

# Link



The magazine for people with  
Spina Bifida and Hydrocephalus

October/November 1994

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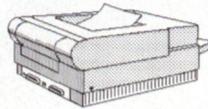
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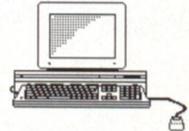
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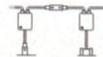
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## Comment

**OUR** successful Spina Bifida Week in August, carried out in association with the makers of Cantassium Folic Acid, resulted in ASBAH appearing on 11 television programmes, 52 radio programmes and in dozens upon dozens of newspapers and magazines round the country.

The week highlighted the importance to all women of a folic acid supplement in their diet before conception in order to reduce the risk of their babies being born with spina bifida and related birth defects. How telling, the week afterward, to see the results of a new survey at Queen Charlotte's and Chelsea Hospital (see page 6) which revealed that only 3% of mums-to-be attending their ante-natal department had

taken folic acid tablets before becoming pregnant - the same appalling level of supplementation picked up by surveys in Cardiff and Leeds as long ago as last year. When will we learn to follow the critical Department of Health recommendation that all women should boost folic acid levels in their bodies before conception and throughout the first 12 weeks of pregnancy?

**AND** who's teaching us? The Government is failing to push the message. Even the pharmaceutical industry, which for obvious reasons would like to highlight the specific benefits of folic acid supplements endorsed by the Government itself, is hamstrung by regulation and can make only the most general of advertising claims. So who's

trying to fill the gap? ASBAH, the Wolfson Institute, all those parents who helped with the Spina Bifida Week and, given half a chance on the advertising front, Cantassium.

**ANOTHER** ASBAH success has been our hydrocephalus shunt campaign, launched in the last issue of *LINK*, which invited readers to write in for an alert card and an information leaflet for their family doctors. The response so far has been fantastic.

**ASBAH's** Bursary Fund, which helps young people continue their education after leaving school, is the subject of a series of interviews starting on page 18.

The article had the added spin-off of leading us to Paul Darke, who is taking a PhD on the way disabled people are portrayed on film and who has agreed to write us a regular column. Turn to page 17 for the first of his thought-provoking articles.

*Liz Cawthorne*  
Editor

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ASBAH is a registered charity

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Cover: Kylie Pratten and Charlotte Gabbitas, who both have hydrocephalus, on a sponsored bike ride. See H N News, p iv.

## ASBAH's new regional focus for East England and the East Midlands

A NEW region at ASBAH was launched on October 1 - with the aim of giving better support to workers and clients, and an ambassadorial role among local authorities for regional co-ordinator Mary Malcolm.

It is the third regional office to be set up by ASBAH over the last few years in a move towards decentralisation, a better use of resources and enabling staff to give the best service to clients by working in closer-knit teams.

The Eastern Region will be based in Peterborough at national centre and takes in 10 counties - Nottinghamshire, Lincolnshire, Suffolk, Cambridgeshire, Norfolk, Essex, Leicestershire, Northamptonshire, Bedfordshire, and Hertfordshire.

Only five of the counties - Nottinghamshire, Cambridgeshire, Leicestershire and Northamptonshire, and Bedfordshire and Hertfordshire - currently have fieldwork cover. However, the Eastern team will aim to give the best service they can to clients throughout the region.

Here is a list of staff who form the East Region team:

- Co-ordinator - Mary Malcolm
- Disabled Living Adviser (part-time) - Julie Llewellyn
- Secretary - Becky Sewell
- Fieldworkers - Mary Castle (Cams), Sue Davies (Herts and Beds), Barbara Dawes (NE Essex), Janet Stewart (Notts) and Pat Waller (Leics and Northants).

Mary Malcolm was previously assistant fieldwork manager at Peterborough. She has developed an expertise in welfare rights advice and advocacy, which she will continue to offer to ASBAH as a whole.

Explaining the changes, Mary said: "Eastern Region has been set up at no extra cost to ASBAH. This has been achieved by the using our existing premises and by redeploying staff. We look forward to close contact all round."

The next region planned, when finance is available, is North Region, to be led by Joan Pheasant. ASBAH already has two other regional teams - one covering London and the South East and the other Northern Ireland.

# Make your willpower work for ASBAH

If you and your family value our support now, a simple bequest will help to sustain it in the future. For details, please contact:

Paul Wootton  
ASBAH, 42 Park Road  
Peterborough PE1 2UQ  
Telephone 555988

MILLY Rollinson (*right*) has joined ASBAH as services manager - heading up the combined fieldwork and disabled living services departments. Previously, she worked for 17 years at the Spastics Society, her last post being community manager at their Huntingdon regional office.



Milly's main aim, quite simply, is to make sure we give a more cohesive service for people with hydrocephalus and/or spina bifida by making the most of the resources available.

She started out in social work, her first job being social welfare officer for the blind with Bedfordshire County Council. Over the years, as a social worker, she was involved in childcare, mental health, care of the elderly and people with a wide range of disabilities. As community manager at the Spastics Society, she ran services which included residential provision for adults, a respite care scheme for children, social workers and a telephone helpline.

She said: "After 17 years I felt it was time for a change and I liked the sound of working for an organisation with clear ideas about the direction in which it is going". Milly (50) lives in Bedford and rates her main interests as gardening and socialising with friends.

## New motor service

A FREE telephone service for disabled motorists who travel outside their home territory has been launched by the Disabled Motorists' Federation.

Route-finding and Access Maps (RAMP) can help disabled drivers find:

- Attended pump filling stations.
- Wheelchair accessible cafes and restaurants.
- Toilets built specially for disabled users.
- Wheelchair accessible overnight accommodation.
- Wheelchair-friendly tourist attractions.

With 24 hours' notice, the computerised service can supply coloured road maps of the best routes between named places, more detailed maps of urban areas and lists of directories. Addresses and information about places and facilities en route are also given.

*To use the service disabled drivers, or drivers with disabled passengers, should call 0743 761181, stating their starting point, destination and setting out or arrival time. The service is manned Monday-Friday, office hours.*



*ASBAH's telesales staff at Peterborough let it all hang out when they let their hair down at a recent office 'fancy dress day'. The work didn't stop - in fact there was a definite buzz in the air from 9 to 5! Telesales manager Tom Logan - seen sprawling Mohican-style at the bottom of the photo - reckoned the fun and games was all worthwhile, but he was left wondering a bit about some of his colleagues.*

## Housing advice line in London

The London Housing Aid Centre (SHAC) runs two help lines for those needing advice about housing in the capital.

Members of the public should phone 0171-404 2614. Advisers and agencies should call 0171-373 9277. Lines are open Monday to Friday, 9.30am-1pm and 2pm-5.30pm (closed Wednesday morning).

Please note that the telephone system has no engaged tone. If, therefore, the phone keeps ringing, it means that the advisers are busy - so keep trying!

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# Government fails the acid test

**THE MESSAGE to mothers-to-be about the benefits of taking folic acid tablets before pregnancy, so reducing the risk of their carrying babies with spina bifida, is still not getting through. In fact, a new survey shows that nothing has changed about the appalling level of ignorance in the last 15 months.**

This is despite the Department of Health's endorsement of the widely respected advice which it received in December 1992 that an extra 0.4 mg of folic acid should be taken before conception and during the first 12 weeks of pregnancy - to cover the critical period when the neural tube is being formed. After the first 28 days of pregnancy, no amount of folic acid supplementation can repair any damage to the neural tube.

Doctors who carried out the latest survey - at Queen Charlotte's and Chelsea Hospital, London - say there is a need for much greater effort to get the advice across to mums-to-be through the media, family planning clinics and even in leaflets inside the packaging of female sanitary wear.

Professor Nicholas Fish and senior house officer Nicholas Clark, of Queen Charlotte's, reported in the August issue of the *British Journal of Obstetrics and Gynaecology* that 417 women attending the antenatal clinic for their first visit between July and October 1993 had been questioned about the level of folic acid awareness.

None of these women, who became pregnant after the Department of Health took the folic acid advice on board, had followed the Government's twin precepts: that they eat more folate-rich foods before pregnancy AND that they take folic acid tablets at the same time. A few had done one or the other, but not both. Eight (2%) had modified their dietary intake alone, and 12 (3%) had taken folic acid tablets.

After realising they were pregnant, a further 106 (26%) had taken some action to increase their folate intake.

Of two women who had had previous neural tube defects, one had taken 5 mg folic acid per day before conception, and the other astonishingly was unaware of the need to increase her folate intake.

A total 277 women (67%) did not know the Department of Health had recommended anything about folic acid.

Of those who were aware, only 37% received the information before conception from people like their GPs, other health workers, the media and friends.

Twenty five were aware of the recommendations but took no action while a further 17 took folic acid tablets on the advice of their GP without knowing why.

Dr Clark and Professor Fisk suggest that a broader-based and continued health education campaign is needed.

"Opportunities for targeting reproductive age women include use of the media, family planning clinics, secondary schools, or leaflets inserted in the packets of sanitary wear", they say.

The Queen Charlotte's and Chelsea Hospital results reinforce two other studies, carried out as long ago as last year, at Leeds General Infirmary and University Hospital of Wales in Cardiff.

In the Leeds study, only 2.4% of women questioned during their first hospital antenatal visit had

boosted their folic acid levels before becoming pregnant. In 35 other patients (5.7%) folic acid supplements had been prescribed, but only after pregnancy had been confirmed.

In the Cardiff study, only 14 (3%) of women questioned had taken folic acid tablets before conception.

Meanwhile, an editorial in the latest issue of *The Pharmaceutical Journal* has highlighted the problems faced by the industry in advertising the benefits of folic acid supplements.

The prestigious publication says that, while one part of the Department of Health is anxious to raise women's awareness about the issue, another - namely the Medicines Control Agency (MCA) - is "doing its best to spoil the efforts of others in the same Department trying to get over a message of great importance to all women of reproductive age."

*The Pharmaceutical Journal* said it was instructed by an MCA official to "pull any further advertisements" for a folic acid preparation for which medicinal claims were being made.

The journal says there is a clear precedent for the MCA to "turn a blind eye" until the regulations are changed. (These prevent medicinal claims being made for food products, like unlicensed folic acid preparations - even though the preventive effect of the product is endorsed by the Government, which has already circulated details of suitable folic acid products to the media). "Something clearly needs to be done. As things stand, the Department's left hand is working in opposition to its right hand".

*Liz Cawthorne*  
Editor

## Gift from the police chopper squad

EIGHT-year-old Elisabeth Hammond enjoyed a visit to the Metropolitan Police Air Support Unit, after the unit raised £1,000 for ASBAH.

Elisabeth, who has spina bifida, was shown round the machine with Caroline Berkley, ASBAH's south east region disabled living adviser.

The money had been raised at a Family Fun Day on 3 July for more than 250 people organised at the chopper squad HQ in Epping Forest where Elisabeth's dad, Sgt Paul Hammond, works as a helicopter observer.

PC Chris Raindle, one of the fun day organisers, said: "It was great to raise money for ASBAH because it was appertaining to a member of staff."

■ Pictured are Inspector Phil Whitelaw handing over the cheque to Elisabeth Hammond and Caroline Berkley.



## Help & Advice

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

London, Surrey, Kent, Sussex

123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (0181) 449 0475  
Regional Co-ordinator: Gina Broughton, BA (Hons).

Lincs, Cambs, Leics, Notts, Northants, Norfolk, Sussex, Essex, Herts, Beds

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

Northern Ireland

73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (01265) 51522  
Regional Co-ordinator: Meta Harvey, BSc, Cert Ed.

Rest of England and Wales

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



## Railway children

A GLORIOUS sunny day attracted about 50 people to Sheffield ASBAH's first summer fun day which may become an annual event.

Children and adults enjoyed a picnic and rides on the narrow gauge railway, put on free by the Abbeydale Model Engineers Club, in a field off Abbeydale Road, Sheffield.

# HIGH SCORES FOR ASBAH

IN THE week which would have been their daughter's 34th birthday, George and Doreen Stiles staged a charity football match in aid of ASBAH.

It was the 17th consecutive year that the Jennifer Anne Stiles Memorial Trophy was played for by local youth teams in East London - the aim being to help remember "Our Little Lady" in a

practical way and raise money so that other similar children may benefit.

Mr and Mrs Stiles' first daughter, died just four months after being born on 3 May 1960.

In the last two years, the Stiles family and friends have raised more than £3,200 for ASBAH, with the play-off for Jennifer's Trophy becoming an annual feature in

Walthamstow, London, where they live.

The under 12s match - this year between New Forest Rangers and Walthamstow Youth - took place at the Wadham Lodge Sports Ground in May.

Other fundraising support has been gained from Alan Cole and Pat McCabe, who ran the London Marathon in aid of the appeal.

## Honours

THE UNIVERSITY of Hertfordshire will confer an honorary doctorate of science on Dr Adrian Stokes OBE on 24 November. Dr Stokes, who has spina bifida, once served on ASBAH's executive committee.

The honorary degree comes "in recognition of his distinguished contribution in the field of computer science and in the improvement of facilities for disabled people". Earlier this year, Adrian Stokes was appointed visiting professor in information management at Nene College.

THE FIRST man to be knighted purely on the strength of his work for the country's disabled people was dubbed a Knight Bachelor by the Queen in July. Sir Peter Large is chairman of the Joint Committee on Mobility for Disabled People.



## They Exelled for charity!

● A WHIP-ROUND among workers at a specialist freight company in Peterborough resulted in £160 being raised for ASBAH. The total was doubled to £320 when Exel Logistics' parent company, the National Freight Company, matched the amount pound for pound.

ASBAH regional liaison officer Deidre Pawsey and fundraiser Michelle Downham are pictured here receiving the cheque from Exel Logistics' managers Tony Simons and Malcolm Swift.

## RADAR call for disability audit

RADAR is preparing an 80-page response to the consultation paper, *Disability of the Agenda*, assistant director Mary Holland said at the end of last month.

It was due to be published by the time LINK appears, and we shall cover it in our next issue.

In the meantime, RADAR - the umbrella organisation for all disability groups - is also keeping one eye on European developments following the Department of Employment's announcement that the Priority Supplies Scheme (PSS) is to be scrapped because of new EC rules. RADAR has called on the Government to set up a disability audit to examine all future EC laws.

The cancellation of PSS - which gave sheltered workshops a degree of priority when quoting for contracts in the public sector, is expected to have a major impact on Remploy - the largest employer of disabled people in the country.

The company, which employs more than 8,000 disabled people, has already been hit by recent overseas manufacture of Ministry of Defence clothing in Africa and Eastern Europe, where labour is cheap. The MoD currently provides 65% of Remploy's textile business with orders for military clothing.

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FOR  
**DISABLED**  
**PEOPLE**  
**NOW!**

## RIGHTS NOW! LATEST MOVES

# YVIA user forum sharpen teeth on the Government discrimination proposals

A CRITIQUE of the Government's consultation paper on its slow moves towards civil rights for disabled people has been produced by our *Your Voice in ASBAH* users forum (YVIA).

In its own paper, circulated at ASBAH's AGM on 24 September, YVIA said that the "most frustrating" elements in the Government's document were the bits left out - those which would outlaw discrimination against disabled people in education and in transport.

YVIA said the logic behind this seemed to be that there was no point bringing forward a comprehensive package of employment measures if disabled people were denied appropriate education and training to help them get jobs, or if they were not given the means to be able to travel to work.

And *Your Voice* was also disappointed by the Government's proposals - found in the consultation paper *Disability on the Agenda* - for a National Disability Council.

"We believe its intended powers are nowhere near strong enough, and should relate far more closely to those given to the Commission for Racial Equality or the Equal Opportunities Committee", commented YVIA.

On the issue of employment, YVIA said the present quota system should be kept but more rigidly enforced. Disabled people should not have to register to count towards the quota but, if the scheme was promoted more positively, more people would want to register.

*Continued on next page*



● YVIA chair Jon Burke: "powers nowhere near strong enough".

From page 9

## User forum sharpens its teeth

YVIA was concerned that employers would have the final say as to whether a job was practical or not, without knowing enough about an individual's potential. "Like anyone else, disabled people are realistic and are not going to apply for a job they don't think they're capable of doing. There should also be some independent arbitration available if there are disputes as to the practicality of a certain job", said YVIA.

Small firms should not be exempted from legislation but should have more time to comply and more Government help in meeting standards. There should be restrictions, laid out in the proposed Code of Practice, on the range and circumstances of medical questions and examinations.

Proposals to make unjustifiable discrimination actionable at industrial tribunals were welcomed. People with grievances should not be restricted to the use of small claims courts as these will limit the pay-outs available.

Rounding up their views on the employment proposals, YVIA said: "It was felt that the existing employment committees should be made more accountable, particularly on a local level. They should also inform the work of the new Disability Council. The group did not agree with the idea of a central committee chaired by a minister, unless it was to serve a useful direct purpose."

YVIA could see no reason for treating discrimination in the supply of financial services any differently from the supply of goods and services, but urged Government not to limit claims to the small claims court. As is the

case with race and gender laws, there should be no upper limit on damages.

YVIA said there was a great danger that institutional prejudice would linger if financial services - insurance, banking, pensions - remain outside the scope of anti-discrimination laws. This was because there would be no sanctions available to challenge existing wrongful assumptions about the capabilities of disabled people.

"If this is the case, there is obviously no chance of disabled people ever getting a fair deal".

YVIA challenged Government complacency in this area saying that, just because no examples of discrimination could be found, does not mean they do not exist. The proposed self-regulation would not change ingrained attitudes.

ASBAH executive director Andrew Russell commented: "The assumption that society's attitudes will evolve in a benign way, without the force of law to help achieve the level playing field, is optimistic.

"The issue of civil rights hinges on outlawing discrimination in recruitment for employment, in the workplace itself, in providing insurance and financial services, and in access to public buildings and leisure pursuits.

"Just as it is illegal to discriminate against people simply on the grounds of their race or their gender, it can be made illegal to discriminate on grounds simply of disability. It may take a little time before society is ready to take this step but I believe it will take it and that the alleged huge costs of this step will turn out to be quite manageable and will lead to a society that is richer in important ways, not poorer."

*The Department of Social Security has invited responses to its consultation paper by 7 October, and ASBAH will take YVIA's views on board in formulating its own submission.*

# MAIN

**THE VIEWS of the people have been invited on a new document outlining Government measures to tackle discrimination against disabled people.**

*Disability on the Agenda - A Consultation on Government Measures to Tackle Discrimination Against Disabled People* has been circulated to individuals and groups affected by or interested in issues affecting disabled people.

ASBAH executive director, Andrew Russell, and the Your Voice in ASBAH group (YVIA) have taken up the Government's invitation to respond to *Disability on the Agenda*. The deadline for receipt of comments was 7 October 1994. The document concedes that disabled people may encounter discrimination as they go about their daily lives.

The consultation document says the Government gives a high priority to helping disabled people live independently and with dignity. A wide range of measures has been introduced, including:

- raising spending on disability benefits from £5 billion in 1978/9 to £17 billion in 1993/4, boosting purchasing power by two-thirds.
- giving priority to disabled people in employment and training programmes - over £160 million was spent on special help alone and 53,000 disabled people were placed in work.
- changing care and support policies to place greater emphasis on helping disabled people to live in their own homes, in addition to raising spending on services for disabled people of working age by 80% in real terms.

*Disability on the Agenda* says the Government has worked hard to change these attitudes through a continuing policy of education and persuasion - backed up by

# POINTS ON THE...

legislation where it is practical and does not place an unreasonable burden on business.

*Disability on the Agenda* identifies five key areas on which views have been sought:

## 1. Employment

■ In order to make the labour market as accessible as possible to disabled people, replacing the quota scheme - requiring employers to employ at least 3% registered disabled people - with a voluntary system. (There are not enough registered disabled people to enable all employers to employ their full quota. Only a third of this eligible to register do so - about 1%). The new voluntary system to be backed up by a statutory right for disabled people not to be unjustifiably discriminated against in employment.

■ In what circumstances is discrimination regarded as fair.

■ The factors employers should have to consider in deciding whether it was reasonably practicable for them to overcome difficulties created by a disability.

■ The types or degree of disability which the definition "substantial disability" should cover and what specific conditions might be excluded or included.

■ What relationship a new obligation on employers, such as Access to Work, has to Government help.

■ The proposal to exclude firms with fewer than 20 employees from the new right, in line with the quota scheme, and whether any other types of employment or employer should be excluded.

■ Whether there are any reasons why employers should be restricted from requesting information about disability in job advertisements or at interviews.

■ How information and advice on employing disabled people could be provided to employers.

## 2. Building Regulations

Building regulations now apply to all storeys of non-domestic buildings and to most extensions to such buildings. Provisions are included for people with impaired sight or hearing as well as for wheelchair users. Possibly extending building regulations to new homes.

■ Possible measures to be consulted on include: main entrance access, wider external and internal doors, suitably large lifts, accessible toilets at entrance level, accessible switches and sockets.

## 3. Access to Goods & Services

■ The Government is considering making it unlawful for any person providing goods or services to treat people unfavourably solely on grounds of physical, sensory or mental disability.

■ How best to ensure that disabled people receive the same quality of goods as other people without imposing impossible burdens on business.

■ Discrimination would be outlawed in a variety of areas including access to public places, accommodation, entertainment facilities such as cinemas, theatres and restaurants and facilities for transport and travel.

Exceptions would include:

a) where existing physical barriers prevent access.

b) where compliance would be unsafe or the new law clashed with any earlier statutory provision.

c) facilities for education (provision for education is already governed by comprehensive legislation).

d) financial services (for reasons given in the next section).

Individuals wrongly denied access would be able to take civil proceedings to recover damages for financial loss or injured feelings. Damages for injured feelings might be limited to a fixed sum or upper limit. Claims within these limits could be subject to the small claims procedure which is relatively simple.

## 4. Financial Services

■ Although the Government does not believe legislation is required in this area, it will be inviting the British Banks Association, the Building Societies Association and the Association of British Insurers to issue Statements of Good Practice on the treatment of disabled customers.

## 5. New Advisory Body

■ The Government believes there is a strong case for setting up a new independent body - the National Disability Council - which would monitor discrimination against disabled people and advise the Government on the effect of existing efforts to combat discrimination. The Government sought views on how the National Disability Council could best work with existing bodies in the field of disability and

# ...GOVT AGENDA

## ***Birdwatching by ear!***

THE Royal Society for the Protection of Birds has launched its first-ever audio nature trail at the charity's Radipole Lake nature reserve in Weymouth, Dorset.

The trail follows a peaceful circular route, through reed beds and scrubby woodland and alongside open water. It consists of well-marked stopping points, each of which corresponds to a number section on the taped commentary carried by the user on a personal stereo.

Although the commentary has been designed specifically with visually impaired people in mind - concentrating on bird song, scents and textures accompanied by vivid descriptions and anecdotes - the RSPB hopes that it will be used by all the reserve's visitors.

Registered blind people may borrow the equipment free of charge (leaving a small deposit), while sighted visitors are asked for a £1 fee.

If the audio nature trail is a success, the RSPB hopes to provide similar facilities at some of its other 128 sites. *More information, tel 01767-680551.*

## ***'Godiva City' exhibition***

GODIVA CITY is a new permanent exhibition at the Herbert Art Gallery and Museum in Coventry.

Using a variety of media and interactive techniques, the exhibition illustrates the development of craft skills used in the area over the centuries and gives an insight into the lives of working people.

Disability groups were widely consulted by the project team and this has resulted in the appropriate siting of objects and labels, the use of non-reflective glass, provision of handling areas and the development of tactile tours.

The premises in the centre of Coventry are accessible to wheelchair-users and have a unisex WC designed for disabled visitors. Admission to the exhibition is free.

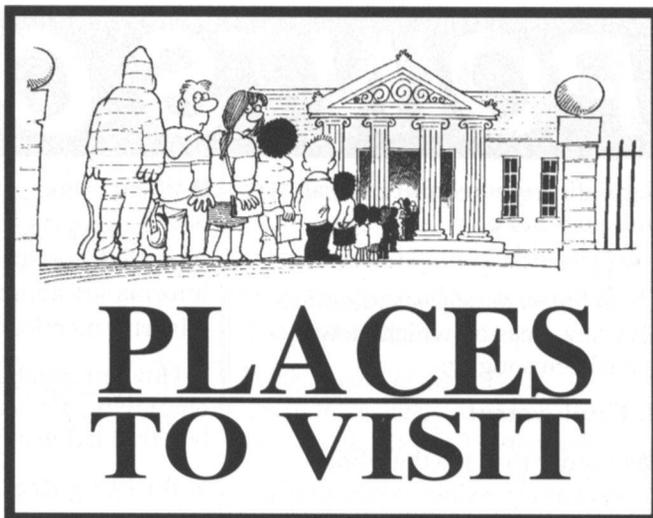
*Herbert Art Gallery & Museum, Jordan Well, Coventry, CV1 5QP, tel 01203-832381.*

## **South East England**

THE South East England Tourist Board has issued a revised information sheet giving information on access for disabled visitors to a range of attractions in East and West Sussex, Kent and Surrey.

Places covered include historic buildings, gardens, museums, boat trips, vineyards, steam railways, zoos, theme parks and factory tours.

*Places to Visit for Disabled Visitors in the South East is available from SEETB, The Old Brew House, Warwick Park, Tunbridge Wells, Kent TN2 5TU, tel 01892-540766.*



## ***Arts and crafts in the Welsh countryside***

A NEWLY opened centre in the Welsh countryside is running a variety of residential courses for both disabled and able-bodied guests.

Studio Fronceri offers courses in such subjects as drawing, painting, fabric painting, toymaking, flower craft and woodcarving. There are also 'wildlife breaks' in association with the Dyfed Wildlife Trust.

*Bill or Lindsay, Studio Fronceri, Rhydlewis Llandysul, Dyfed SA44 5SX, tel 01239-858945.*

## ***Newbury & District access guide***

A NEW edition of an access guide to Newbury & District has been produced by the Newbury District Liaison Group on Disablement. For the first time, it also includes information on Lambourn, Pangbourne, Theale and Tilehurst.

The guide has sections on public buildings and services, utilities, shops, finance, health, transport and travel, churches, recreation, voluntary organisations and public toilets.

*Newbury & District Access Guide 1994 is widely available in the area - from council offices, the community health council, libraries, the Tourist Information Centre, Citizens' Advice Bureaux, social services and day centres.*

## **Tall ship sailing on the Lord Nelson**

The Jubilee Sailing Trust has published its winter 1994-95 programme in the Canaries. The voyages are open to physically disabled and able-bodied crews aged from 16 upwards. Sailing experience is not necessary.

*Jubilee Sailing Trust Ltd, Test Road, Eastern Docks, Southampton SO1 1GG, tel 01703-631395.*

# Hydrocephalus Network NEWS

ASBAH, ASBAH House, 42 Park Road, Peterborough PE1 2UG.  
Telephone: 0733 555988 • Registered Charity Number 249338



AUTUMN '94

## FLYING START FOR SHUNT CAMPAIGN



*ASBAH's disabled living services co-ordinator Rosemary Batchelor with one of the alert cards we are giving away..*

ASBAH's shunt campaign has got off to a flying start - with 10 requests a day pouring in since it was launched in the last LINK magazine. We are giving away free information leaflet to GPs, and an alert card for people with shunts to carry at all times.

The campaign has been started by ASBAH in order to raise awareness among family doctors and the general public about symptoms of shunt blockage in order to avoid the worst happening - blocked shunts going undetected, which can be life-threatening even over quite short periods of time.

Disabled living services co-ordinator Rosemary Batchelor (*pictured holding an alert card*) is handling inquiries at our national centre in Peterbor-

ough from people with hydrocephalus shunts who want to use this free service.

**Just send your name, address, together with your GP's name and address, two 19p stamps, and we'll do the rest!**

We'll send you an alert card for you to carry at all times. And we shall send your GP a copy of our leaflet which gives detailed information about hydrocephalus and the symptoms to look out for in cases of shunt blockage.

Mrs Batchelor said: "Hydrocephalus is, thankfully, comparatively rare but its rarity can mean that many family doctors and hospital staff are unfamiliar with the symptoms of a blocked shunt.

*continued on page ii*

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## SHUNT CAMPAIGN

"This campaign is all about raising awareness among GPs who may not have seen a patient with hydrocephalus before.

"The alert card, which is small enough to fit into a wallet or a handbag, will advise the public and hospital staff at times of emergency that the holder has a ventricular shunt."

Both the alert card and the four-page GP leaflet have been produced by ASBAH's Medical Advisory Committee.

Chairman Dr Martin Bax said: "Sadly, there are still people with hydrocephalus whose shunts block, and who don't get the immediate attention they need and deserve.

"This material from ASBAH will, I think, go a long way to overcoming this situation. It will heighten awareness of the risks to people with valves and advise on symptoms and signs which can lead to referral and prompt, safe treatment."

The free four-page leaflet for GPs gives space for the patient's name, with date of birth and address. It also details the obvious signs of a shunt blockage - including headache, vomiting, dizziness, reaction to bright light, drowsiness and fits.

There are also sections explaining what is hydrocephalus, how it is managed and what happens when a shunt becomes blocked.

Recently retired GP Dr

Patricia Tomlinson (pictured), who was medical officer at Lord Mayor Treloar College, Hampshire, attended by many students with spina bifida and hydrocephalus, said: "The symptoms can be very vague, and it is easy to blame a headache on a sinus problem or migraine.

"It can be extremely difficult for a GP or junior hospital doctor, who may have little experience of shunts, to make an accurate diagnosis.

"The most important thing for the doctor is to think about the shunt as a possible cause of the symptoms and seek advice from a specialist hospital. It is essential for the patient or carer to remind the doctor of the presence of the



shunt and, if appropriate, show the information sheet for GPs."

■ **Sign up to the shunt campaign by writing to:**  
**Rosemary Batchelor,**  
**Disabled Living Services**  
**Co-ordinator, ASBAH House,**  
**42 Park Road, Peterborough,**  
**PE1 2UQ. Please enclose two**  
**loose 19p stamps.**

## A few words of support

I WOULD like to write a few words of support to the many parents of babies born with hydrocephalus, *writes Mr W E Campbell from Baguly, Manchester.*

As grandparents of twins, we went through the most traumatic period of our lives two years after the boys were born three months premature. Both had fluid on the brain caused by bleeding when they were still in the womb.

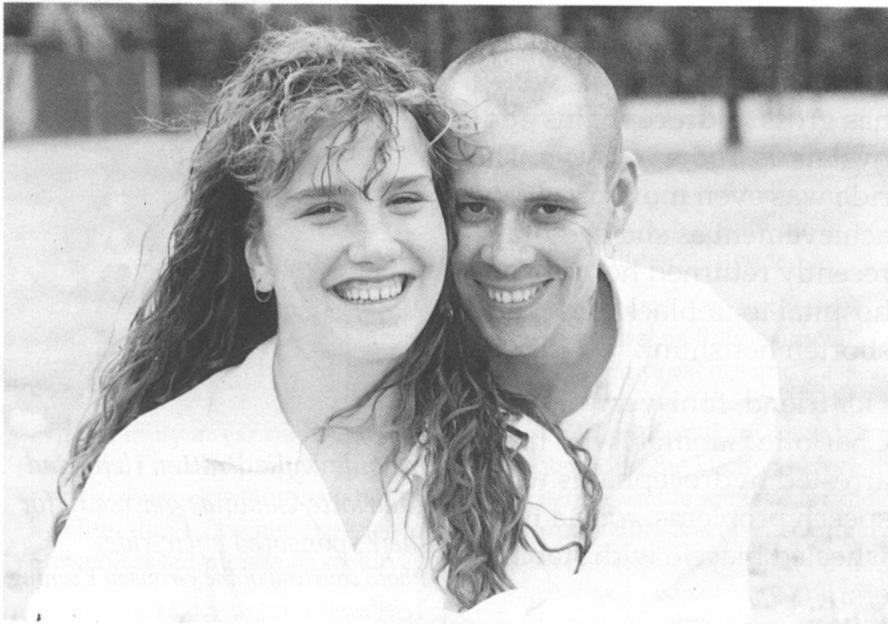
While Kane is stable and now a normal three-year-old, Guy has been beset by problems. At seven months he contracted meningitis but, although he pulled back

from the brink of death, it made his condition worse.

Guy has a tube draining fluid from his brain into his stomach. He had 13 or 14 operations but, with patience and experimenting, the doctors have at last succeeded. He is now a living example of what you can achieve with care, patience and love.

Out of all this come my daughter Jeanette and husband Martin with tremendous courage and devotion. So my advice to parents is please don't despair. Your children are in the good hands of the doctors and nurses, and most of all faith.

# Happy days for Charlotte



*Charlotte Day and boyfriend Dex Tilley enjoy the sunshine near Charlotte's home*

TALK to Charlotte Day or pass her in the street and she seems a bubbly, bright and beautiful teenager with little to dim her sunny personality. Only on closer questioning reveal her amazing fight for normality, after being struck by hydrocephalus seven years ago.

Today the 15-year-old is making plans for further study and then a career in caring, and enjoying the attentions of her boyfriend, Dex Tilley.

But memories of the time she was chronically ill in hospital, starting just days before her eighth birthday, are evident in quite unexpected ways.

She refuses to eat bananas and corn flakes because those were the foods she had on the day she was rushed to

Addenbrooke's Hospital in Cambridge suffering from severe pains in her head, drowsiness and sunken eyes.

She also wears a necklace, which she says she never takes off, put on her by her grandmother while she was in a coma.

Charlotte said: "I went in and out of a coma, lost my speech and became paralysed down my left side. I was a vegetable for nearly 1.5 years."

She also recalls various stages in her progress on the long, hard road to recovery.

"I remember tapping my foot to a song by Dolly Parton when I went for a scan in London. It was the start of my love for country music.

"I also remember waking up once at Addenbrooke's and

seeing snow outside. It was the first time I had seen really deep snow and I wanted to touch it. Some of it was put into my hands and my fingers started moving again because of the coldness."

At one time, doctors believed Charlotte would never fully recover, even if she gained consciousness.

It was her own self-will and determination, together with support from her family and hospital staff, that helped her pull through.

"I got sick of laying there and was upset about being in hospital at Christmas, Easter and on my birthday. Determination got me where I am now. I was also helped by physiotherapy and an excellent speech therapist."

Another spur to get back to normality was returning to school to find friends frightened of her.

"I had a shaved head and many of my friends were scared to come near me."

Charlotte had about 13 operations in all and various shunts before being given the one she has now, which drains cerebrospinal fluid to her heart.

She also has a special reservoir which helps prevent a build-up of fluid in her brain.

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Among the problems she faced were chronic memory loss, difficulties with figures and poor handwriting - the last problem is one she puts down to missing out on at school.

Charlotte is also forbidden to fly over 3,000 feet, go upside down, be hit on the head, play contact sports, go on gravity games or bend down low.

However, all these restrictions have not stopped her from being lively company and an active member of school.

She has spearheaded events, including sponsored dances, a readathon and a disco, which have raised more than £1,500 for various charities and a 13-year-old cancer sufferer.

Her next task is to raise money for ASBAH which she heard about three years after leaving hospital.

She said: "I want to do something for ASBAH because they help people like myself and people worse than me, and I feel very fortunate."

Charlotte, who lives in Peterborough, this year completed three weeks' work experience at ASBAH's head office and, when she leaves school, plans to do a BTec caring course at a local college.

"I want to look after people with spina bifida and hydrocephalus," she said.

## TRIKE CHALLENGE

TWO girls from South Humberside proved you are never too young for a challenge by doing a sponsored cycle ride for ASBAH.

Kylie Pratten, aged six, who has gross hydrocephalus and nystamus, rode a tricycle. The ride was even more of an achievement as she had only recently returned home from hospital to unblock and then shorten her shunt.

Her friend, four-year-old Charlotte Gabittas, who has arrested hydrocephalus with speech problems, rode a two-wheeled bicycle with stabilisers.

For both children, the three circuits of Haverstow Park, Cleethorpes, on 2 September was quite a challenge.

But they were determined to do something for ASBAH - spurred on by their mums, Gill Pratten and Chris Gabittas.

Mrs Pratten said: "Our local newspaper will do an article which should encourage people to sponsor the girls. Apart from that, we are relying on family and friends."



*Friends Kylie Pratten (left) and Charlotte Gabittas get ready for their sponsored cycle ride.*

*Photo courtesy of the Grimsby Evening Telegraph*

Mrs Pratten hopes the story of the girls' effort in HN News will give hope to new parents of hydrocephalic children.

She said: "These early years haven't been easy but, with hard work and the girls' determination, they did their best. They are very rewarding children."

□ *The girls made £250 from their sponsored cycle ride for ASBAH. Readers will agree that was a terrific effort!*

**CALLING all mothers with hydrocephalus shunts - a Californian mum wants to hear from you in order to conduct a survey.**

**Nancy Bradley married, gained a degree and gave birth to a son in 1987, despite having 10 hydrocephalus shunt revisions.**

**If you would like to take part in the survey, write to: Nancy Bradley, 8403 Boyne Street, Downey, CA 90242, USA. Or contact Rosemary Batchelor, living services co-ordinator at ASBAH in Peterborough, for a copy of the questionnaire.**

## Tracey's video diary

- a review by Liz Cawthorne

COMBINING the extraordinary with the mundane was, I believe, the greatest achievement of Tracey Proudlock's video diary *Mother's Pride*.

The programme went out on BBC2 on 26 July to an audience of mainly able-bodied people, yet Tracey talked in a matter of fact way of being married to a long distance runner and herself sometimes not being able to walk out of the bathroom due to having spina bifida.

The video gave snapshots of every day activity at various points during Tracey's pregnancy which were given a freshness by her view of life, shaped by her experiences as a disabled person in society.

There were poignant moments, too, when Tracey chokes up over thoughts of the baby being

disabled - not out of the difficulties it would bring to herself, but because of the experience she had growing up in a society which segregates disabled people or gives them "special" treatment.

All this contrasts with Tracey's sense of fun and the humorous exchanges she has with husband Liam, family and friends.

There is drama, too, in the suspense we feel as Billy's official birth day approaches and passes. Seven days later, the contractions start and are faithfully recorded on a notepad in the kitchen before the decision is made to leave for the hospital, with Tracey checking that Liam has enough vegan food in his lunch-box to keep him going.

Our involvement grows as we see Tracey in labour and finally giving



birth to a healthy baby any mum (or dad) would be proud of.

Photo: BBC TV Publicity.

## Disability on film by Paul Darke

IN THIS, my first film column for *LINK*, I want to start by asking a question: Why aren't there any films about people who have spina bifida and/or hydrocephalus?

There are films about most other disabilities - cerebral palsy has *My Left Foot*; multiple sclerosis has *Duet for One*; even autism has *Rain Man*. Deafness and blindness have *Children of a Lesser God* and *Wait Until Dark* respectively. But there are none about people with spina bifida and hydrocephalus.

Don't get me wrong, I do not praise the films that I have mentioned - in most cases they are highly negative and deeply stereotypical - but merely stress that they exist. Film makers often see other impairments as worth exploring, yet we (people with spina bifida and hydrocephalus) do not merit any attention. Why is that? One suspects that people with spina bifida and hydrocephalus have ascribed to

them (wrongly) certain social and cultural values that make it far too bleak to treat cinematically.

Our impairment is the stuff of TV dramas - very bleak TV dramas - with scenarios that are so pessimistic that they make you want to just switch off and commit suicide there and then. Film on the other hand, more often than not, tries to uplift its audience (after all it is usually referred to as "mere entertainment"), which is why cinema films about disability often have people with disabilities triumphing over adversity - what are commonly called "Supercrip" films - usually with the aid of an able-bodied character.

I would argue that there are many people with spina bifida who have overcome great odds and that their (our) lives are not at all like that portrayed in negative TV dramas. But socially and legally we are often

(wrongly, again!) perceived as the hopeless of the hopeless. But what we must remember is that one cannot divorce how society sees and treats one group of people from how that society represents that group in its culture (film, TV etc); and the representation of people with spina bifida in this culture explicitly shows how this culture sees us: badly. We must push society to change how it sees us, and only then will film and TV makers do the same.

I would not, as many disability writers do, prescribe that spina bifida - or any disability - should be portrayed in any specific manner, after all, even the most negative portrayal has an element of truth in it for someone. What I would hope to encourage is a wide range of representations, portrayals that cover the whole range of experiences that we, and all disabled people, go through.

# Students' cash boon

FOR those of you considering going into further or higher education, ASBAH can offer practical help in the form of cash grants - easing at least one of the pressures of student life.

A special fund run by ASBAH offers people with spina bifida and/or hydrocephalus the chance to gain a grant of anything from £200 to £2,000 - to help pay for accommodation, travel, course fees, books, equipment or field trips.

The ASBAH Bursary Fund is the charity's largest fund. It was set up following a generous anonymous donation.

About a dozen people a year gain grants from ASBAH through the Bursary Fund, and examples of people who have recently been successful are given over the following three pages.

Applications for grants for recognised courses or qualifications can be made at any time prior or during the course, but grants must be claimed within the academic year/period for which they are agreed.

ASBAH area fieldworkers often play a key role in introducing the Bursary Fund to young people interested in continuing their education. They are also on hand to help with applications.

Those wishing to apply will be asked to give details of the name of the course and what the money is needed for on an application form. Details of any other organisations which have been approached for grants are also required.

The Bursary Fund does not, however, have unlimited amounts of money to give away.

Applications are considered on a first-come, first-served basis and not every application will be successful. Indeed, for the current year, virtually all available money has been earmarked and not a lot is available for 1995/96.

Neither can ASBAH be the only source of support for the student. "ASBAH cannot be the sole funder of the course of study, so we are keen that applicants also approach other bodies for funding - indeed that is essential", said executive director Andrew Russell.

A person can apply for a single lump sum for one academic year or ask for the lump sum be divided up and paid over two or more years.

■ For details and an application form, write to Mr Andrew Russell, Executive Director, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.

## Henrietta's double award



Henrietta Collins (left) receives a cheque for £100 after winning this year's Midlands Area Education Award from last year's winner, Nicola Steatham (right).

HENRIETTA Collins, who is 23, is fulfilling a life-time's ambition to become a speech therapist - helped by two separate cash awards from ASBAH and Midland ASBAH.

Over the two-year MSc degree course in clinical communication studies she will receive £1,250 from the ASBAH Bursary Fund.

In addition to this, she has gained £100 as this year's winner of the Artingstall Award - set up in memory of a previous chairman of Midland ASBAH, who was interested in the development of young people with spina bifida.

## A look



## *Dentist on two wheels*

**KEEN** cyclist Geraint Catherall is gaining financial help from ASBAH's Bursary Fund while doing a dental technology course at Manchester Metropolitan University.

Over the last two years, the 20-year-old received £600 from the fund for books and equipment.

And a further £600 has been authorised, if required, for this - his final year of the course.

Geraint, from Clwyd in Wales, said: "I contacted ASBAH to see if you knew if anybody could help me. The fieldworker told me there was an ASBAH fund I could apply to.

"The money has helped quite a bit towards different things I've needed."

Geraint, who has hydrocephalus, is also helped by an access fund, run by his local education authority for people undergoing hardship on courses not eligible for student loans.

When he finishes the three-year course, Geraint wants to try for a higher national diploma and then a degree in dental technology.

Henrietta has already completed a BA combined honours degree in human communication and communication disorders with psychology at Manchester University and was due to start her MSc in September at Sheffield University.

Henrietta, from Stretton-under-Fosse, near Rugby, said: "I'm really looking forward to starting the course. It will be a lot of hard

work but, after all these years, I'm going to become a speech therapist. It's something I've always wanted to do."

ASBAH's Warwickshire fieldworker Jenny Green helped Henrietta with her Bursary Fund application and put her in touch with other trusts which offer student grants. Their efforts certainly paid off, reaping a total of £3,500 for

tuition and living costs.

Without this financial help, Henrietta would not have been able to go ahead with the course as her local education authority does not fund higher degree courses.

Area fieldworker Jenny Green commented: "It has taken Henrietta a year to get things sorted out, but she is a very determined young lady."

# **at our Bursary Fund**

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## Film researcher's life-saver

PAUL Darke, who is doing a PhD on how disability is depicted on film, has described his ASBAH grant as a life-saver.

Ironically, the 32-year-old only heard about the ASBAH Bursary Fund by accident but, without the £3,000 award, he would probably never have been able to take the course.

Paul, who has spina bifida and hydrocephalus and commutes the 80-mile round trip to Warwick University from his home near Wolverhampton, explained: "I wrote to ASBAH to ask if you knew anyone who could help me, and you said we do.

"The Bursary Fund was a life-saver. It was a major contribution which made my PhD course possible."

He added: "I took English and history as a first degree and then American literature as my MA.



"I wanted to do something on cinema, because it's an area which I'm very interested in, and on disability because I'd never done anything on it before and not much had been done on it before."

Paul won further funding of £775 from three other organisations for books, computer equipment and travelling expenses.

But this financial help was not enough to see him through the

course full-time over three years. As a result, he has been forced to complete the final year part-time over two years because the fees are cheaper.

His wife, Marie-Claire, is currently taking a year off from a Master's degree course in social work, also at Warwick University, to have their first child.

After completing his studies, Paul hopes to be a teacher.

## Grant gives greater independence



THE £500 given from the ASBAH Bursary Fund to Shelley Hughes for study was "empowering" because it gave her greater independence.

The 27-year-old (pictured left), who has spina bifida and hydrocephalus, was introduced to the fund by Elizabeth Lawlor, ASBAH area fieldworker for Cheshire, North Staffordshire and the Wirral.

Her grant was used for books, travelling expenses and residential weekends during a year's counselling course.

Unfortunately, Shelley had to drop out of the course at Stoke-On-Trent College for health reasons just weeks before the end, but her grant will not be wasted. She is

planning to start the whole course again in 1995.

Although she has eight years' counselling experience, working full-time for the Alcohol Advisory Service and Bereavement Care, as well as taking private clients, she realises the importance of having a formal qualification.

Shelley, who lives in Stoke-On-Trent, said: "I felt it was important to gain a certificate in counselling because it means people can trust me and take me more seriously. At the moment, anyone can be a counsellor."

She added: "The money I received from the ASBAH Bursary Fund was very helpful and empowering. I also thought the way it was handled was very good."

# A lifelong commitment

**"Adult in body .... but still with child-like needs" - statement from mother of a 25-year-old man with spina bifida and hydrocephalus.**

*Maddie Blackburn, ASBAH research fellow until this summer, describes parents' perceptions and needs in supporting the young adult with spina bifida and/or hydrocephalus.*

*In the third of four articles addressing research undertaken during the ASBAH fellowship, Maddie Blackburn provides a synopsis of some of the concerns and considerations raised by parents in caring for and supporting young adults with spina bifida and/or hydrocephalus. Maddie is indebted to the parents who took part in this study and who gave generously of their time to describe their experiences.*

*She would also like to thank ASBAH's disabled living and fieldwork services for their assistance in locating families, Dr Martin Bax for supervising the study and Dr Clifford Strehlow for his statistical assistance.*

Aims of the study:

- To seek information from parents about their son's or daughter's current health status.
- To identify future service requirements.
- To obtain information about the long-term effects that caring for a disabled son or daughter has on the family.



**Maddie Blackburn reports on the needs of parents who have children with disabilities**

## INTRODUCTION

Most able bodied young adults have left home or are considering doing so by the time they are in their early twenties. This was certainly not the case for many disabled young adults in some of Dr Bax's early work (1989) and in this present study. While some young people with disabilities may choose and are able to live independently, many young adults continue to depend on practical support and assistance from both parents and carers throughout life. Frequently, this care is provided at home. The important role which parents make in caring for the disabled child and adult have been reported in recent publications (*Family Fund, 1993; Hurst & Baldwin: Cowen, 1994; Beresford, 1994*). Dr Bax and his colleagues in 1989 also acknowledged the important contribution made by parents in supporting the young disabled person after childhood. Advances in technology now enable many people with complex disabilities to survive into adulthood. The implications for ageing parents who continue to provide such care therefore cannot be ignored.

## WHO TOOK PART?

This section formed part of a larger study addressing "the health and social needs of 98 young adults with spina bifida and/or hydrocephalus". In a separate interview, parents were invited to give their views about

their son/daughter's personal needs. 65 parents, mainly living in the North Thames Region took part. There were 48 mothers and 17 fathers, who were mainly between the age of 40 and mid 50s. Three couples completed the interview/questionnaire together. The initial letter inviting participation was sent to the young disabled person. There were several reasons why all 98 parents did not participate. Some young adults asked us not to contact their parents, particularly those disabled people who were living independently or in residential care. Two young people were adopted and had no contact with their natural parents and three parents had died. Three parents refused to take part for personal reasons. The total response rate was 66.3%. Parents were invited to self administer a questionnaire (98%) or complete it with assistance from the researcher (2%). Most questionnaires were completed during the researcher's interview with the young person at home. Five were completed in the hospital setting.

## WHAT QUESTIONS WERE ASKED?

Retrospective information was obtained about the following: parental employment status, the son or daughter's present and/or previous education, health care facilities, independence training programmes, benefits, transport, household adaptations, respite provision and the impact of supporting the person with a

*Continued on page 22*

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disability on personal health, social relationships and employment. Information was obtained about their son/daughter's future education, health care or employment/training plans.

**WHAT DID THE STUDY TELL US?**

Several parents reported that their child's physical disability had affected their own personal health and relationships. Continuing to support the disabled person in adult life required access to a variety of services and specialists tailored to the individual family's, as well as the young person's needs. Many parents felt that their family life had suffered because of over dependence by their adult son and daughter. However, many parents freely admitted that they often colluded in perpetuating such dependence, finding it hard to delegate or share the responsibilities which they had masterfully handled, often alone, for over two and a half decades (particularly toileting: 22% of parents were still assisting with continence management). Understandably, parents sometimes regarded themselves as the "experts" of their sons' and daughters' needs but sometimes were reticent to ask for assistance, even though 44% rated their son/daughter's health problems as being severe.

**PERSONAL RELATIONSHIPS**

Although over half the participants were still in their first marriage, 29% of women and 21% of men felt that the long-term responsibilities of caring for their son or daughter had affected their relationship.

*Table to illustrate marital status*

	Number	%
Married	37	57%
Divorced	6	9%
Separated	1	1%
Widowed	4	6%

**Remarried 7 10%  
or regular  
new partner**

Total number = 65 (we have heard that two participants have died since these interviews took place).

38% of women and 21% of men felt that other relationships had also been effected; for example with other family members and friends.

*Impact of the young person's disability on relationships*

	Yes
<b>Mother's relationship with partner affected</b>	27%
<b>Father's relationship with partner affected</b>	21%
<b>Mother's relationship with other kids affected</b>	38%
<b>Father's relationship with other kids affected</b>	21%

**PARENTS HEALTH**

*Did son or daughter's disability affect parents' physical health?*

	Yes	No	Not answered
<b>Mother</b>	57%	37%	6%
<b>Father</b>	33%	33%	34%

Although all parents recognised that some illnesses had other casual links, clearly back pain and some neck problems were exacerbated by many years of assisting their son/daughter with bathing, toileting and lifting. Of particular note with the following:-

*Personal physical problems reported by parents (N=65)*

	Mother	Father
<b>Back</b>	22%	13%
<b>Neck</b>	5%	2%
<b>Respiratory</b>	2%	2%
<b>General strain</b>	13%	10%
<b>Prolapse</b>	3%	0%
<b>Cardiac</b>	5%	3%
<b>Cancer</b>	0%	2%

54% of mothers and 32% of fathers reported that their emotional health had been effected. Many

parents were extremely uncomplaining about their life long responsibilities for their "adult children" but worried about who would help look after their sons/daughters when they were either too old or no longer fit enough to do so themselves. Clearly, this was less of an issue for those young adults who were already in residential care or living independently or with partners.

**RESPIRE**

75% of the young adults still lived at home. 68% of the parents would like their sons/daughters to continue living at home (for the time being). Only 5% of parents thought their son/daughter could presently live independently, although many hoped that they might do so in the future. Surprisingly only 2% used respite care regularly. Reasons for this low level of use were reported as follows: (a) shortage of respite facilities, particularly in urban areas (b) many parents were so used to providing most of their care that they found it difficult to consider leaving their son or daughter in the care of others, even for short periods or if they felt "burnt out"! (c) some families who had previously used "respite care" stated that they would not use it in the future because they felt it had been detrimental at the time to their son or daughter's physical health and/or behaviour.

**ACCESS TO ADULT HEALTH SERVICES**

Only 14% of parents reported difficulty in obtaining specialist adult health services. This relatively low level is probably due to the fact that many of the families in this study are now using a new adult disability service, which was described in the last issue of *LINK*. This small percentage is probably unrepresentative of parental opinions around the country where few adult disability services are currently available (Morgan, Blackburn, Bax, 1993).

**ADAPTATIONS**

46% of homes had been adapted to accommodate the needs of the disabled person. 35% would like further modifications, preferably to include "independence" flats within the home, downstairs toileting facilities, additional handrails, stair lifts etc. Many parents requested ground floor accommodation.

**EDUCATION**

23% of parents were unsatisfied with careers advice and a similar number thought that curriculum should allow greater opportunities for examination and/or continuous assessment. 21% felt that sex education in school was poor and ill-prepared the young adult for personal relationships.

**CONCLUSION**

Where the young person lives at home with the family (N=78%), it is important to acknowledge the potential physical and emotional demands which may be made on parents by the long-term caring process throughout the young person's life. Although many parents freely acknowledged that they would like their sons/daughters to become more socially and physically independent, knowing what services are available and being able to access them, if they are, might enable more young people to become increasingly aware of their own needs and share in some of these responsibilities with their parents.

(A more details account of methods, results and recommendations is included within the full report of "The health and social needs of young adults with spina bifida and/or hydrocephalus", Autumn 1994).

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1. Cowen, A (1994) *Taking Care*. The Family Fund and the Joseph Rowntree Foundation.
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3. Hurst, MA, Baldwin, SM (1994) *Unequal Opportunities: Growing Up Disabled*. HMSO: ISBN 0117018287.

4. Thomas, A, Bax MCO, Smyth, D (1989) *The Health and Social Needs of Young Adults with Physical Disabilities*. Mac Keith Press.

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**FURTHER READING**

Family Fund (1993) *After 16 - What Next?* Free to young disabled people and carers. £3 to others.

Turnbull, H, Turnbull, A, Bronicki, GJ, Summers, JA, Roeder Gordon, CR (1990) *Disability and the Family: A Guide to Decisions for Adulthood*. Paul Brookes Publishing Co, London.

Eiser, C (1993) *Growing Up With a Chronic Disease; The Impact On*

*Children and Their Families*. Jessica Kingsley Publishers.

**USEFUL ORGANISATIONS**

**Action Group for Children and Adults with Learning Disabilities and their Carers**, 17/18 London Road, Edinburgh, EH7 5AT. Tel: 0131-661 5818.

**Care Search** (for advice about residential care), Fairway, The Hudnalls, St Braivels, Lydney, Glos, GL15 6SQ. Tel: 01594 -530220.

**Disability Alliance** (advice on disability benefits), 1st Floor East, Universal House, 88-94 Wentworth Street, London E1 7SA. Tel: 0171-247 8776 (*minicom available*).

**The Disability Law Service**, 16 Princeton Street, London WC1R 4BB. Tel: 0171-831 8031/7740.

**British Council of Organisations of Disabled People (BCODP)**, De Bradelei House, Chapel Street, Belper, Derbyshire DE56 1AR. Tel: 01773-828182.

## LINK BACKS 'EXCELLENT' SERVICE AT THE CHELSEA & WESTMINSTER

AT LEAST 15 telephone inquiries and four written referrals by GPs have been received for the new adult disability service at Chelsea and Westminster Hospital - described by Maddie Blackburn in the last issue of *LINK*.

The service has been set up by consultant physician Dr Richard Morgan with support from consultant urologists, orthopaedic surgeons, neurosurgeons and geneticists, together with hospital nurses, continence advisers, specialist health visitor (Maddie Blackburn), ASBAH's disabled living service, a clinical psychologist, an occupational therapist, physiotherapists, and technicians for urological, neurological and orthopaedic investigations, radiographers and wheelchair/appliance advisers.

ASBAH member Margaret Twyford, of Surbiton, Surrey, who with husband Alan is making use of the service, commented: "It's excellent. It's the only one of its kind in the country - except for Chailey Heritage in Sussex."

She added: "The service offered at the Chelsea and Westminster Hospital is important because, once you reach 16, you can't go to the hospital where you've always been. You go along for an assessment with Dr Morgan and then go back for an all-day appointment to see whoever you need to see. Everything is done in one day and lunch is provided."

For further information or advice about the service please contact Debbie (Dr Morgan's secretary), tel 0181-746 8146 or Maddie Blackburn, tel 0181-746 8629.

# 'Named person' to help parents through schools red-tape tangle

THE MAJOR piece of legislation concerned with Special Education Needs since the 1981 Education Act has been Part III of the Education 1993 and the *Code of Practice on the Identification and Assessment of Special Education Needs*.

The Code, although not mandatory, does provide a framework for the way that local education authorities (LEAs) identify and meet the special education needs of children and young people and must have due regard.

Besides covering issues such as school special education needs policies, school-based assessment and provision; criteria for assessment and statements; statutory assessment; annual review of statements; LEA special education needs support service; briefing, training and development: a significant factor of particular importance to parents is the LEA's responsibility of identifying a "named person".

Section 4/70 states: "When the LEA send the parents the final version of the Statement, they must inform the parents in writing of the name of the person who in future can give the parents advice and information about their child's special education. This is the parents' named person". Part 3 of the Code recommends that "LEAs and parents might discuss the identity of the named person at the start of the assessment process".

Several voluntary organisations including ASBAH are being asked by many LEAs to nominate a "named person" who, being independent from the authority, can help parents during the making of an assessment and subsequent statement, and provide

advice and information relative to a particular special educational need.

Section 4/73 of the Code of Practice emphasises the advantage of the named person "being someone who is independent of and not employed by the LEA."

Initially, I, as education adviser at ASBAH, will be acting as the "named person" for those children who will have special education needs as a result of having spina bifida and/or hydrocephalus. Wherever possible information and advice will be given to parents via the fieldwork service and specialist advisers but there may be occasions when I will be called on to negotiate with LEAs the contents of a statement and possibly act as "advocate" or

"witness" at a special education needs tribunal.

Should your child have special education needs arising from spina bifida and/or hydrocephalus, it is advisable for you to obtain and read *Special Education Needs - A Guide For Parents* which is available free of charge either from the Information Department at national office in Peterborough or DFE Publications Centre, PO Box 2193, London E14 2EU. Tel: 0181-533 2000.

#### *Education guide on tape*

*SPECIAL Education Needs - A Guide For Parents*, produced by the Department for Education, is now available in audiotape-cassette format. If you have difficulty obtaining it, please contact me for further information.

*Reports by Peter Walker,  
ASBAH Education Adviser*

## **EXCELLENT SOURCE BOOKS FOR MAINSTREAM SCHOOLS**

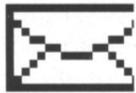
THE *Independence and Interpretation* series of books, produced by Folens Publishers in association with RADAR, are an excellent resource for mainstream schools endeavouring to work with pupils with disabilities.

The contents provide realistic advice and support for members of staff who are developing and implementing a special educational needs policy which fosters understanding of disabilities and supports the integration of disabled pupils into mainstream education.

There are four books in the series - *Pre-vocational Skills; Sport and Mobility; Living Skills* and *In-Service: Practical Approaches, Attitudes and Equipment*.

The photo-copiable activity sheets in each book for use by students and teachers are very informative and challenging.

I have had the opportunity of seeing them being used in a Yorkshire secondary school and would recommend their use in all schools to foster a greater understanding of people with specific physical disabilities and the development of independent living skills.



I was very interested in the letter published in the last

*LINK* from Arthur Smith of Horsham about his son Chris and your comments about the need for early bowel management. I found myself in a similar position to Chris when in 1991, shortly after retirement, I was involved in very long hospitalisation due to pressure sores.

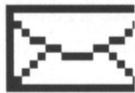
I have never had any trouble with bowel management in my life, but when lying in hospital, taking antibiotics and other tablets, there was inevitably some diarrhoea - a side effect of medication - and I was advised to have a colostomy in order to relieve the poor skin situation on my bottom.

This may seem a radical option but since it was done I have had a long period with no sores and, as an additional bonus, I never have to worry about access to or height of toilet seats. No one able to stand can have any idea of the advantage of this for those who cannot stand.

The colostomy is easy to manage. Though I originally hoped to have it reversed, I certainly do not now, and I understand the feelings of Chris.

**Donald S Drew  
Clapham, London**

*Editor's note: This is a "radical option" and, although a satisfactory system of bowel management and skin care would have been preferable, I can understand Donald's sense of relief on getting his problems resolved.*



WHAT'S wrong with the world today?

What is wrong is the way the community reacts to people in wheelchairs and people like me with a speech problem. Every time you talk to them they think that you are deaf or unintelligent. This type of attitude really makes me mad. Sometimes I think it's them who are unintelligent or deaf, not us.

When I was about eight years old and my brother was four, we would go for a walk and bump into my mum's friends. I would talk to them but I was not good at it, so my brother would repeat what I had just said and that got me a bit mad too.

When I started school at the age of eight, the cooks would take the Mickey and pull my hair out, and the helpers would force feed me because I would not eat something I didn't like.

At 11 I went to boarding school. I cried every night at first, but after

a month it was like being part of a big family. The teachers and staff were like mum, dad, nan and grandad and the other pupils were like brothers and sisters. That's how it should be at all schools.

One thing in the community has changed - people have woken up to the fact that not everybody is the same but have the same feelings as everyone else.

So what would I do to change the world and how people react to our ways? I would try and get them to work with people in wheelchairs and people like me for a year, so they could understand the feelings we go through every day and every night when we go out shopping, to a party or disco, or out to a pub.

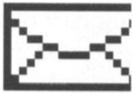
Every day someone is weeping but the world is sleeping and not waking up to the real world and the lives of people like me and people who are in wheelchairs, or who are deaf for life.

**Michelle Sylvester  
Folkestone, Kent**

*Editor's note: Michelle has congenital upper motor neurone bulba palsy and epilepsy but I think many of our readers will recognise her experiences and views as their own. Michelle is training to be a care assistant at Parkfield Special School, Folkestone, and this year her story was published in her local newspaper.*



*Michelle Sylvester window shopping. Photo courtesy of Folkestone Herald.*



THE following poem  
arose out of a  
marvellous holiday

which I've just had on a Share  
Music course in Keswick, *writes*  
*Richard Clark from Scorton,*  
*Richmond, North Yorkshire.*

There are three courses held  
throughout the UK, consecutive  
weeks, July and August, in North,  
South and in Wales.

These courses are open to disabled  
people aged mainly 18-40, who  
either just have an interest in  
music, and wish to learn an  
instrument, or already play one.  
Help is provided on a one-to-one  
basis for about 25 participants of  
varying disabilities.

*For more details contact the co-  
ordinator Dr Michael Swallow, 15*  
*Deramore Drive, Belfast, BT9 5JQ.*

### Ode to the Calvert Trust

I've just been to The Calvert Trust  
Based at Little Crossthwaite  
The Fresh air's blown away the  
rust  
And livened up the heart rate.

With organiser, Brian Dodd,  
Apart from music sharing  
Some rugged country we have  
trod  
We've really been quite daring.

Our group instructor, Nicholas  
Ball,  
He really kept life frantic  
One day he drove us down the  
wall  
We learnt abseiling antics.

The day before, on Monday,  
We had sailed on Bassenthwaite  
Water  
It really was a fun day  
Do this again, we oughta.

On Wednesday, we went riding  
When the heavens, they just  
opened.  
Just patiently time-biding  
Till the afternoon, we cop-en-ed.

At which time, some went on  
horseback

24 - 25 October

FORTHCOMING EVENTS

**Two-day Mencap conference, 'Work in the 21st century for people with learning disabilities', Grand Hotel, Birmingham. *Claire Greenwood/Wendy Poole, Mencap, 97 Friar Street, Droitwich, Worcester WR9 8EG, tel 01905-796679.***

**Wednesday, 26 October**

**Hydrocephalus Study Day, Chatsworth Hotel, Steyne Gardens, Worthing, W Sussex. 9.30am-4pm. Organised by Sussex ASBAH. *Speakers: Dr G McCarthy, consultant neuropaediatrician, Chailey Heritage/Royal Alexandra Hospital for Children, Brighton; Mr C Hardwidge, consultant neurosurgeon, Hurstwood Park Neurological Centre, W Sussex; Leonie Holgate, ASBAH. £12.50 professionals, £6 parents or adults with SB/H. Mrs Margaret White, tel 01293-871217.***

**Friday, 28 October**

**Closing date for receipt of contributions to the DSS review on the work of the Benefits Agency. *Garvin Bowen, DSS, Room 1819, Euston Tower, 286 Euston Road, London NW1 3DN.***

**Saturday, 12 November**

**ASBAH professional conference, 'Management of the Neuropathic Bladder and Bowel', St George's Hospital, Lincoln, 9am-4.15pm. *Speakers: Ewan Mackinnon, consultant paediatric surgeon, Sheffield Children's Hospital; David Thomas, consultant urologist, Lodge Moor Hospital, Sheffield. Details: Lynn Thomas, ASBAH, tel 01733-555988.***

**Thursday, 17 November**

**'Disability Living Allowance - from claim to appeal', one-day Disability Alliance training course, at 356 Holloway Road, London N7. £75 members, £90 non-members, £50 concessions. *Details: Sue/Vincent, tel 0171-247 8776.***

Whilst others drove a trap.  
Along the narrowest of tracks  
I was ready for a nap.

On Wednesday night, twenty past  
ten,  
I finally had a rest.  
On Thursday morn we'd start  
again  
With another severe test.  
To turn, then, to the music side  
We had to work all t'morning.  
We had to be alert; bright-eyed  
As soon as t'day was dawning.

Our work was fully orchestrated;  
Led by Richard Stilgoe,  
Who beautifully demonstrated  
Almost anything, it will go.

The atmosphere; the fells; the lake;  
The wind: Our lungs inflated.  
Some perfecting it was going to  
take.  
Pure harmony; belated.

In the background, Andrew Auster  
(He led the choir on Sunday)  
Who, a gentle approach did foster.  
He played bassoon, from Monday.

The front man, Nigel Osborne  
A composer man by trade.  
My nerves, they got a bit torn  
As foundations they were laid.

Tim Yealland led the art work  
He really set the stage  
I'm finding it a real jerk  
As I come to t' end of page.

For a performance at the Tithe  
barn  
To culminate the week.  
We're nearly at the end o' t' yarn  
How inspiration I did seek.

As YVIA's Zem Rodaway  
Will echo, I am sure  
It's really been quite a holiday  
Among Lakeland verdure.

**Saturday, 19 November**

ASBAH Study Day, 'Managing Continence in Spina Bifida', Park Dean School, St Martin's Road, Oldham, Manchester. 9am-4pm. Speakers include: Mr A P Dickson, consultant paediatric urologist, Booth Hall Children's Hospital; Gill Ward, consultant clinical psychologist, Booth Hall. Cost: £5.50 including coffee, lunch and tea. *Mr Brian Black, 94 Ullswater Road, Flixton, Manchester M41 8SN.*

**Saturday, 26 November**

Your Voice in ASBAH meeting, Peterborough, 12 noon. *Details: Zem Rodaway, 140 Compass Road, Hull, Humberside HU6 7BE tel 01482-854947.*

**Easter Bank Holiday weekend, 1995**

Olympic hopeful Rob Barsby attempts Wash Windsurf Challenge in aid of ASBAH and RNLI. *Details: Deirdre Pawsey, Appeals Department, ASBAH, tel 01733-555988.*

**16 -19 July 1995**

Annual Mobility Roadshow and 'Ideas into Action', 7th International Conference on Mobility and Transport for Elderly and Disabled People, Transport Research Laboratory, Crowthorne, Berkshire. *Conference details: Paddy Payne/Louisa Rogers, Baltic Conventions, The Baltic Centre, Great West Road, Brentford, Middx, TW8 9BU, tel 0181-847 2446.*

**14-16 September, 1995**

'Fast Forward into the Future', 8th International Congress of the International Federation for Hydrocephalus and Spina Bifida, The Collaroy Centre, Sydney, Australia. *Details: HSB Conference Secretariat, GPO Box 128, Sydney, NSW 2001, Australia.*

**FOR SALE**

RENAULT Espace, Atlas conversion, high roof and ramp for carrying wheelchair and occupant in comfort. Four passenger seats. Tel: 01603-39306.

ALFRED BEKKER Accelerator, brake hand controls to fit following three cars: Mini; Metro, up to 1992 model; Astra without airbag. £75 each. Tel: 01376-583055.

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

**WESTGATE-ON-SEA, KENT (GREENWICH ASBAH)**

SEMI-DETACHED bungalow available all year round. Since bought in 1976, we have added new lounge/diner, summer house in garden, shower/toilet room for latest wheelchair hygiene and gutted kitchen, installing disabled facilities for wheelchair use. Also bathroom/toilet, 3 double-bedrooms to sleep 8, plus cot. Full central heating, colour TV, drive-in takes 3 cars. Westgate has 2 sandy bays with wheelchair access and toilets. NO steps anywhere and low off-season rates. *Doug Endersby, 12 Veda Road, London SE13 7JF, tel 0181-690 0342.*

**NEW FOREST (S HANTS ASBAH)**

FULLY equipped caravan designed for wheelchair access throughout, sleeps 5-6, club with indoor pool, shop etc, sited at Bashley Park New Milton. *Contact Joan Searle, tel: 01705- 376816.*

# LINK Rates

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Display Rates on application, from the Publicity Manager.

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