Convenor notifies complainant within 4 weeks of decision regarding setting up of panel.
	↓	
	Independent Review Panel (if deemed necessary by Convenor)	
	↓	Send within 1 year of the date the person became aware of the events leading to the complaint.
	↓	
3. Ombudsman	Health Service Commissioner (Ombudsman)	No time limit for Ombudsman's response.

Note: Community Health Council should be informed of complaint.

LEA concedes part-time academic help for Andrew – but parents battle on

PARENTS of a 15-year-old, who fought to keep a qualified teacher at a unit for physically disabled pupils at a mainstream school, have struck an uneasy compromise with the local education authority.

But, unfortunately, although the LEA has agreed to fund four hours a day extra academic help to the pupils, the school claims to have been unable to find someone of the right calibre to fill the post.

As a result, the job has been taken on by the school's head of special needs and, when he is absent, the job is done by a nursery nurse.

Battling mum Paula Targonski – featured on the front page and page 3 of the Aug/Sept '97 *Link* – says her son Andrew's grades have gone down since the extra academic help in the unit has been reduced.

Speaking from the family home in Sedgley, West Midlands, she said: "We did get an agreement to get four hours a day teaching help rather than the LEA withdrawing help altogether, as previously planned.

"So we have a positive result and something that is better than nothing. But, in reality, the full-time teacher hasn't been replaced with a part-timer. The job is being done by the head of special needs. If he's off on a course, there is no one to fill in, except an NNEB.

"This means we're a long way from where we want to be. An NNEB isn't a qualified teacher and can't help Andrew and the other pupils in the unit academically."

Andrew attends all the classes he can at Coseley School – part of Dudley Metropolitan Borough Council – but some are not wheelchair-accessible.

Paula Targonski and her 15-year-old son Andrew

For subjects which are not taught in accessible parts of the school, such Information Technology, English, Textiles, Business Studies and Maths, Andrew needs academic help at the unit to work through the GCSE syllabus.

Help & Advice

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

London, Surrey, Kent, West and East Sussex

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

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

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

Northern Ireland

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

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

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

Rest of England and Wales

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

ASBAH welcomes and appreciates the support of its commercial partners.

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

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

Major inquiry finds Further Education provision wanting

A MAJOR inquiry into the provision of further education provision for people with learning difficulties and disabilities has found the whole system wanting, despite the existence of pockets of good practice.

The Tomlinson Committee, set up by the Further Education Funding Council, found clear evidence that many groups were being excluded – particularly adults with mental health difficulties, young people with emotional and behavioural difficulties and people of all ages with profound and multiple disabilities.

Prof John Tomlinson, who led the three-year inquiry, reported: "For those who are taking part, the quality of provision is not good enough and, as a result, student experience is too often unacceptably inferior."

A total of 131,000 students with learning difficulties and/or disabilities were in further education, five per cent of the total student population, he reported earlier this year. Courses were provided in specialist residential colleges, in mainstream FE colleges and in sixth form colleges round the country.

One consequence of shortage of educational opportunities was that it led inexorably to inability to perform in the economic market place.

Unemployment rates among people with disabilities are around two and a half times those for non-disabled people (21.6% compared with 9%, using International Labour Organisation definitions).

"There can be little doubt that many of our citizens are failing to contribute as they and society would wish because low educational opportunities have reinforced the difficulties presented by disability."

Prof Tomlinson, director of the Institute of Education at Warwick University, called for a major, integrated overhaul of staff and management training and organisational development to bring the system up to speed. This needed to be backed by earmarked national funding.

Inspections should be strengthened so they could provide evidence of the match between student needs and college-wide 'inclusive' environments. Monitoring of provision, the use made of funding and analyses of future needs must become more rigorous, both within college and by the Further Education Funding Council.

Inspection reports on the specialist residential colleges must be published, as they are for the mainstream FE colleges.

In their self-assessments, which will increasingly become a feature of a more mature system, all colleges should vigorously measure their progress towards inclusive learning.

Individualised student records should be developed as a statistical tool so track could be kept on what is happening.

"Everything we propose is within the grasp of the system if we all want it enough, because its full growth or its seeds are already present somewhere: we are not recommending an idealistic dream, but the reality of extending widely the high quality which already exists in pockets, locked in the minds and actions of the few who must become the many."

In July, the FEFC announced that it would implement immediately over 30 of the Tomlinson recommendations, and hopes to implement the rest in the next two or three years.

It has already set up: a sector-wide staff development programme; increased funds available for additional support for disabled students; given greater recognition in its funding arrangements to the costs of specialist support equipment; improved its national student data collection; and started research to establish benchmark costs for the specialist support purchased by colleges.

The FEFC will also ensure that greater account of the needs of people with learning difficulties or disabilities will be taken when drawing up strategic plans. It will pilot schemes to have a named person responsible for each student's further education development plan; and will seek to introduce programmes which target students with profound or multiple learning difficulties.

It will continue to fund students to attend specialist colleges where necessary but will have contracts only with colleges which have effective complaints procedures and systems to protect vulnerable students. It will also ask mainstream FE colleges whether they can match a student's requirements before agreeing a specialist placement.

Janice Shiner, the FEFC's director of education programmes, said: "The Tomlinson recommendations are a major priority within the Council. A large number have already been adopted. Staff are now working hard on the outstanding recommendations. These all need further work before the Council can make decisions."

See panel on opposite page for* ASBAH's comments *on the Tomlinson Inquiry into Further Education provision for people with learning difficulties and disabilities.

A thousand thanks

BRAVE Flynn family members hurled themselves 300 feet from a cage attached to a crane to raise money for ASBAH South East Region and Macmillan Nurses.

Larry, wife Anne and daughter Sarah-Jane were among a seven-strong bungee jump team who raised almost £1,000 apiece for the two charities by completing the fall by London's Chelsea Bridge.

Larry, who organised the event over a drink at The Portland Arms in Stockwell SW8, commented: "It's the most frightening thing I have ever done!"

He chose the two charities because his father-in-law has lung cancer and because a former local darts league organiser at the pub regularly raised money for ASBAH.

Larry said: "It was only after we had arranged to do the jump that I realised that someone who goes to the pub has spina bifida."

Bungee jump organiser Larry Flynn and his daughter's boyfriend Mark Healy hand over a cheque to ASBAH adviser for South London, Rachel Nicholls

No problem too big or too small for equipment helpline

ONE phone call can give you information on gadgets to help overcome every-day living problems such as tap turners and kettle tippers and, larger items, like bath seats and wheelchairs.

With a grant from the National Lottery Charities Board, the Disabled Living Foundation has set up a new helpline to respond to enquiries on equipment needs, drawing from its comprehensive information database.

The DLF Helpline is:
0870 603 9177
Minicom: 0870 603 9176.
Open Monday to Friday,
10am to 4pm.

Calls are charged at 8p per minute.

So, if you have difficulty getting out of the bath, or if you are having problems cooking or you want information on other charities, self-help groups and equipment suppliers, call the DLF Helpline.

ASBAH's comments on Tomlinson Inquiry into Further Education provision

ASBAH commented as follows on the recommendations of the Tomlinson Committee:

● The individualised approach to learning described as 'inclusive learning' seems eminently sensible if it provides the best match between each student's requirements and the provision made.

For students with spina bifida and/or hydrocephalus, the whole range of learner support needed should be taken into account when providing the best match of needs and provision. It should be emphasised that 'inclusive' does not necessarily also mean integrated as for some students 'best match' may still be made in a specialist college.

● We are concerned that potential students who live in rural areas cannot readily access FE courses as transport is still a major problem.

● There is still a strong emphasis on funding courses linked to vocational qualifications. Often students with SBAH are in need of courses for the acquisition of life skills and requirements for independent living, without these necessarily having to lead on to vocational courses.

● Some students with hydrocephalus will require the support of someone to monitor their work and keep them on task. Pastoral care in colleges must be easily accessible and readily available as they can also have organisational difficulties.

● ASBAH welcomes acknowledgement of the need for improved and enhanced partnership in planning. We feel that voluntary organisations which specialise in specific disabilities and learning colleges should be invited, by colleges, to become more involved with a student's programme and progress.

● The idea of a 'named person' should be extended from the statementing stage to FE.

● Many positive recommendations have been made in the report but we are concerned that there may not be sufficient resources made available to support their implementation.

Civil rights for

Other people's property

By Beverley Rowe
Your Voice In ASBAH

WHEN you use the word 'discrimination' in the context of disability, very often the first things that come to mind are not being able to go into buildings because of steps and not being able to get on buses and trains etc – in other words, an access problem. Today I am going to concentrate on another aspect of discrimination: a form that I have faced throughout my life almost as regularly as the last. It's what I call the subtle approach.

My first memory of discrimination was of quite regularly being given money and sweets when I was in the street and in shops etc. I'm sure these people did this out of pity for me and felt that they were helping me. All they did was make me feel embarrassed and even a little guilty, in a way, because I think it was hard on my brother when he did not get the same treatment.

Another example happened a few years ago when I was sitting at a coach station, admittedly very near a Sunshine Variety Coach, drinking a can of coke. A woman rushed up and tried to put 10p in my can until she realised what it was and scuttled off again. That time I just found it very funny but is it any wonder that I now have a hang-up about street collecting?

People are sometimes extra 'kind' to me

An example of this is when I came home at weekends from school in my early teenage years and very often I would be told that a neighbour, who was only a few years older than me, would be coming to take me for a walk sometime over the weekend. Whether she thought she was doing my mum a favour or being kind to me, I'm not sure, but, if it was for me, I would have much rather she had just knocked on the door and asked me if I wanted to go out – you know, like friends do. It made working out who real friends were quite difficult for a while.

Many people still treat me as a child

Until I got married five years ago, whenever I waited in hospital waiting rooms, other people would be called Mr, Mrs, Miss, but I was called Beverley. My only conclusion was that staff perceived me as a child needing reassurance.

My space is often invaded

When I have been at parties etc, there have been several uncomfortable, embarrassing moments caused by people who have insisted on 'helping me to enjoy myself' on the dance floor by grabbing hold of my chair and sometimes even my arms and dancing unrhythmically about with me. This would not be acceptable to most of the able-bodied people I know.

People do not always respect my privacy or respect my feelings

When I am out, many people ask me if I need help. That is fine by me. We should all be there to offer and give help to each other when it is needed or wanted, but some people do insist on helping even when you say 'no'. Whether they feel I am refusing out of pride or to make themselves feel better, I do not know. But what I do know is that they are not listening to me or even thinking about what I really want.

People have asked me questions they wouldn't ask an able-bodied person who they did not know. The weird thing is that I answer them. I feel that I was conditioned to do this. They feel they have the right to ask me.

When rushed into hospital, my then boyfriend, now husband, was called. I was then fully examined with him standing there without any questions asked. I can only assume that they assumed he was my carer. Some people still see him as that, and he has been told on several occasions what a great bloke he must be to have married someone like me and they don't know how he does it! Those people should try living with *him* sometimes!

People seem to have trouble seeing me as the giver

An example of this is where I work, I have to go through several sets of doors each day and I am quite happy if someone in front holds the door open for me. Sometimes I know someone is behind me and I open the door for them. Do they come through and say thank you like I do? Oh no, they rush ahead and hold the door again thinking I've got stuck! What does that say?

From these examples, you can see why sometimes I've felt like other people's property and, although these events and many more have happened to me, they are just a tiny part of my life. To change these attitudes does not cost anything but just requires that people think about what they are doing and saying and why. The Disability Discrimination Act falls a long way short of what I feel disabled people are entitled to, but one thing I believe it will help do is to raise the consciousness of the people we meet on the street every day.

disabled people

AT our annual meeting in September, three speakers took up the theme of civil rights for disabled people.

Beverley Rowe, *Your Voice In ASBAH* member, highlighted some of the 'subtle' ways in which she had experienced discrimination since childhood.

Then Zem Rodaway, also from *YVIA*, posed the question – is the Disability Discrimination Act doing enough to ensure disabled people enjoy full civil rights in society?

Finally, Neil Betteridge from RADAR (Royal Society for Disability and Rehabilitation), considered how other disability groups and indeed the new government regarded the new legislation – see page 12.

Disability Discrimination Act – A sharp attack or a toothless smile?

By Zem Rodaway
Your Voice In ASBAH

THERE has been a great deal of criticism of the Disability Discrimination Act (DDA) – justifiably so, in my opinion. However, is it really just a toothless smile in the face of discrimination, or is it having any benefits at all on society?

Despite the fact that there has been legislation outlawing discrimination on grounds of sex or race since the 1970s, when it comes to the discrimination faced on a daily basis by many of Britain's 6.5 million disabled people, the government has always promoted 'education' and 'persuasion' as the way forward.

This may have worked in a few isolated cases. However, many companies which may be service providers, as well as employers, are looking at profitability and complying with existing legislation, and don't have the time or the will for 'optional extras'.

There has been an increasing movement for civil rights legislation – 17 attempts to introduce such legislation between 1982-1994. The government then introduced the DDA in 1995. But has it put disability on the agenda, or does it deserve the title of 'Doesn't Do Anything Act?'

From my perspective as a Disability Rights Worker, I would like to suggest there has been some benefit to having a Disability Discrimination Act, even in its present form.

Some employers are now including training on the Act for their employees. This may be for the right reasons, or it may be simply to try and avoid responsibility if one of their employees is taken to an industrial tribunal under the new Act. Whatever the reason, such training at least brings the issue of disability out into the open, and focuses attention on it. I have been asked to provide training for a variety of organisations and all sorts of questions have come up, eg what's an induction loop? how can we get our leaflets transcribed into braille or onto tape?

Some people have had preconceived ideas that a particular impairment prevents a person from doing a particular job.

Such training also gives the opportunity to talk about language in relation to disability, or to address some of the issues Beverley raised, like when and how to offer help.

Often people have been blissfully unaware of the discrimination disabled people face. People have really been surprised when I have talked about past difficulties obtaining motor or life insurance, or of being referred to as a 'fire hazard'. I always assure people at this point that disabled people are no more liable to spontaneous combustion than the rest of society.

I would hope that whatever people may have learnt in training sessions will also spill over into their everyday life. For example, an office worker may also be involved in a voluntary organisation, or with their child's school. Everyone has some involvement in society – even if it is just going to the shops, library or pub.

Many local authorities and other organisations are now undertaking access audits of their buildings, and some institutions have organised consultation meetings with disabled people to canvas their ideas. We all know that the world isn't going to change overnight, but at least some changes are beginning to be made. Such audits may ideally be done in consultation with disabled people's organisations.

Having said this, many companies

continued on page 12

Zem Rodaway, from page 11

are still unaware of their obligations and many disabled people are still unaware of their rights. How can we use the new Act, if we don't know what rights it gives us?

I believe disabled people need to be pro-active in fighting for change in society. Sometimes just a letter will produce results. We need to be aware of the help and advice available in our local area – maybe from our trade union, if it is an employment issue, or the local disability organisation, Citizen's Advice Bureau or Law Centre. Nationally, RADAR or the Disability Law Service can be contacted for advice.

Here are some examples of ways in which the Act has helped:

● A woman has won her case against Wisdom toothbrushes, who, instead of seeing what adjustments they could make when Barbara Tarling's condition worsened, began disciplinary procedures and sacked her. Hopefully, they are now wise after the event.

● A group of three deaf workers were being denied access to staff meetings at their company. Under the DDA, the employer must make a 'reasonable adjustment' to allow disabled people access, in this case, by providing sign language interpretation.

One of the many problems with the new law is that only parts of it are in force, and there is no sanction unless a disabled person complains. However, we can all encourage good practice, for example:

● A new set of customer information leaflets is being printed at work. Could a large print, braille or audio version be made?

● The office is being redecorated. Could a different colour scheme assist a visually impaired person to find his/her way around?

● A local building society is being renovated. Could the cashpoint machine be sited lower down, so it can be reached from a wheelchair?

● Could the step up to the post office be replaced with a ramp.

And what of the future? The DDA can be seen in two ways – breaking down barriers, with people beginning to talk about disability issues, and disabled people included in companies' equal opportunities policies, harassment policies and so on. Perhaps levels of awareness are beginning to rise.

On the other hand, in some circumstances discrimination can be 'justified' under the legislation. This would appear to make discrimination officially 'legal' rather than outlawing it!

The government proposes to set up a Commission to look into Civil Rights legislation. I believe we should continue to campaign for such a law whilst making as much use of the current Act as possible – both in terms of taking up claims of discrimination, and of increasing the level of disability awareness in the general public.

Finally, to return to my original question: the DDA – Is it a sharp attack on discrimination or a toothless smile, smiling benignly at the face of discrimination?

I believe the answer lies somewhere in the middle. It is certainly not a sharp attack, there are too many loopholes for that: the definition of disability, the fact that businesses with fewer than 20 employees aren't covered as employers, but are covered as service providers. But neither is it completely toothless. Some members of the public are gaining more awareness of disability issues and some disabled people, some of the time, can make use of the DDA, if they know about it, and have the support to do so.

Civil rights for disabled people: an agenda for change

By Neil Betteridge
Head of Projects and Campaigns at RADAR

SOME organisations feel we should get rid of the Disability Discrimination Act (DDA) which, they believe, was never any good, and start again with a clean slate.

RADAR believes the DDA is deeply flawed and can identify the parts which need to go, but we believe the good parts should be retained to ensure the work already done isn't wasted but goes forward to civil rights legislation which we all need and should enjoy.

In the short term, the focus is Roger Berry's Private Member's Bill which, in the new year, should give an airing to unresolved issues such as the definition of disability under the Act, the exclusion of employers of fewer than 20 people from the Employment Section of the Act, and the absence of a Commision which makes the new laws hard to enforce.

We could get this wrong, we may get a backlash from the mainstream, so it is important that we think about it carefully and get it right.

It is important not to relent now after all that has gone before over years and decades. We are, in effect, getting a second bite of the cherry and we might not get a third for a very long time.

● Since this speech was made, in September, the government has made an announcement about establishing a Disability Rights Commission, a Ministerial Task Force and the enforcement of the remaining parts of Section 3 of the DDA. RADAR welcomes all these measures but is concerned that it may take several years to get new, stronger legislation.

Golf captain's appeal goes with a swing

A GOLF captain, whose five-year-old grandson has spina bifida and hydrocephalus, has adopted ASBAH as his charity during his year in office.

And in a single day, £1,025 was raised for ASBAH, at a special golfing event held in May.

Dave Turner expects there to be other equally successful fundraising events before his year as captain of Bush Hill Park Golf Club in London N21, comes to an end, in April.

He said: "The fund is running at £1,600 (October) and there are all sorts of important functions like the dinner dance still to come.

"When I see all the £5 and £10 notes in the collection boxes, it amazes me how generous people are."

He added: "Choosing ASBAH as the captain's charity seemed the obvious thing to do as my grandson has spina bifida. Early on, the family had support from ASBAH but it wasn't crucial in the end. He is doing very well."

Tennis stars in the making

A COME-and-try Tennis and Activity Day, organised by ASBAH adviser Elizabeth Miers, has resulted in two people winning trophies in an international tournament.

Debbie Simms and Phil Moss, both aged 30, had hardly picked up a tennis racket before 1st June but are now playing three times a week at a local tennis centre.

Debbie, from Prenton, Wirral, said: "Elizabeth asked me to go along to the Tennis and Activity Day, and I wasn't going to turn up on my own, so I asked Phil to come too.

"I had never really picked up a tennis racket before that. We met tennis coach Craig Jones there, who asked us if we'd like to join the regular coaching sessions."

About 15 people with spina bifida and/or hydrocephalus took part in the Tennis and Activity Day at Wirral Tennis Centre. One participant, Alison Brown, aged 26, from Chester, plays regularly at Wrexham. She now has a new tennis wheelchair, some of the money for which was donated by Vauxhall. Other participants have started playing regularly and are hoping to start a basketball group.

Debbie and Phil are lucky that all their coaching sessions are free, thanks to sponsorship from Cyclone Wheelchairs.

Debbie, who is also mum of four-year-old Eleanor, said: "There are five or six of us who train altogether twice a week at the Bidston Tennis Centre, and Phil and I usually get together at weekends for a game.

"We weren't very good but were encouraged to keep going. I had never done a wheelchair sport before and was quite surprised at how much fun it was. Phil has done wheelchair basketball but he is now concentrating on tennis."

Wheelchair tennis players are graded according to ability and at an indoor tournament in Nottingham in November, Debbie won a trophy after getting through to the ladies final in the 'C' Division.

Phil, of Rockferry, Wirral, who uses an adapted basketball wheelchair to play, came away with a trophy as a doubles finalist. He also got through to the singles semi-finals. The youngest tournament competitor was 16; the oldest was in their 40s.

Debbie now has a second-hand tennis wheelchair to help her move more swiftly around the court.

Elizabeth Miers said: "Debbie and Phil are doing brilliantly. Thanks to 14-year-old Shelly Oliver, from Birkenhead, the sister of Douglas, who raised money to hire the courts for the Tennis & Activity Day, which got it all started."

Picnic gathering in South Thames

by Denise Taylor
Secretary, ASBAH South East Region

SOUTH Thames ASBAH secretary Margaret Holmes invited a member of ASBAH South East Region to attend an annual picnic. I was able to go and had a brilliant day.

The picnic, which took place in Swanley, was well attended and the food was delicious – prepared and provided by the local association.

Swanley Park is delightful with a miniature railway, large paddling pool, a boating lake and an adventure playground.

This event, which has been going for about eight years, provides a good opportunity for members, families and friends to get together in a relaxed setting and it gave me a chance to find out how important the local associations are.

It was a smashing day. Thanks for inviting me and don't forget my invite next year!

A BOOKLET giving information on the implications for disabled people, their families and carers of the Gloucestershire case is available FREE to organisations and individuals. **The Needs Must Campaign Pack** *can be ordered from: RADAR, 12 City Forum, 250 City Road, London EC1V 8AF.*

Fast forward to the next century as goers explore *Choice, Independence*

OUR work in giving disabled service-users greater involvement in ASBAH received two immense boosts this autumn.

On top of an £80,000 grant to take the work forward from the National Lottery Charities Board, our six-year-old participation programme was given a ringing endorsement from people taking part in the first residential conference staged by our user-group forum, *Your Voice In ASBAH (YVIA).*

Many of the participants at the *YVIA* conference – held in South Wales at the end of October – liked what they heard about the participation programme so much that they agreed to explore the setting up of local groups in their own localities.

Conference organisers left with the clear impression that there were good prospects for groups to be established in eight areas, with the foundations for another lively South Wales group seeming to be laid during the conference itself.

Around 50 people, aged between 18 and 71, attended the three-day conference at the wheelchair-friendly Jane Hodge Hotel, set on a hillside overlooking the Vale of Glamorgan.

The event – dubbed *CIC '97*, standing for *Choice, Independence and Control* – attracted participants from as far afield as Morpeth in Northumberland and Sussex.

The conference itself proved to be so enjoyable that there were instant demands for something like it to be held again pretty soon.

YVIA chair Alan Twyford said he hoped that would soon be possible. He said it was an exciting time for *YVIA* and lots of things would be happening in the near future.

Gwyneth Bishop, from Pontypridd, acknowledging that she was the oldest person present, complimented *YVIA* on putting together a conference programme which bridged the generation gap.

"I certainly enjoyed myself, and I know an awful lot of other people did as well. I didn't really expect all age-groups to be catered for but I was wrong," she said.

A feeling was widely expressed that the time allowed for the various workshops was too short. People were spoiled for choice. They felt fewer topics could be covered but in more depth. But the sh
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"I can't fault any
weekend. In my

Fitting all the pieces of the weekend together, organisers, from left to right: Marcia and Paul Conroy, Zem Rodaway, Margaret and Alan Twyford, and Jon Burke

s conference-
e and Control

FIFTY people, aged 18-71, took up the invitation to spend a weekend in Wales with *Your Voice In ASBAH* – to improve skills, find out about service user-involvement in ASBAH – and most had a wonderful time!

TONY BRITTON reports.

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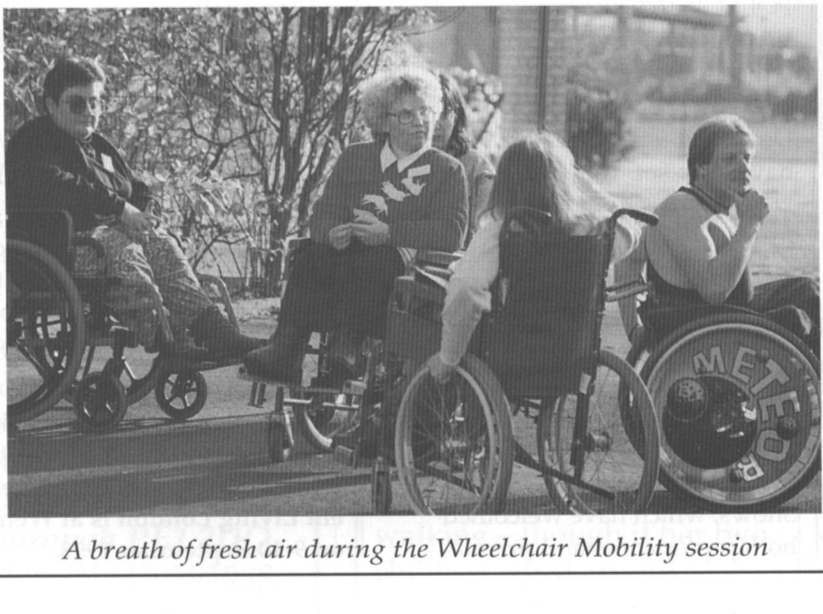
Taking a break during the Your Voice In ASBAH *training weekend*

deserves a round of applause for organising the weekend."

● The lottery money, from the England committee of the National Lottery Charities Board, will put our pioneering disabled member involvement programme on a firmer footing over the next three years. It will pay for a series of special training courses, conferences and for a dedicated, part-time organiser, who will be based in Peterborough.

So far, the work has led to the setting up of *Your Voice In ASBAH*, more disabled-users joining our committees, and a series of training weekends designed to give disabled members the skills and experience to become involved in national ASBAH and local associations.



A breath of fresh air during the Wheelchair Mobility session

Darke culture *by Paul Darke*

FILM festivals are popping up all over the place, each offering something new, similar and the same as many others that already exist.

Quite bizarrely, they are often a showcase of the best, worst and indifferent attitudes that culture has towards disability. I say bizarrely because they are never recognised as having anything to do with disablement in any form whatsoever, yet they always have either numerous films about or with disability as a central theme.

Take the Birmingham and London Film Festivals for example. Their range of films about, or within the subject area of, disability is startling, (all GB and US unless otherwise stated): *In The Company of Men; Regeneration; The Tango Lesson; The Diary of a Madman* (a short); *The Ugly* (New Zealand); *Live Flesh* (Spanish); *Sling Blade; Sixth Happiness; Bernie* (France); *The Kingdom* (Denmark); *Beyond Silence* (Germany); *Sick: The Life and Death of Bob Flanagan, Supermasochist; In Case I Never See You Again* (Mexico); *Richard III* and the silent film *Orphans of the Storm.*

Unfortunately, some of the most significant and exciting of these films in both the Birmingham and London Film Festivals are in inaccessible cinemas. Thus, it is easy to dismiss any film about disability as being about the 'human condition' or the 'art of cinema' if you never see a disabled person in the audience.

Fortunately, *Live Flesh* will probably get a distributor and, as such, will be shown around the country. The tragedy is that the other films mentioned – which will probably be more significantly challenging (ie Germany's *Beyond Silence* or Mexico's *In Case I Never See You Again,* or even *Sick ...*) – will not only never get seen outside of their one or two screenings in the London Film Festival but they will never even be seen on television either (shame on Channel 4).

Occasionally a film festival does have disability specific events (either about disability or for disabled people); Leeds and Birmingham have done so over the past few years. But this is insufficient and not the right direction to go in, I believe.

The government must ensure and participate in the creation of a systematic distribution network where works of art – be they disability-orientated or not – are not merely shown once to an elite few and then forgotten about, but are available to everybody, everywhere.

Film festivals (and other culture festivals) are better than nothing: they at least provide a single screening of a number of films / art performances / works which will then disappear. I believe, though, that we all deserve a little more than better than nothing.

Pluralism – the promotion and validation of as wide a multiplicity of perspectives and experiences as possible – is essential if a society is to grow and illuminate itself with all its people; and the pluralistic culture that film festivals (and Channel Four) embody are merely the bourgeois posturing of a patronising elitist view of pluralism. Let's hear it for real pluralism.

Not A Cabbage Rose

NOT A Cabbage Rose is the story of a couple who adopted a baby with severe spina bifida and hydrocephalus, who was expected to live only a few weeks.

In fact, Claire Rose lived for 12 years, defying experts' predictions that she would be a 'cabbage', to enjoy her life and all it could offer.

It is author Jenny Rose's story as well as Claire's; of her love and devotion to the child who triumphed over immense difficulties.

Price: £3.95. Foundery Press, 20 Ivatt Way, Peterborough PE3 7PG. Tel: 01733-332202.

Independent Living show dates 1998

FOLLOWING the success of 1997's Independent Living Shows – which took place in Bristol, Glasgow, Sandown Park and Doncaster – the dates for 1998 have been set.

There will be two shows – one in Manchester and one in the popular Wembley exhibition venue.

The Wembley date replaces the Naidex exhibition, which was always well supported by exhibitors and visitors alike.

The new Independent Living Shows, which have welcomed both professional and private visitors, have provided exhibitors and visitors with an informal and relaxed environment in which to meet, compare products and update themselves.

Michelle Boland, exhibition director, said: "Our primary aim is to provide an exhibition which is easy to get to, full of the most interesting exhibits and supported with good quality, interesting free seminars."

Independent Living North-West takes place on 18-19 March 1998 in Manchester while Independent Living London is at Wembley on 9-10 September 1998.

HYDROCEPHALUS NETWORK NEWS

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

Winter '97/98

ASBAH survey on children with hydrocephalus and eating problems

MANY of you will already know that ASBAH specialist adviser (medical/continence) Paula Thompson is doing some research into any links between people with hydrocephalus and associated eating problems.

Paula would like to thank everyone who has responded so far.

Once again, she would be very grateful if any parent, who has a child with hydrocephalus and eating problems, would take the time to fill out the questionnaire which appears on page 2 of this issue of *HNN* – even if you have contacted Paula in the past about the subject.

Paula says: "The results, which I have already found to be very interesting, will be published in the near future, so watch this space!"

Paula's interest in hydrocephalus and asssociated eating problems began last year when ASBAH Services staff received two or three calls on the subject within about a week.

Support for people with BIH

FOLLOWING the feature in the Winter '96/97 issue of *Hydrocephalus Network News*, we are planning to set up a Support Group for people with Benign Intracranial Hypertension.

For more information, contact Lyn Rylance, Services Dept, ASBAH, 42 Park Road, Peterborough PE1 2UQ, telephone 01733-555988, fax 01733-555985.

INFORMATION OFFICER GILL WINFIELD ...

HAS recently discovered she likes red wine following a visit to France, and she and her family now make several trips a year to replenish supplies. "We hope to go over again soon to stock up for Christmas," she says.

As well as days out to Boulogne, Gill enjoys a weekly aquafit class and walking – though if her two children, aged 10 and 12, are present she has to pretend they're going on a picnic as they don't like strolls in the country.

The children's favourite holiday is under canvas so Gill does a lot of this, "though it always seems to rain when we go camping," she says.

HYDROCEPHALUS NETWORK NEWS

Contacts

Network Co-ordinator: Rosemary Batchelor 01733-555988.

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Medical (National): Julie Llewelyn 01733-555988.

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Education (North): Mike Dodd 01484-510202.

Occupational Therapist, (Northern Region and START): Rose Hinchliffe 01943-609468.

Medical (North and North West): Geraldine Binstead 01943-609468

Education (Northern Ireland): Lorna Johnston 012477-72191

Medical/Continence, (Northern Ireland): Marie McGonnell 016487-64748.

Hydrocephalus (Northern Ireland): Lorna Johnston 012477-72191

User-group forum project worker (Northern Ireland): Helen Quinn 01265-51522

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

Eating problems questionnaire

Child's name ________________ Date of birth ________

Address ______________________________

____

Postcode ________________ Tel No: ________

Do you have an ASBAH adviser, if so, who? ________

Disability: SB SBH H

Does child have shunt? Yes / No

Date inserted ________________ Type: **VP VA OTHER**

State number of shunt revisions, if any ________

Any other medical problems? ________

____

Allergies: ______________________________

Child's height ____________ weight ____________

Parents' names ______________________________

Other children in family: Yes / No

Name ______________________ Age ________

Name ______________________ Age ________

Name ______________________ Age ________

Age at which eating problems began ________

Does your child have problems with any of the following?

Retching Yes / No **Reflux** Yes / No

Specific textures, eg lumps Yes / No

Temperatures Yes / No **Amounts of food** Yes / No

If you answered 'Yes' to any of the above, please specify: ________

____

Is she/he a 'fussy eater'/'slow eater'? Yes/ No

Please specify: ______________________________

Any other eating problems? ________

____

Have you consulted a health professional regarding any of the above problems? If so, who? ________

How does this affect family life? ________

Any family history of eating problems? ________

____

Anything else you feel is relevant *(continue on separate page if necessary)*

____

Please return completed questionnaires as soon as possible to: Paula Thompson, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

Slit ventrical syndrome

By Michael Vloeberghs
Senior lecturer in paediatric neurosurgery
& honorary consultant paediatric neurosurgeon
Queen's Medical Centre
University of Nottingham

ONE error that can be made is to think that the human ventricular system (the well-known four cavities within the brain) is static and that the ventricles do not modify over time.

At birth, or even within the womb, as can be seen on prenatal ultrasound, the ventricles are rather small. Within the first year of life, there is quite a lot of change in the brain and so in the shape and size of the ventricles.

With increasing age the ventricles become larger because of the unfortunate decrease in brain cells we all go through. These changes are easily picked up on CT scan or MRI scans. This also means that the actual size of the ventricular system has very little importance except in the extreme case where the ventricles are so large that there is hardly any brain left.

During each heart beat, a shock wave is produced that changes the shape and size of the ventricles. With a particular sequence on MRI scanning, this movement can be picked up and studied. This movement is also the object of a combined research project between the engineering department and myself.

All this is to say that we are dealing with a dynamic system where there is constant modification of shape and volume.

What are slit ventricles?

Slit ventricles are small ventricles, sometimes so small that they are barely visible on CT scan or MRI. Slit ventricles can occur after severe head injury or viral infection of the brain. In both conditions, the brain becomes so swollen that the fluid is pushed out of the ventricles.

More of interest to this discussion is the appearance of slit ventricles after cerebrospinal fluid diversion – shunts, for example. One of the criteria for a happily functioning shunt is decompression of the ventricular system when compared to the previous CT scan or MRI. Inherent to any shunt system is the change in the pressure in the skull and brain. In some patients this can lead to a siphon effect, much as when you siphon petrol from a car. What happens next all depends on the resilience of the brain. At a very young age, the brain is very watery and will easily change shape. The ventricles will usually become smaller, sometimes up to a point that they become slit-like. Unfortunately, this effect is unpredictable and very little can be done about it.

It is important to know that not all small or slit ventricles cause symptoms. What proportion of patients with small ventricles develop slit ventricle syndrome is not really known. We know that the patients at risk of developing slit ventricle syndrome are those who were shunted at an early age and where a low drainage pressure shunt system was used. This does

continued on page 4

What's in the Dec / Jan Link

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

Slit ventrical syndrome

by Dr Michael Vloeberghs

from page 3

not imply inadequate treatment. It just means the effect of a shunt can be unpredictable.

What is slit ventricle syndrome?

Slit ventricle syndrome is a constellation of symptoms which, for example, can appear in patients with a functioning shunt and in whom the brain has lost part of its elasticity. The symptoms consist of headaches, vomiting, drowsiness etc. Infuriatingly enough, these symptoms resemble those of shunt malfunction.

The appearance of the symptoms is very cyclical, often with the regularity of a clock for example, the patient is well for three weeks, then violently ill and sleepy for 24 hours and then well again. There is more often than not no cause for the symptoms, although a minor viral illness can kick off the symptoms. Often the patient is taken to hospital and imaging is done which shows the ventricles to be small, or even unchanged, compared to previous imaging.

To increase the frustration, the symptoms disappear spontaneously. Until the next time, that is.

What actually happens?

We have been able to confirm by MRI scans on several patients the 'gut feeling' many have had about slit ventricle syndrome.

In ordinary circumstances, the shunt drains the cerebrospinal fluid (CSF) from the ventricles to whichever cavity of the body. This causes, in certain patients, the ventricles to collapse. The ventricle closes on the ventricular catheter that drains the ventricles and blocks off the outflow of CSF. That's when the symptoms appear. The pressure in the brain rises very quickly and the patient becomes ill. Because the brain has lost some of its elasticity due to the initial disease that caused the hydrocephalus, the ventricles do not blow up rapidly and the symptoms can persist. After a while, the ventricles get slightly bigger and the normal CSF drainage resumes. All these changes, in shape and size, may not be easy to detect and often the illness goes unexplained.

What can be done?

This is a difficult question. The crucial point is to make sure that the shunt is working properly. This means you must make sure you are not dealing with intermittent shunt blockage due to malfunction of the system. Often this can be done by measuring the pressure in the skull (ICP = intra cranial pressure monitoring) and with extra imaging (CT scan or MRI). Once you are satisfied with the functioning of the shunt, there are several options available. In our department, we tend to proceed with volume expansion procedures.

This means that, since the ventricles are small, you can give the ventricle, and so the catheter inside the brain, some extra space by removing a scale of bone on the side of the skull. This is called a subtemporal decompression. This simple procedure carries very little risk and resolves the problem.

Other volume expansion procedures consist of moving larger portions of the skull to make the total volume bigger, for example, forehead advancement. This type of procedure is more elaborate and is suitable for very young children. Tampering with the shunt system is usually a bad idea if at least you are satisfied with its functioning.

Moves like changing to a higher pressure valve or adding an anti-siphon device at a later stage can sometimes cause a fatal rise in intracranial pressure, particularly in those patients who have had a shunt or who have suffered from slit ventricle syndrome for a long time.

I am often asked what the role of endoscopy is in slit ventricle syndrome. We have treated a number of patients with slit ventricle syndrome with endoscopic third ventriculostomy. This was only possible because these patients presented with shunt failure and large ventricles. The important message is that slit ventricle syndrome does not preclude endoscopic treatment but the ventricles must be large enough to allow access.

Choosing your child's school – your rights and the law

by Michael Imperato

DECIDING which school you would like your child to go to is something which will exercise the minds of all parents, but do they really have a choice at all?

In fact, parents only have the right to express a preference. The responsibility for determining a school's admission arrangements rests with the admission authority. For most schools this will be a local education authority (LEA). For voluntary aided schools, such as church schools, this will be the governing body.

The admission authority can only refuse to admit a child to a school of the parents' preference:

a) If the number of applications has reached what is known as the school's standard number and to admit more would prejudice the provision of efficient education or use of resources.

b) If the school is an aided school and admission would be against admission provisions set up to preserve the school's character, eg a Catholic school can give priority to Catholic children.

c) Where the school is selective and the child has failed its entrance exam.

Admission authorities must publish each year their admission policy. In respect of non-denominational schools, this becomes relevant if the school is full. Most admission authorities will then operate a system where preference is given to children who have older siblings already in the school and / or who live close, ie within its catchment area.

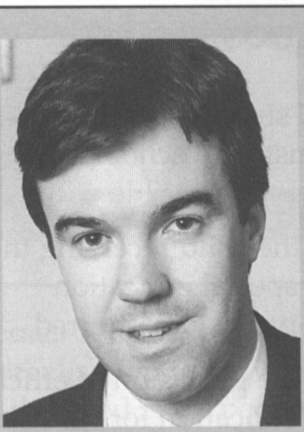
If a child is refused a place, parents can appeal to an independent panel. The admission authority would have to show the appeals panel that one of the three reasons by which they could refuse a place was relevant *(see above)*. In non-denominational schools this will usually be reason (a). In those circumstances it will be important for the parents to try to show that the school may have allowed a few extra children in previous years.

If the appeal panel accepts that the school is full, they must then go on to balance the wishes of the authority against those of the parents. If the parents can produce a good reason why their child needs to go to this particular school, this might tip the balance in their favour, eg perhaps the child has a minor disability and this school is well placed to cope with it.

Children with special educational needs (SEN) will be in a stronger position if they have a Statement. To have a Statement, a child must have been assessed by the LEA as having educational needs which require extra support and provision. Part 4 of a Statement will specify the type of school considered appropriate and possibly name it. The named school is obliged to take the child, even if full. If its governors object, they would have to show why they couldn't provide what the child needed even with the support provided under the Statement. It will be extremely difficult for the governors to prove this.

Many people think that a Statemented child must go to a special school with other children with severe disabilities. That could not be further from the truth. A child with

continued on page 6



Michael Imperato lives in Cardiff. He is a former teacher, a school governor and a solicitor with the national firm of Russell Jones and Walker. He is based in its Bristol office, but next summer should be moving to a planned new office in Cardiff. Contact telephone: 0117-927 3098.

Choosing your child's school, *from page 5*

SEN should be educated in a mainstream school as long as that is compatible with:

i) the child receiving the special education provision required.

ii) the provision of efficient education for children with whom the child will be educated.

(iii) the efficient use of resources.

If you wish your child to be kept in a mainstream school but the LEA says no schools will take him or her, ask, how does it know? Has it consulted all the schools in the area?

Parents have a right to have the mainstream school of their preference named in their child's Statement. If the LEA does not think the child should go to the school, the onus is on them to prove why not.

What if the parents of a child with SEN wish for him or her to go to a particular special or private school? Here the onus is on the parents to justify why the child should go there and not to any alternative which has been suggested by the LEA. The child's parents can request this even if the school's fees are very high or if it is at the other end of the country. They may even insist that the child needs to go to a school abroad. In a recent case, the Prime Minister's wife, Cherie Booth, successfully acted for parents who insisted their child should go to a specialist school in Boston, USA.

Any parents with children with SEN who are in dispute with their LEA about which school their child should attend will have to go to the SEN Tribunal to resolve the issue (see article by Peter Walker, *Link* No. 169, April 1997).

Parents do not have a choice of schools, rather a preference. Those with children with SEN have a good chance of placing their child in their preferred school if it is mainstream, and they can even have their child placed in an expensive foreign school of their choice in some circumstances. Either way, parents initially denied their preference will always have the opportunity to appeal and, with the help of ASBAH specialist advisers (education), they should not fear taking on their LEA.

Support groups update

● THE Anencephaly Support Group is a small contact group offering support by telephone and letter, and information on the condition.

It links families and, in some parts of the UK, can give area contacts.

It also produces an Information and Medical leaflet – please send a stamped addressed envelope if you require either of these.

There is no subscription fee, but donations are welcome.

Contact: ***Mrs D Lindesay, Anencephaly Support Group, 29 Hawkwood Close, Malvern WR14 1QU. Tel: 01684-573974.***

● THE Dandy Walker Syndrome Group for the UK is run by ***Julie McKeown, c/o ASBAH's Services Department, 42 Park Road, Peterborough PE1 2UQ.***

● THERE is also a Dandy Walker Syndrome Network in the USA. Contact: ***Desiree Fleming, 5030 142nd Path West, Apple Valley, MN 55124, USA.***

● THE Self-Help Hydrocephalus Network (SHYNE) is a group for people with late onset hydrocephalus. Contact: ***Jane Franklin, SHYNE, Greenways, Ashbrittle, Somerset, TA21 0LE.***

● THE Hydrocephalus Association for USA publishes a 12-page quarterly newsletter.

It also produces various Fact and Information Sheets, including: *Learning Disabilities in Children with Hydrocephalus, Social Skills Development in the Child with Hydrocephalus* and *Eye Problems and Hydrocephalus.*

More information and subscription details from: ***The Hydrocephalus Association, 870 Market Street, Suite 955, San Francisco, CA 94102, USA. Tel: 00-1-415-732-7040. Fax: 00-1-415-732-7044. E-mail: hydroassoc@aol.com***

A Supermarket Visit

By Mrs Gwen Bayley from York

I could forget for England
Should a championship be proclaimed.

When haste is required at the till
My problem dogs me still.

I would forget my head were it not tied on
Had a safety chain fitted (my shunt) to no avail!

A good friend is a wonderful help
Two heads are better than one?

Not so many items left behind
Requiring my retracking to retrieve.

Determination is what's required
This challenge to overcome.

Send your letters, articles, comments and feedback to:

Mrs Rosemary Batchelor, Senior Adviser Health and Policy Issues, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

HN NEWS letters

THANK you for helping us make contact with other parents of children who have hydrocephalus.

We had 38 responses following the appeals for contact which appeared in the Dec '96/Jan '97 *Link* and the Spring *Hydrocephalus Network News (HNN)*. Of these, 19 families live in or near London.

We subsequently organised a coffee morning at which we met five other parents/carers. We hope to hold another coffee morning before the end of 1997.

This entire exercise has been a great success and would not have been possible without your help. Thank you.

One of the more interesting outcomes of our experience is the realisation of how great the need is for people to make contact on an informal and personal basis, even for those who live in areas covered by independent local associations. Is there a greater role here for ASBAH as a facilitator? Perhaps our experience can be put to good use?

Finally, I'd just like to say how much we value the *HNN*. It's an invaluable way for us to keep abreast of the issues and to learn of the experiences of others – in particular, the *True Stories*.

John and Jacqui Bowmer
Flat D
11 Barkston Gardens
Earl's Court
London SW5 0ER

OUR youngest son Nathan, aged 14 months, was born with congenital hydrocephalus.

We have recently been told by his neurosurgeon in Liverpool that this was caused by a believed bleed he had several weeks before his birth at term, which is very rare in full term babies.

The hydrocephalus has damaged Nathan's sight but at present we are unsure of the extent of the damage. He is awaiting yet more tests.

Nathan had his first shunt at four weeks old and had his first shunt revision at eight months, from which time he has continued to make good progress.

We would like to contact other families where a full term baby has had an intraventricular bleed.

Jenni & Tony Jarvis
48 Church Close
Shawbury
Shreswbury
Shropshire
SY4 4JY

True story

By Debbie Sanderson, from Skelton-on-Ure, North Yorkshire

Debbie Sanderson, aged 26

I WAS diagnosed with hydrocephalus and fitted with a VA shunt as a baby in 1971. I had a normal childhood and schooling and never saw a neurosurgeon for a check-up because nothing went wrong.

Then in 1994, when I was 22, I started to suffer from really bad headaches and a stiff neck. My GP gave me headache tablets and said my shunt was no longer in use after all this time, so it could not go wrong.

I insisted on seeing a specialist and the neurosurgeon arranged for me to have a brain scan. I never made it to the appointment as I collapsed two weeks later. I needed a full revision and a VP shunt was inserted.

I spent six weeks in hospital. At first I couldn't walk and couldn't talk. I left hospital with severe depression and panic attacks. Also my periods have completely stopped. But the doctors won't connect these problems to my shunt revision.

I believe that a shunt revision has a profound effect on your body. Having that one revision wrecked my life and changed me as a person.

Until I was 21, I went through all my life thinking that my hydrocephalus was cured. So when my shunt failed, it was such a shock. I then realised that I have an illness which is for life.

It has helped me to have very understanding employers – I have kept the same job all through, even though I have needed to take a lot of time off for the operation and then for depression. It has also helped to have been able to talk to a woman of similar age, who has had even more shunt problems than I have.

It is amazing that such a simple operation should have caused major trouble for me. But good things have come out of it. My GP is now very understanding and I know that, if I ever have a suspected problem, I will be referred straight to the neurosurgeon, which is reassuring.

I think all suspected shunt problems should be investigated immediately to prevent problems like mine happening. Patients often have more experience of what is wrong than GPs, who may not have treated many people with hydrocephalus.

If you have a true story you would like to tell other members of the Hydrocephalus Network, send it to: Rosemary Batchelor, HNN Co-ordinator, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

YES! I would like to take out an annual subscription – four issues a year – of 'HN News.' Annual subscription rates: £2 (UK); £5 European and overseas surface mail; £10 by airmail.

Service user's name ______________________

Parent's name (IF APPLICABLE) ______________________

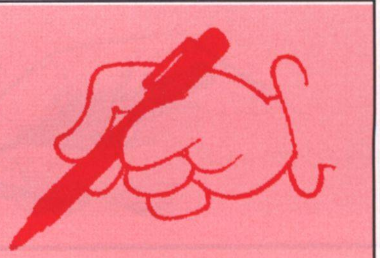
Address ______________________

____

Postcode ______________ **Tel:** ______________

I enclose a cheque/postal order payable to 'ASBAH.'
All payments should be made in Sterling.

Please cut out or photocopy completed forms and send to: Lynn Thomas, ASBAH, 42 Park Road, Peterborough PE1 2UQ.



Dave's diary

I recently fulfilled a life-long ambition: eating Afternoon Tea at the Ritz. A desire prompted less by culture and refinement than thoughts of heaped cake stands! These were thoughts shared by my friend Tanya, who agreed to drive me to the Ritz.

After an agonising six weeks wait for a reservation, the Great Day arrived. I duly stuffed myself into a suit and immediately began to overheat. The suit wasn't necessary because the Ritz only requires jacket and tie for us blokes. But I was out to impress T. She, of course, saw through this pathetic attempt at a cool image and squashed my ego by asking 'when's the interview?' At least she didn't ask when I was in court! With these words ringing in my ears, we set off.

Three hours later we'd travelled down every major road in London, looking for the Ritz, and I had serious doubts about Tanya's navigation. Eventually we arrived and I tried to recall where the City of Westminster (where the Ritz is) kept its disabled spots. If you go anywhere else, it seems, you get jumped on. I was about to issue directions when Tanya spotted an empty street full of meters. So we parked there instead.

Tanya and I consider ourselves to be civilised people but we soon managed to reduce the refined event of Afternon Tea to something not far short of a chimps tea party. We were swiftly in trouble with the staff.

I attempted to avoid imminent heat-stroke by ditching my jacket. A waiter scuttled over and requested I put it back on. So then Tanya decide she wanted a picture of me. I agreed, if I could have one of her in that cocktail dress-thing. She snapped off a sneaky shot of me stuffing cake into my gob, and I was about to get my turn/revenge when we were again buzzed by staff, who said 'no photographs allowed'. Pity, I'd liked to have recorded the afternoon tea, which was the polished silver and dinky crustless sandwiches of my dreams.

The meal was excellent, if problematic. We peasants muddled through, with minor mistakes. Among other mishaps: we poured out tea without using the silver strainer (you get a mouthful of bits), and wondered if you ate the combined (crustless) sarnies singly or in threes. Being left-handed (a sign of the Devil in some countries), using the right-handed cake fork properly would have been impossible without getting food up my nose. Eventually hunger overrode manners and we attacked the cakes with determination, if not the right implements. All was swiftly consumed.

While Tanya made use of the facilities, I went mad and ordered glasses of Champagne to end the meal. They came and Tan took a tiny, tiny sip, before reminding me she was driving and not drinking! So, embarrassed, I sat and grimly drank two glasses of the most expensive alcohol I'd ever bought. I swiftly retired to the loo (very posh!), only to find when washing and drying my hands, some old guy doing it for me! Weirdness! I was most unnerved. I only clocked the coin dish on the way out and twigged he was employed to do this. That's my Ritz experience. A great, if strange, day out.

The Ritz 0171-4938181.

David Fulford-Brown

DATES FOR YOUR DIARY

28 February 1998

ASBAH Study Day, Worcester College. *Further details: Geraldine Long, tel: 01789-763090.*

16–20 March 1998

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

18–19 March

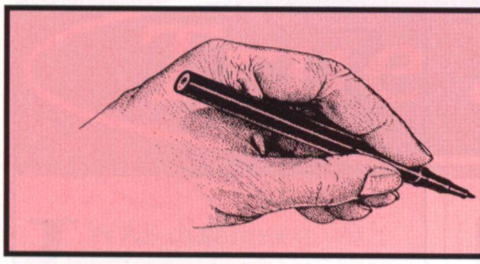
Independent Living exhibition, North-West, Bowlers Conference Centre, Manchester. *For free tickets call: 01275-836465.*

Saturday 21 March

ASBAH Study Day in Cornwall. *Details: Lynne Young, tel: 01726-861062.*

17–20 April

Adventure Training Weekend for young people with spina bifida and/or hydrocephalus, aged 11-17 inclusive, organised by national ASBAH at Low Mill Residential Centre, Askrigg, Leyburn, North Yorkshire. Cost: £50 per participant. *Further details: Rebecca Sewell, tel: 01733-555988.*



Letters

IT'S TIME the supermarkets took disabled mothers in wheelchairs seriously. Even when we can find shopping trolleys which clip on to wheelchairs, there remains nowhere to put the baby, except in one arm (or, and this is **not** recommended, in the shopping trolley itself).

What we really want is a shopping trolley which clips on to the wheelchair AND has a baby-carrying section. Then our hands will be free to wheel our way round the shop and do the shopping. Baby will be safer and we'll get round the stores quicker.

It will also be a shopping trolley which able-bodied mothers and their babies can use in safety when taking wheelchair-dependent relatives out shopping.

Simple really. So let's ask the supermarkets to focus some of their marketing skills on the increasing number of mothers using wheelchairs.

Kirsten Battle
Cippenham
Slough, Berks

LORRY (Lorraine) Laing, who has spina bifida, is looking for an e-mail pen-pal. She is 35 years old and lives in a group home in a rural town in Ontario, Canada.

In this community, there are a few group homes as well as supported independent residents among the disabled residents.

Lorry, who is involved in a therapeutic horseback riding programme, says it is a great place for disabled people to live and work.

She has a gentleman friend called Francis from a nearby town, Carleton Place, and they get together for movies, bowling or dances.

If you would like to write to Lorry, she can be reached via **<daphne@storm.ca>.**

ASBAH's presence at the Mobility Roadshow, which was held at the Transport and Road Research Laboratory, Crowthorne, Berkshire, in July, was as successful as ever.

Over the three days, we met dozens of professionals and many new service users, and caught up with many service users we had not seen for a while.

This year, HRH The Duchess of Gloucester, ASBAH's patron, opened the international biannual event, which attracted more than 50,000 people.

Leonie Holgate, myself and volunteers, were delighted to welcome the Duchess to ASBAH's stand.

We were also privileged to meet Transport Minister, Glenda Jackson, who also attended the show.

Every type of mobility aid was on display and there were many opportunities for people with disabilities to test drive adapted cars and other mobility aids.

We talked to many people over the three days and gave out lots of folic acid leaflets. We worked hard but had lots of fun!

Liz Clayton
ASBAH adviser for Berks,
S Oxon, part Hants & S Bucks

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

I THOUGHT *Link* readers might be interested to hear about an event which my daughter took part in to raise funds for Bedford and District ASBAH.

Becki *(pictured below)* is 15 years old and has spina bifida and hydrocephalus. She took part in a local four-mile Fun 'Run' and managed to complete the course in 1 hour 17 minutes – her personal best.

She raised £326 for the local association and was sponsored by many local businesses, whose names were displayed on both wheels of her chair in exchange for a donation.

Becki thoroughly enjoyed the 'run' and I felt it may help others to read of her achievement.

Some readers may remember Becki on the TV appeal programme, *Lifeline,* back in 1987 when she was four.

Mrs Janet Ellison
Riseley
Bedford

HOLIDAY ACCOMMODATION

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

WEYMOUTH BAY

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

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.*

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.*

mar y sol

Mar y Sol – Tenerife

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

Algarve – Portugal

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

FOR SALE

SPECIAL hand-built tricycle suitable for 4 years to 10 years. Has adjustable back trunk support and footshoes and strap support. New condition. Red in colour. £300. No offers. 01455-840223.

LINK Rates

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Small adverts for the next issue of *LINK* (February) should be submitted by Monday, 12 January. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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