

# Link

The magazine for people with  
Spina Bifida and/or Hydrocephalus



August/September 1995

Issue No 159 Price 80p





**LORD MAYOR  
TRELOAR SCHOOL**  
FROYLE ALTON HAMPSHIRE  
GU34 4LA

Supported by the Treloar Trust Registered  
Charity No 307103

**EDUCATION, INDEPENDENCE AND CARE FOR  
YOUNG PEOPLE AGED 8-16 WITH PHYSICAL  
AND LEARNING DISABILITIES**

- National Curriculum
- Full range of subjects to GCSE level
- Large Learning Difficulties Department caters for those who require a modified curriculum.
- A unique interdisciplinary programme (FLAME) run by a team of staff for young people with Cerebral Palsy
- Support from Therapy and Medical teams; Rehabilitation Engineering; and experienced care staff
- College Chaplain; counselling service and careers advice

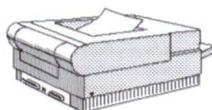
For further information, please contact  
Admissions Secretary on 01420 547425

The only computer company to give  
**ALL its profit to Charity**

It makes excellent sense to deal with

**COMPUTER SENSE**

for all your Apple computer service and sales



A wholly-owned subsidiary of the Association for Spina Bifida and Hydrocephalus, managed by staff who are all highly experienced in the sales, support and maintenance of Apple computers.



- New equipment
- Repairs and maintenance
- Maintenance contracts
- Networking
- Software
- Paper, ribbons etc

**Computer Sense Ltd**  
Unit 7  
Grovelands Business Centre  
Boundary Way  
Hemel Hempstead  
Herts HP2 7TE

Tel: 01442-252555  
Fax: 01442-219222

**GBL WHEELCHAIR WAREHOUSE**

**RANGES FOR ALL AGES AND REQUIREMENTS**



Folding or Rigid,  
Manual, Lightweight  
Wheelchairs

Authorised Dealer  
for: Sunrise  
Medical

STAIRLIFTS

HAND CONTROLS  
AND CAR ADAPPTIONS



ELECTRIC  
WHEELCHAIRS

**OFFICE  
OPENING  
TIMES:**

Weekdays  
09.30am - 6.00pm  
Saturdays  
10.00am - 2.00pm



**SERVICES**

New or Secondhand, Repairs and Parts  
Hire and Insurance, Free Advice, Showroom Accessible

**GBL Wheelchair Services Ltd. Units 1-3, Shield Drive, Brentford, Middlesex TW8 9EX tel: 081-569 8955 fax: 081-560 5380**

**GBL Wheelchairs Limited. Unit 3 Martello Enterprise Centre, Courtwick Lane, Littlehampton,  
West Sussex. BN1 7PA tel: 0903 733528 fax: 0903 733530.**

**GBL Eastern, Ermine Street North, Papworth Everard, Cambs CB3 8RH tel: 0480 831212 fax: 831414**

# Do disabled parents have less rights in court?

A NEW campaigning body, set up to oppose discrimination against parents because they are disabled, gained powerful support from ASBAH when we took part in Radio 4's *Face the Facts* programme in June.

The programme featured two families where disabled parents who were seeking the support of social services found instead that their children were removed and put into care – after social workers won court orders, claiming the parents were unfit to look after them.

"We have been contacted by a growing number of disabled parents who have come into conflict with social services departments, when they have approached them for help caring for their children," John Keep, of RADAR, told *Face the Facts*.

"In the very worst cases, disabled parents have lost the custody of their children to the local authority. They have been made to feel like criminals. We feel this is totally unacceptable behaviour and must stop."

ASBAH fielded one family for the

programme – a blind mother who had a caring relationship with her young son. The boy needs physiotherapy for a spinal disability but aggressively objected to professional therapy, so his mother maintained his physical exercise programme.

Social services, alleging gross neglect, put the boy on their 'at risk' register after the mother failed to obey a court order that her son must keep physiotherapy appointments. Eventually, when he was taken from the home to be put in the care of foster parents, an ASBAH fieldworker told how she was called to break the tragic news that he would no longer be living with his mother.

Social services tried to obtain a court order which would have prevented the mother speaking to the programme. Instead, after hearing from the BBC, the judge made a limited order which allowed her to tell her story but prevented identification.

The other family featured – a couple, both with a learning disabilities – told how their twin sons were taken away, after seeking social services support.

They were judged to be incapable of caring for them after a catalogue of mistakes were relayed to a lengthy court hearing.

Their abilities as parents were observed in a court-controlled family centre when, said the family's informal advocate, the whole process seemed designed to fault them, instead of deciding how to support their parenting.

A spokesman for the Association of Directors of Social Services said care proceedings had to go before the courts which then ruled in the best interests of the children.

*Parents Too!* is a new coalition of 35 disability rights organisations, which is collecting examples of disabled parents being discriminated against by the professional authorities. The coalition was set up by ParentAbility (a peer group network attached to the National Childbirth Trust) and by RADAR.

It is compiling a directory of sources of advocacy, information and support available both nationally and locally. *Details from John Keep, 197 Colesmansmoor Road, Woodley, Reading, Berks RG5 4DD (tel/fax 01734-628512).*

## Contents

ASBAH is a registered charity

▲ Shock treatment urged	4	▲ Darke at the cinema	16
▲ Staff news	5	▲ To screen or not?	17
▲ Tributes to Tom Davies	7	▲ Clothing services	19
▲ START right	9	▲ When baby comes	20
▲ Sharing while learning	12	▲ The LINK diary	25

Cover: *Beside the seaside and a message about folic acid – Sonya Moyes and daughter Sophie. See page 4.*

# Hammering home the vital message

CORNISH FAMILY URGES SHOCK TREATMENT ON VALUE OF FOLIC ACID

SCORES of inquiries about the importance of taking folic acid before conception and during pregnancy were coming in during the weeks leading up to Spina Bifida Week, 31 July - 6 August.

As well working with health writer Dr Miriam Stoppard on a syndicated radio tape as this issue of *Link* went to press, ASBAH staff were identifying numerous health centres and hospitals prepared to display posters and leaflets. We were also introducing newspapers, magazines, radio and TV to families prepared to describe their own experiences of having children with spina bifida.

One such family, from Cornwall, volunteered to tell their story in order to hammer home the *Foresight not Hindsight* message of Spina Bifida Week. This means women should take folic acid well before pregnancy to minimise the

chances of having a baby with with spina bifida.

Sonya Moyes was not advised to take folic acid until planning her second pregnancy – after her first child was born with spina bifida and hydrocephalus.

She is now keen that other women planning a family take folic acid in order to prevent neural tube defects developing in their unborn infants, so they do not have to go through the same ordeal as herself.

Sonya did not find out her first baby had spina bifida until it was born. She had been given two antenatal tests which were incorrectly read, showing her baby had Down's Syndrome, instead of spina bifida.

When baby Sophie was born, hospital staff found she had a two-and-a-half inch hole in her back.

Sonya, from Padstow in Cornwall, said: "It was a hell of a shock and very upsetting. I had no idea what spina bifida or folic acid were.

"If I had been forewarned about spina bifida, maybe I would have had a termination – even though I wouldn't be without Sophie now. But, if I'd taken folic acid, I might never have been faced with that decision."

Faced with the difficulties of raising a disabled child, including severe mobility and incontinence problems, Sonya and husband Jamie turned to ASBAH for help.

ASBAH's Cornwall fieldworker Lynne Young told them about the importance of taking folic acid which has been shown to cut the rate of pregnancies affected by spina bifida by three-quarters.

So, when planning for her second child, Sonya made sure she took a folic acid supplement. She took the vitamin for three months before conception and then three months into the pregnancy.

And it worked. In July 1993 – nearly two years after their first baby – Sonya gave birth to Natasha, a healthy, normal baby.

Sonya, 24, said: "At 15 weeks we were sweating until the tests came back but everything was OK.

"There was no reason for me having a baby with spina bifida – it must have been just a lack of folic acid in my body.

"I wouldn't wish what we went through on anyone. If everybody knew what spina bifida was and that folic acid can help prevent it, then they would take it.

"As it is, nobody knows what spina bifida is and that by taking folic acid you can avoid it. You've got to shock people into taking it – that's what people need."



*The Moyes family – dad Jamie, mum Sonya, Sophie, aged four, who has spina bifida and hydrocephalus, and Natasha, aged two – on the seafront at Padstow in Cornwall.*

**The Government is taking its time before starting its £2.3 million campaign to educate women about the benefits of taking folic acid supplements before pregnancy.**

**"Initially, there was a delay because the Department of Health seemed to want to privatise the campaign," said ASBAH executive director Andrew Russell. "Now that has been sorted out, it looks as though the Department of Health wants first to have another go at educating doctors and nurses, instead of spending the money where it is most needed – on a long-overdue public health information campaign. We have waited long enough."**

ANN WILD, former fieldworker for parts of North London, is the new part-time national mobility adviser for ASBAH.

She started her new job at the beginning of August, replacing John Naudé who left ASBAH earlier this year to train to become a vicar.

Herself a wheelchair user due to spina bifida, Ann will be working mainly from South East Region office in New Barnet, North London, although she will spend one day a month at national centre in Peterborough.

Her main interest in mobility is to take account of the whole person and not just the wheelchair.

Ann is 32 years old and captain of the British Women's Wheelchair Basketball Team. She said: "I take a holistic view of mobility. It's important to take care of yourself first, then do all the things you want to do."

"I'm looking forward to meeting so many people and hearing their points of view."

Ann is also interested in mobility abroad, in this country, access to transport, arts and crafts. She will be able to offer help on wheelchairs and other mobility issues.

JULIE KNIGHT has been appointed fieldworker for Avon and part of Wiltshire.

Mrs Knight, aged 32, comes from a nursing background, specialising in learning difficulties.

Her last job, in Manchester, was running a service for people who presented difficulties to carers. She then took a break to have a baby and did some childminding.

With her new job, she is looking forward doing something different and still utilise her skills.



Julie, who now lives in Bristol, said: "I am looking forward to dealing with a broad spectrum of people."

In her spare time she enjoys painting children's pictures and cards, reading and working on an allotment.

She started her part-time job with ASBAH on 24 July and will be based at home. Her post is being part-funded by Bristol ASBAH.

## ASBAH COMINGS AND GOINGS

LIVERPOOL under-16s fieldworker Val Cushing has left ASBAH to become a full-time physiotherapist in the south.

Val, 51, had worked as a fieldworker in Merseyside for a total of five years – from 1982-3 and then from 1992-5.

Her most lasting impression of the job is the way families cope so well. She said: "They don't need help all the time, only when they are having difficulty. The children are brilliant, they accept so much."

Val has moved to Hertfordshire to be nearer her family and to work as a physio-therapist at Meldreth Manor School, run by Scope. She said: "I am working with children aged 12-15 who have cerebral palsy and lots of other problems, including visual impairment."

# Officers & Staff

**Patron:**  
HRH The Duchess of Gloucester, GCVO

**President:** Dr Jeffrey Tate, CBE

**Chairman:** Mr Patrick Daunt

**Hon Treasurer:** Mr Charles Ortner

**Executive Director:**  
Andrew Russell, MA

**Finance Director:**  
Derek Knightbridge, FCCA

**Assistant Director (Personnel):**  
Paul Dobson, BA (Hons), FIPD

**Senior Services Manager:**  
Teresa Cole, MICA

**Senior Appeals Manager:**  
John Williams

**Services Manager:** Milly Rollinson CQSW  
**START Manager/Northern Regional Co-ordinator:**  
Joan Pheasant, NNC

**Disabled Living Services Co-ordinator:**  
Rosemary Batchelor SRN FETC

**Publicity Manager:**  
Tony Britton

**Research and Information Officer:**  
Gill Winfield Cert Ed

# Disability rights round-up

## A look at the Government's Disability Discrimination Bill

NEW laws to counter discrimination against disabled people should come into force by the end of next year, as the Government's Disability Discrimination Bill continues to make progress through the House of Lords.

All this is in spite of speculation in some national newspapers that an extension to Parliament's summer recess might have given the Bill insufficient time to pass through all the stages required for it to receive a royal seal of approval this autumn.

RADAR – the Royal Association for Disability and Rehabilitation – says the Bill is on course to receive Royal Assent in October and, therefore, become law by the end of 1996.

RADAR has been lobbying hard to make the best of the Government Bill after the more radical Civil Rights (Disabled Persons) Bill, sponsored by Harry Barnes MP, was thrown out. Most of the 40 amendments RADAR put forward during the Committee Stage of the Government Bill in the House of Lords were rejected.

However, as *Link* went to press, a push was still being made for an 'enforcement body' similar to the Racial Equality Commission which would make implementation of the new legislation much stronger.

Jane Oberman, RADAR's parliamentary officer, said: "This enforcement body is very important as it will strengthen the legislation and not leave it up to individual disabled people to enforce the new law."

RADAR's other amendments included getting rid of exemptions for small businesses, improving the definition of a disabled person and getting the best access proposals on transport and education.

The Government Bill is also criticised by Rights (for Disabled People) Now! because the group says it is more limited in scope than the Harry Barnes' Bill. Rights Now! is opposed to the Government Bill because it says:

- An advisory council will be no use in getting people to change their behaviour and there will be no help available to disabled people to take cases forward.
- Anti-discrimination legislation cannot effectively tackle day-to-day discrimination unless a strong enforcement body like a Disability Rights Commission is established.
- The definition of disability does not cover all people discriminated against on the basis of disability.
- The definition of disability used in anti-discrimination legislation should be based on the experience of discrimination and not on impairments.
- Discrimination is legitimised in certain areas.
- Small firms are excluded from the employment part of the Bill, and education from the section on access to goods and services.

## Vote for ASBAH

ASBAH has been shortlisted to benefit from the next Liverpool Victoria Charity Challenge pro-snooker tournament, which has a total prize fund of £300,000 – with £100,000 going to the winning charity.

The tournament is a televised sporting event which brings together 16 of the world's top snooker professionals who will play on behalf of 16 charities. Sixty-four charities have been shortlisted, but only 16 will be represented at the event itself.

The lucky 16 will be the most popular charities as voted for by the public. You can help by voting for ASBAH in a special feature which will be printed in *The Daily Star* on **Tuesday, 22 August**. The results of the vote will be printed in *The Daily Star* when each charity will be drawn against their player for the tournament.

Please put the date in your diary now and remember to buy the paper on this date and vote – even charities knocked out in the first round of the tournament will receive a minimum of £8,000.

The charity challenge will be held in Birmingham 3-6 January next year.

## Education Advice – what ASBAH can provide

ASBAH is able to give advice, information and, where necessary, act as advocate in the area of education.

These services are available through our education advisers, Peter Walker (national) and Karen Sharma (Northern Ireland); disabled living adviser, Leonie Holgate, or the appropriate fieldworker.

However, ASBAH Services Committee has **not** agreed to staff becoming 'Named Persons' to act as adviser/advocate in a formal capacity under the Education Act and Code of Practice.

ASBAH is available to assist parents and 'Named Persons' where the child involved has spina bifida and/or hydrocephalus.

## Tributes to Tom Davies, our longest-serving fieldworker



TOM Davies, ASBAH'S longest serving fieldworker, who died in May, has been described by those who knew him as a "lovely man."

He was 61 years old and had worked as our South Wales fieldworker for 17 years. He leaves a wife and nine-year-old daughter.

The former social worker joined ASBAH in 1978 and became a friend and a listener to the families and individuals he served in his patch.

Brenda Sharp, secretary of South Wales ASBAH, said: "He was a lovely man.

"I will miss our contact regarding both new and old families and seeing him at our annual and welfare committee meetings. We will very much miss his valued contributions."

Margaret Stanton, ASBAH fieldworker for Gwent, added: "Tom was a valued colleague and a special friend. We shall all miss him dearly."

Teresa Cole, senior services manager at national centre, said: "Tom was one of the first fieldworkers I met when I joined ASBAH in the early '80s and he was already a well-known and popular member of the team. Since that time I have valued his cheerful dedicated work with ASBAH and know how much he will be missed by everyone who came into contact with him. As manager, it has been a privilege to know and work with him. His passing leaves an enormous gap in all our lives."

Lesley McKernan, from Barry Island, whose daughter Claire was featured in the 1991 ASBAH national TV appeal, said: "Tom was very caring. If he couldn't see you, you always knew he was there. You knew he would welcome a phone call."

His wife, Solange, has been comforted by the many messages of sympathy she has received. She said: "People remember Tom as he was - he had a good sense of humour and was very kind.

"He liked exercise and walked a lot and was a very healthy man until last November. He was a marvellous husband and a good father."

### Moves to start local association in Plymouth

TONY Sprague wants to hear from other people in Plymouth wanting to start up a local association.

Mr Sprague has spina bifida and wants the new group to offer support to affected families and individuals in the area.

*He can be contacted at: 6 St George's Terrace, Stoke, Plymouth, PL2 1HR. Tel: 01752-509594.*

# Help & Advice

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

#### London, Surrey, Kent, Sussex

South East Region Office, ASBAH, 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, Suffolk, 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: Margaret Young.

Northumberland, Durham, Cleveland, N Yorks, S Yorks, W Yorks, Tyne & Wear, Humberside

North East Region Office, Five Oaks, Ben Rhydding Drive, Ilkley, W Yorks LS29 8BD. Tel (01943) 609468. Regional Co-ordinator: Joan Pheasant NNC.

#### Rest of England and Wales

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

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 details. Prescriptions for drugs or medicines should not be sent to AlphaMed.



JANE LONES (pictured above) retired as principal of Lord Mayor Treloar National Specialist College of Further Education in July.

She had worked for the college for more than 25 years, firstly as head of science in the separate girls' school.

After amalgamation of the boys' and girls' establishments Dr Lones became senior mistress with special responsibility for careers education and advice.

## Treloar college principal retires after 25 years

Then, 10 years ago, she became head of the upper school which was located at Holybourne. On April 1 this year her job title changed to principal, as the college for students aged 16-25 years separated from the school at Froyle.

She recalls with pleasure how one of her first 'A' level biology students, who had spina bifida and hydrocephalus, gained a university place.

A few years later the number of students with spina bifida and hydrocephalus rose until it became the main disability at the college – at one time 83 out of a total of 270 students.

In more recent times the number of students with spina bifida has fallen, but all staff have built up a

valuable expertise in helping these students access a normal educational programme.

Lord Mayor Treloar National Specialist College has had long links with the City of London since its founder, Sir William Purdie Treloar, was Lord Mayor of London in 1908.

Dr Lones was greatly honoured recently when she was given the Freedom of the City of London in recognition of her service to the college and the education of disabled people.

From 1 September, the new college principal will be Graham Jowett. His previous job had been manager for studies of care, health and science at Crawley College.

*Photo by Clive Totman*

## Alf Morris marks milestone event with ASBAH

A BOOKLET has been produced to celebrate the 25th anniversary of a major milestone in disability rights.

On 29 May 1970, the Chronically Sick and Disabled Persons Act received Royal Assent. It was the first time legislation had recognised disabled people's needs.

Up to that time, disabled people were mostly either controlled in institutions or hidden within the protection of family homes.

Its creator, the Rt Hon Alfred Morris MP, later became (in 1974) the world's first Minister for Disabled People in Harold Wilson's Labour government.

In the booklet – *Be It Enacted ... 25 years of the Chronically Sick and Disabled Persons Act 1970* – Ann Darnborough and Derek Kinrade recount the fascinating campaign to get the law on to the statute



*Alf Morris (centre) pictured with senior ASBAH managers John Williams and Teresa Cole at our recent START launch in the House of Commons – held on the same afternoon as a reception which marked the 25th anniversary of the passage of his milestone Chronically Sick and Disabled Persons Act.*

book and record tributes to Alfred Morris.

The authors also criticise the current cutbacks in services, the disparity between those offered by local authorities, and an increasing tendency to charge for them when they are available.

In the final section, 18 contributors from leading disability organis-

ations give their views on what now needs to be done.

*Be It Enacted ... 25 Years of the Chronically Sick and Disabled Persons Act 1970* costs £2.50 (including p&p) and is available from RADAR (the Royal Association for Disability and Rehabilitation), 12 City Forum, 250 City Road, London, EC1V 8AF.

**ASBAH has started its own needs assessment service, START, because many social services departments are failing our user group. MIKE GEORGE wrote this report about our new service for COMMUNITY CARE magazine.**

**M**ANY social services departments appear to be failing a group of clients which should be near the top of the priority list for needs assessments.

According to preliminary results of a survey by the Association for Spina Bifida and Hydrocephalus, most of those aged between 16 and 30 had not been assessed during the first two years of community care implementation.

ASBAH estimates that approximately 15,000 people have spina bifida and/or hydrocephalus, and some have additional disabilities including epilepsy, cerebral palsy, deafness or blindness. Most also have special mobility and accommodation needs, as well as those of continence management, medical care and help in the home.

For most of ASBAH's service users the period from 16 to 30 years is crucially important for the transition to independent living, yet only one in five people in this age range had had their needs assessed for community care, and a further 18% were not sure if they had. These figures conceal considerable variations between social services departments. Just under a quarter said they had no help at all from their social services department.

The quality and appropriateness of assessments and subsequent service delivery is equally important. Some assessments, for example, led to what were felt to be incorrect cuts in support.

"Assessments have to be far more sophisticated, and the current emphasis on the provision of services rather than individually-tailored support means that users miss out on important opportunities.

"This shift from case management to care management is crucial, and potentially detrimental," says Andrew Russell, executive director of ASBAH.

He is trenchant about service users' ability to achieve a great deal – if there is appropriate support for young adults. "Otherwise people can be handicapped throughout the rest of their lives, and all their potential

is wasted," he says.

And he is hard-hitting about some social services' apparent inability or unwillingness to see that part of their role embraces service users' personal development. "What people mean by care management really needs to be challenged," he adds.

ASBAH's research also shows that socialisation, relationships, and sexual knowledge are enormously important to service users.

"There's a massive amount of misinformation around and consequent personal tragedy," says Russell. Good information and counselling is crucial, but often not available.

Russell accepts that relatively few care managers and occupational therapists are likely to have adequate knowledge of all these

# START



# RIGHT

areas, or of the more specialist agencies that could help: "But that doesn't alter the fact that there's a gap between what needs assessment was supposed to mean and what happens in practice – our users are being short-changed," he adds.

This gap is what has spurred the association to set up its own Service Team for Assessment, Rehabilitation and Training, START. The team, which includes occupational therapists, speech and language therapists, physiotherapists, continence advisers and others, is being offered to local authorities. Team members will travel to service users' own localities and provide individual assessments, and help in getting relevant support.

*continued on page 10*

## ASBAH SURVEY (preliminary results)

**88% specified mobility as the most difficult area**

**82% need special accommodation, home adaptations or help to live independently**

**66% had problems managing continence**

## New laws on seat belts

EVERY coach and minibus used specifically for transporting children will have to be fitted with seat belts under new regulations proposed by the Secretary of State for Transport.

The regulations would also end the 'three for two' concession which allows three children under 14 to sit in seats where only two seat belts are fitted.

The Government consulted interested parties on the proposals – the consultation closed on 31 May. But it has already said that, subject to Parliamentary approval, it will end the 'three for two' concession as soon as possible.

Coach operators would have 12 months to comply with the regulations on the fitting of seat belts.

Further information can be obtained from the Department of Transport Public Enquiry Office on 0171-276 0800.

## Out and about

INFORMATION on a range of equipment for disabled people is included in the new edition of *Outdoor Transport*.

Pavement and class 3 vehicles, bicycles, tricycles and powered bicycles, steering, hand controls for brake and accelerator, switches, clutch and gears, handbrakes, left foot accelerators and pedal extensions, are just some of the topics included.

There are also chapters on public transport, a bibliography and useful addresses in the book published by the Disability Information Trust.

Costing £10.00 (including p&sp), *Outdoor Transport* is available from The Disability Information Trust, Mary Marlborough Centre, Nuffield Orthopaedic Centre, Headington, Oxford, OX3 7LD. Tel: 01865-227592.

### from page 9, START RIGHT

Team leader Joan Pheasant points out that they aim to work alongside existing staff, though there's also a strong emphasis on user empowerment. Authorities are being encouraged to buy START's services for full assessments, or shorter specialist reports. The team also offers courses for users and/or carers, and staff training.

START has official approval from the disabilities committee of the Association of Directors of Social Services whose chairperson, Kingston-upon-Thames' director, Roy Taylor, instigated a meeting with ASBAH when he heard the association was being forced to close its Five Oaks training centre. The closure, which says Andrew Russell was caused by changes in DSS benefit rules, was a primary reason for the new approach.

If they use START, local authorities must not abandon their commissioning role, or use it as an excuse to take less responsibility for clients, says Taylor.

Quite why there should be such a low incidence of needs assessments among people with spina bifida or hydrocephalus is difficult to fathom, though as Russell suggests, tight resources are a major factor. But there must also be a suspicion that some social services departments are not up to the task of dealing with people who have more 'difficult' disabilities – and that's unsettling.

*Start Right, by Mike George, first appeared in Community Care magazine 25-31 May 1995. Published by permission of the editor of Community Care.*

## One-stop housing shop

A ONE-stop shop has been set up to provide a range of services for disabled people with housing problems.

The Disabled Persons Housing Service (DPHS) will save those affected being passed from department to department or from agency to agency.

The service offers a specialist service which covers everything from housing design to occupational therapy expertise.

It can offer the disabled person most, if not all, of the following:

- Full assessment of both person and property, including likely future needs.
- Counselling, information and advice on all aspects of housing.
- Training and practice in the skills of independent living.
- Ensuring care packages are available and appropriate.

- Co-ordination of multi-agency team-work.
- Specialist architectural input.
- Housing and adaptations including, if necessary, renovation and repair.
- Specialist financial advice.
- A database of housing need and supply.

So far, four such services have been set up by the National Disabled Persons Housing Service and the group is working to promote and support the creation of other local services.

For further information contact Richard Kendall, The Co-ordinator, National Disabled Persons Housing Service, Walbrook Housing Association Limited, 64-76 Curzon Street, Derby, DE1 1LP. Tel: 01332-372141.

## Money-saving idea for house adaptations

NEW building standards are needed to save millions of pounds of public money which are currently being spent on adapting homes to meet the needs of disabled people.

This is the conclusion of Belfast-based Disability Action in a new book on house design.

The charity's chief executive Monica Wilson, quoted in the *Belfast Telegraph*, stated: "The Housing Executive spends between five and six million pounds per annum adapting existing housing to people's needs.

"If all new housing was built to this standard in the first place then 90% of that expenditure would eventually be unnecessary."

Among the recommendations in the book are:

- Level or gently sloping approach to front door.
- Wider doors and entrance hallways.
- Ground floor WC with room for a wheelchair.
- Kitchens should have a clear turning circle for wheelchairs.
- Provision should be made for a 500 mm bath seat at the end of the bath.
- Controls and switches should be at a convenient height.
- Stairs should be 1m wide with a half landing (this is considered safest for future installation of a stair lift or handrails).

*Copies of the book are available from Disability Action, 2 Annadale Avenue, Belfast, BT7 2JH.*

## Now she can post it!



USERS of a resource centre in Stockport will now be able to send letters more easily thanks to a move by Royal Mail to lower a post box.

Clare Fay, who has spina bifida and hydrocephalus, led a campaign with Stockport Disability Group to get the post box lowered.

They said the wall-mounted box was too high to reach from a wheelchair.

And Royal Mail bosses responded to their call by taking a few bricks away from the base of the box near Newbridge Resource Centre – at a cost of £100.

Clare, aged 17, a part-time clerical assistant at the centre in Lower Bredbury, said: "It was ridiculous that we couldn't use the post box. A small change like this means a lot and will make life easier for many people."

Now Royal Mail has promised to modify post boxes in other parts of the borough, wherever it can.

*Photo shows Clare Fay as she posts a letter in the lowered box. She is watched by (left to right) James Hallworth, chairman of Stockport Disability Group (SDG), Liz Williamson, co-ordinator of SDG, Royal Mail representatives, and the mayor and mayoress of Stockport.*

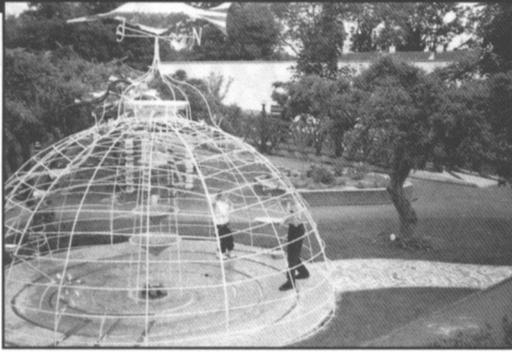
## Making escape easier in fire

RESEARCH showing the work needed to save disabled people from being trapped in building fires has won a top award.

Professor Thomas Shields led the project to identify the problems faced by wheelchair users or those with poor mobility or blindness at the University of Ulster's centre for fire safety research and testing.

A report, describing building design features and other measures required to make buildings safer in the event of fire, was published by the national Building Research Establishment.

Professor Shields was recently presented with the ABE Fire Safety Award by the Association of Building Engineers.



## Meldreth Manor School: an ideal setting for our

**T**HE CHANCE to share experiences and learn more about spina bifida and hydrocephalus from the experts were the main reasons families wanted to attend the ASBAH Family Weekend.

Seventeen families took part in the second annual event, at Meldreth Manor School in Hertfordshire, which has excellent indoor and outdoor facilities for children with special needs. Able-bodied brothers and sisters were not left out either as they could join in plenty of stimulating and fun activities throughout the weekend.

While the children enjoyed the horse-riding, parachute games, swimming and scavenger hunt, mums and dads got down to hearing from experts in

paediatric urology, physiotherapy and hydrocephalus.

Discussion groups over the two days covered topics such as coping with a difficult diagnosis, behaviour/learning difficulties, continence, education problems and general medical.

Louise and Gary Lamb, from Lincoln, thought the weekend would give them an idea of what lies in the future for their 13-month-old daughter.

Louise, 28, said: "Sophie has spina bifida and hydrocephalus. We don't know what's to come – the difficulties we may have to cope with."

Their eldest son John, aged three, also came with them on the weekend.

"We're particularly interested in the

talk on physiotherapy to see what sort of things Sophie can do. We want to see her to walk and the first stage is to get her muscles working and go on from there.

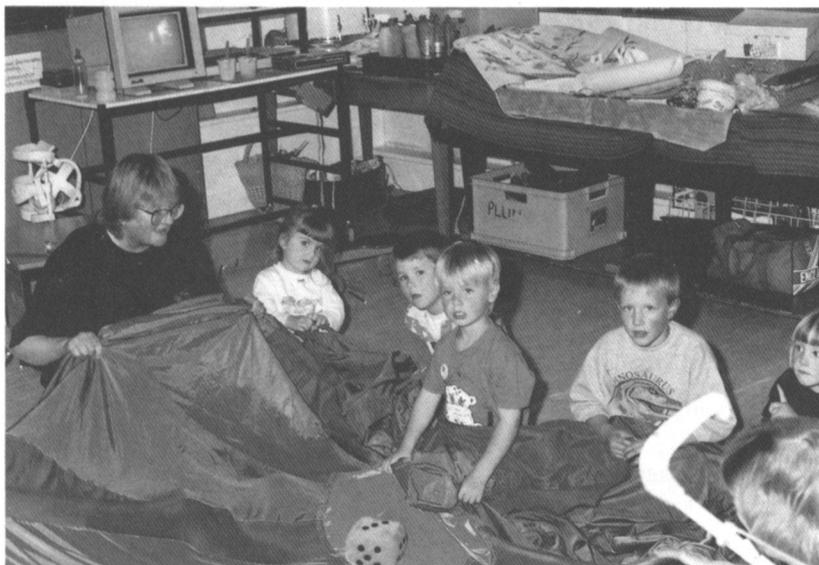
"At the moment she's sitting and doing a commando crawl. She uses her arms a lot and pulls herself along."

Gary, 29, said: "Weekends like this are great because they give you a feel for the general information you can gather."

Louise added: "There's a nice, friendly atmosphere."

Susan and Paul Mitchell, from North London, brought their three children on the weekend – Charlie, who has hydrocephalus, Faye, three, and Rob

# SHARING WHILE LEA



**S**PINA Bifida and Hydrocephalus: the problems you may meet was the title of the opening talk by Martyn Williams FRCS, consultant paediatric urologist at Addenbrooke's Hospital in Cambridge.

Mr Williams explained why babies born with hydrocephalus may have a large head and how to recognise early signs of a shunt blockage.

He explained why spina bifida affected the bladder and bowel and the aims in treating problems with the urinary tract:

- Healthy kidneys.
- A bladder which empties regularly.
- Staying dry.
- Reducing risk of infection.

# Freedom in a wheelchair

USING a wheelchair need not be a confining experience but promotes freedom and independence in someone who has difficulty with walking. The ability to explore the environment plays a large part in a child's development, said Leonie Holgate, disabled living adviser and physiotherapist, who gave a talk at the family weekend called 'Why Physiotherapy?'

The disabled child should be given the choice and in order to do this wheelchair skills and walking should be taught side by side. Leonie said: "The goal is mobility which is cost effective and allows a child to arrive fresh and ready for the next activity."

"It has been seen, by many, to be doom and gloom to use a wheelchair but it can allow more independence and it is possible to travel faster than on two legs. The wheelchair can liberate you and allow exploration of the environment which is so important to a child and need not be seen as 'confining'."

The role of a physiotherapist, when called to see a baby born with spina bifida, is to assess the range of movement and the strength in the baby's legs.

Parents are instructed on favourable positions in which to place the child to encourage movement and, as soon as the child is old enough, allow the child to move around, well protected, to prevent friction burns. This may involve low-level chariots on casters.

Exploration is an important factor in child development and this will help to promote understanding their own size in relation to other objects – body image. Crawling under chairs and tables, even the occasional bump can assist in developing this awareness.

Children may receive visits from the community therapists at home, or visit the local child development centre, depending on the area in which they live. Targets can be set and training can be given to enable the parents to be their child's therapist.

Therapy covers physiotherapy, occupational therapy and speech and language therapy. They engage all the senses. Leonie added: "It's important to give the child space – space to think, dream and so on."



## Family weekend

Susan, 35, said: "Charlie is about to start school this September and over the past 18 months we have realised he has some learning difficulties."

"We felt that coming away on a weekend like this would help us, particularly on the education side and what problems he may encounter at school."

"We also wanted to hear from Leonie Holgate as we felt she would be about to say something about behaviour."

Caroline Smith, from Bungay in Suffolk, attended with her three adopted children – one of whom, four-year-old Anatasia, has spina bifida.

*continued on page 14*

## WARNING

Healthy kidneys can be damaged by "back flow" pressure from a bladder which does not empty completely, so the urine is forced back to the kidneys (reflux). This results in the ureters and kidneys becoming dilated. Various tests can be done to check reflux is not happening and, if it is, how much damage has been caused.

Mr Williams said: "If the urine is infected and goes into the kidney and renal tissue this can be damaged."

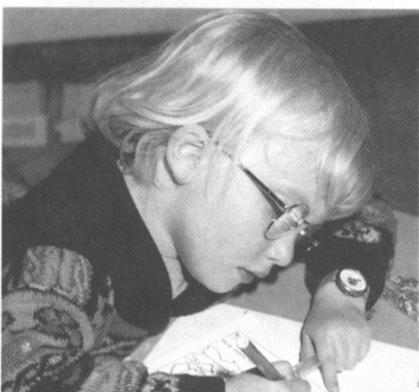
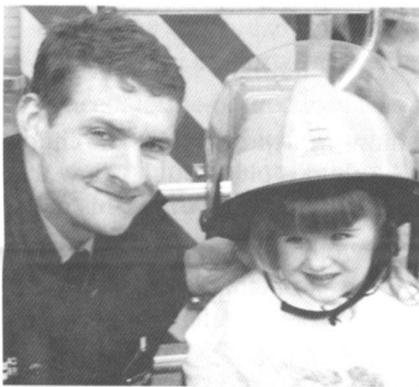
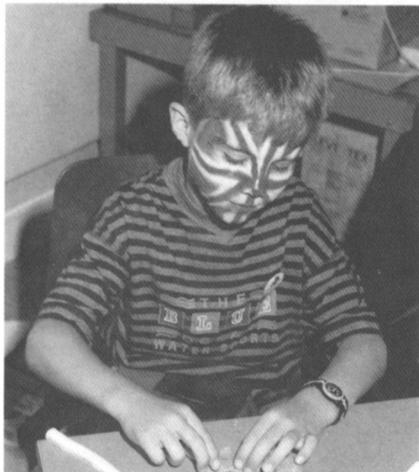
He went on to talk about the "neuropathic bladder" which in some cases may be unable to fill, and in others, unable to empty. Sometimes the bladder may be unable to fill or to empty.

*continued on page 14*

from page 13, talk by Mr Martyn Williams

The present continence management plan for babies and young children is clean intermittent catheterisation which:

## Scenes from the weekend



- Is safe.
- Empties the bladder regularly and completely.
- Is in their own hands.
- Is totally reversible.
- Can be started at any age.
- Often reverses damage done to the kidney.
- Frequently makes them dry (if done every 2-3 hours).
- Gives little or no discomfort – less feeling in this area.

If children are still wet after using intermittent catheterisation, it is important to find out why and then perhaps treat the problem with medication.

If intermittent catheterisation is not suitable or if the patient is still wet, a decision has to be made whether the normal route for urine to come out should be used, or whether to divert the urine in another way.

A diversion is irreversible and involves closing off the urethra and using an artificial channel (conduit) from the bladder to the abdominal wall.

Other methods of draining include an indwelling catheter and a penile appliance.

In all cases there should be regular follow-up with tests for blood pressure (GP) and ultrasound (hospital).

For the bowel, the aims are for the patient to be clean and to be

able to empty when convenient. The stool must not be too soft or too hard and to ensure this plenty of fluids and fibre should be taken.

Mr Williams said it was important to start young with potty training and treat the youngster as you would other siblings.

The child may need support and encouraged into a regular routine, perhaps 10-15 minutes after a meal.

“Try to be relaxed and give them a book or a toy and encourage pushing.”

Medication can be prescribed to help such as bulk-forming agents, stimulants, enemas and suppositories.

In more severe cases, a colostomy can be carried out which involves diverting the bowel onto the surface and collecting the faeces in a bag.

High bowel wash-outs using a Shandling or Cardiomed catheter can also be tried. Surgical intervention involves an ACE (antegrade continence enema) being performed. This uses a catheter via a stoma (an artificial opening on the abdominal wall) to flush out the bowel from the upper part downwards.

Mr Williams concluded with the following advice to parents:

- Incontinence is a challenge.
- Don't give up.
- Get help.
- Treatments are improving.
- Find a consultant with knowledge of spina bifida.

## from page 13, Meldreth Manor, an ideal setting for a family weekend

Caroline, 47, said: “It's nice to come with the children. There's a wonderful playground, riding school and swimming.”

Kenneth and Janet Cottington from Kent attended the weekend for reassurance. Janet, 39, said: “Our two-year-old son Curtis has hydrocephalus and we've heard so many different things from GPs, we don't

know who to believe. We have come here to hear from the consultants and clarify things.”

Philip and Pauline Gibbons, from Northampton, attended with their eight-month-old daughter Gabrielle, who has spina bifida and hydrocephalus.

Philip, 28, said: “We thought it would be good to spend a weekend with families with similar problems and see what their experiences are. We also wanted to associate with people who understand the problems.”

HYDROCEPHALUS and its management was the theme of a talk by Roger Bayston, MMedSci MRCPATH, hon consultant in hydrocephalus to ASBAH.

Dr Bayston talked about the causes of obstruction of cerebrospinal fluid flow in the brain which include congenital hydrocephalus, spina bifida, brain haemorrhage in premature babies, cysts such as the Dandy Walker Cyst, meningitis, head injury, tumour or stroke.

The outward effects of such an obstruction can include behaviour, personality and learning ability problems.

Internally, the most significant effect is increased pressure which results in the heart having to pump harder to get the blood to the brain, leading to damage of the nerve cells.

If not enough blood goes to the brain you feel faint but if this happens over days you will go to sleep and, if it goes on still further, you will go into a coma. Sometimes, it happens suddenly.

*How can we treat it?*

Dr Bayston said: "With hydrocephalus we are talking about a blockage in a rather complicated system. If we can do anything about it, it will be limiting it. A complete recovery will rarely be made. So we ought to be saying we control it, rather than treat it."

Dr Bayston described the development of the first hydrocephalus shunts in the 1950s.

Hydrocephalus shunts can go wrong in three ways:

- Blockage.
- Over-drainage.
- Infection.

According to Dr Bayston, the incidence of infection is quite high. If a baby has a shunt fitted near to birth, there is a 20% chance of infection. In older children, the chances are reduced to 3-5%.

Now that the fitting of hydrocephalus shunts has become a common operation, there have been great efforts to find out why infection occurs and so try to prevent it.

Research has shown that shunt infections almost always start at the operation and that the source of organisms is the patient's skin.

With VA shunts, infections can appear to be flu, measles or other conditions, making it very difficult for doctors to recognise them. Infections from this type of shunt may take years to appear.

With VP shunts, any infection will make itself known within two to six months of the operation and the symptoms usually include abdominal pain or discomfort.

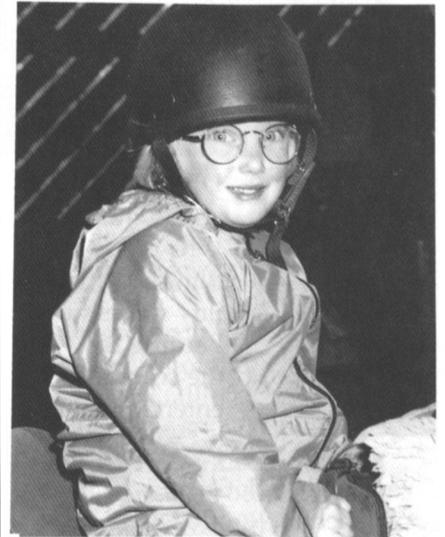
If infection occurs in a VP shunt, any bugs are enclosed and the shunt blocks up, so there is a return of hydrocephalus – headache, dizziness and nausea. There may also be shoulder tip pain, and swelling and redness around the end of the shunt.

Dr Bayston said: "Sometimes surgeons treat this type of infection as a blocked shunt rather than an infection and the shunt can be unblocked many times.

"We must get better at identifying infection. To do so for VA shunts, you can test for antibodies by taking a special blood test. This method is less useful for VP shunts, but a suitable test is now about to be evaluated."

Infected shunts can be treated by surgeons following this procedure:

- Taking the shunt out.
- External ventricular drainage.
- Administration of drugs into the ventricles as well as the blood.
- Re-shunting if necessary, before stopping treatment.



Dr Bayston said: "In my opinion and that of a national Working Party, this is the best way of treating infected shunts."

Treatment of infection without removing the shunt might be achievable by inserting a reservoir and following the same procedure given above, but this method is as yet unproven.

If a child has meningitis (not a shunt infection) it is important to treat the meningitis and not take the shunt out.

Prevention of CSF shunt infection is difficult. Intravenous drugs are no good because what goes into the blood does not reach the ventricles. There was no affect either when surgeons tried injecting directly into the brain.

In future, infection might be prevented by fitting shunts which kill off bacteria. These have been developed by Dr Bayston.

Such shunts have been put into 80 patients in Britain and the United States. A larger trial is going on in South Africa.

Dr Bayston said: "These types of shunts can be used against some bugs but we will never get rid of them completely."

**REPORTS FROM FAMILY WEEKEND: LIZ CAWTHORNE  
PICTURES: NEVILLE ATKINSON and PETER WALKER**

# Darke at the cinema

by Paul Darke



DISABILITY as entertainment! Why are so many films about disability successful? Because they fulfil the criteria for entertainment.

Professor Richard Dyer in his book *Only Entertainment* (published by Routledge) argues that the most successful forms of entertainment are those offering the audience certain things: solutions in a simplified world and the idea that a better world can (and does) exist, if only at present in the movies.

If looked at in view of these ideas we can see why films such as *My Left Foot*, *Coming Home* etc (all successful, box office hits and about disability) are popular. Although Professor Dyer is mainly discussing classic Hollywood musical in his book, I feel it perfectly captures the simple pleasure that makes films about disability entertaining entertainment.

Disability in film is always simplified: the complexities of the social oppression, inequality and marginalisation that people with disabilities have to endure and survive – both as a group and as individuals – every day of our lives is reduced to an individual having to cope with the ‘personal tragedy’ that disability is given as. Consequently, the complexity of being disabled in a complex social structure is reduced to be one character’s problem.

The average able-bodied audience member is given a simplified version of a complex social situation to fulfil its first part of the entertainment ideal.

All that is needed now is a quick solution: a shot of entertainment is to society what heroin is to an addict.

Disabled characters in films usually provide the ultimate and easiest solution for society: death. In movies we have a terrible tendency to die or, in *My Left Foot*’s case, be taken care of by a nurse-like figure who will fill in for society and take away the responsibility for the ‘handicapped’ from society in general. The logic of entertainment states that disability doesn’t need legal rights but a jolly good nurse or death!

And how does this make the audience feel that there can be a better world? The answer, my friends, is blowing in the stories: the better world in disability films is that we do, in the world of film fictions, die peacefully and quietly; we do get taken on by saintly-like nurse figures, and poverty and humiliation are nowhere to be seen. And we never stage demos to campaign for civil rights. And they accuse *us* of being unrealistic!

Roll on the next film that keeps the masses happy and the ‘handicapped’ care for!

## Guide to special schools

Book review  
by Peter Walker  
ASBAH education adviser

*SPECIAL Schools in Britain* is an invaluable guide for educationists and parents who are seeking information about schools which can cater for the individual needs of children with physical, sensory, emotional, behavioural and specific learning difficulties.

It deals with subjects such as assessing a special need, choosing an appropriate special school, colleges of further education and useful organisations, and contains a quick reference chart of establishments in different areas of the country.

It is published by Network Publishing Ltd, St Giles House, 50 Poland Street, London, W1V 4AX (ISBN 07463 06777 6) and is priced £7.95.

### Note on Income Support

DID you know that people aged 16 years and upwards, who are not in full-time paid employment, have a right to apply for Income Support?

Contact your local DSS office for more details and how to apply.

## Help through the benefits maze

UP-TO -DATE help on getting disabled people through the complex maze of 30 different state benefits is at hand – in the annual *Disability Rights Handbook*, now in its 20th year.

The new edition includes a complete section on Incapacity Benefit, which this year replaced both Invalidity Benefit and Sickness Benefit as the mainstay support for 1.6 million people.

Other chapters include a look at charges made for care services and residential care homes, and a section on the controversial Compensation Recovery Unit.

*The Disability Rights Handbook*, edited by Judith Paterson, costs £8.95 (post free) from *The Disability Alliance, 1st Floor East, Universal House, 88-94 Wentworth Street, London E1 7SA*. There is a concessionary price of £5 for people on benefit.

# To screen or not to screen?

THE LACK of information given to women about pre-natal screening amounts to silence between the medical professional and the patient.

This was one of the conclusions of a conference on the social implications of screening for disabilities in the unborn child.

Organised by the Congenital Malformation Register, viewpoints were given by an anthropologist, a midwife, an obstetrician and parents who had made a decision to terminate a pregnancy.

This was followed by a debate in which *Your Voice In ASBAH* member, Tracey Proudlock, was one of the speakers who believed pre-natal screening could be the basis of prejudice against families and individuals affected by disability.

Anthropologist Ian Robinson said the subject of pre-natal screening was based on what was biologically abnormal and its practice was a matter of considerable social importance.

"Pre-natal screening is still controversial and at the margins of medical practice itself. We are pushing the boundaries more and more that it is becoming difficult to understand where 'normal' lies."

He said what is considered a 'normal' child varied from culture to culture. For example, in some parts of the world twins are regarded as a social disgrace; in others children born with teeth or protruding navels are regarded as non-human. In some cultures the female foetus may be left to die.

"In the West we are seeing the foetus earlier and earlier as a person. The screening process is actually calling into question what is human."

## Does screening cast a slur on disabled people and their families?

TRACEY Proudlock of *Your Voice In ASBAH* explained why she thought pre-natal screening for an abnormality caused affected individuals and their families to be stigmatised.

The controversial subject was debated during the second half of the study day at Queen Charlotte's and Chelsea Hospital, London, organised by the Congenital Malformation Register.

Tracey, who was seconder for the debate, said foetal screening was carried out in an atmosphere which was negative for disabled people and parents.

"A 'civilised society' is judged not on how successful it is at screening out disability, but how it accommodates difference," she said.

"Those of us with disability live with 'quality in our life', but to a large extent that quality is socially and politically engineered.

Midwife Jane Grant, who has conducted an in-depth survey of midwives on their views and promotion of pre-natal screening to expectant mothers, said screening was too often offered as routine rather than an option.

In her research, most midwives considered the advantages of tests outweighed the disadvantages, and found it difficult discussing the tests in the context of disability and society.

Ms Grant said: "Until recently, midwives were trained for certainty, not uncertainty. They

"How one acquires one's disability is not the issue – whether by falling under a number 73 bus .... or by birth through spina bifida and hydrocephalus – our rights for inclusion are the same.

"The danger of foetal screening is to further widen the divide between those of us born with disability and those who acquire it later in life."

Proposer of the motion against pre-natal screening was Alastair Kent, director of the Genetic Interest Group. He pointed out that genetics affected whole families so, if one person agrees to be screened, others would be affected by the outcome.

Widespread pre-natal screening, he said, had the possible effect of devaluing individuals born with a disability. There was also the risk of putting blame on parents for having babies with disabilities when these pregnancies could have been terminated.

*continued on page 18*

want to be neutral, independent and offer choice. They might be frightened of expressing their own feelings on the subject or be concerned about overloading women with information."

There was a disregard for uncertainty which amounted to a 'silence between the medical professional and the patient.'

Obstetrician Shoana Hamilton said pre-natal testing was becoming a larger part of pregnancy and she was concerned at the way in which this was being done.

*continued on page 18*

*from page 17, Pre-natal testing in a social context*

As a result, she had conducted a large-scale audit of pre-natal screening to find out how women were being managed and, in the case of negative pre-natal screening results, how the women themselves felt their pregnancies had been managed.

The audit covered seven hospitals in two regions in 1991 and involved 20,000 sets of case notes. The quality of the notes was described as appalling. They revealed that only some women had been counselled on testing.

Dr Hamilton said: "My research showed there was a huge range of ways in which women were told of the results. Many women had tests without knowing what they were for, and there were major inconsistencies in the tests offered."

She continued: "Pre-natal testing has increased dramatically over the last few years.

"In most cases of pregnancy there is a happy outcome and testing obstructs this happy picture. When you are faced with a situation of a very happy mum, explaining there is an abnormality is difficult.

"In a very busy clinic, obstetricians find it easier not to mention pre-natal tests. For the same reason, no

*from page 17, Does screening cast a slur on disabled people ....?*

Mr Kent said: "Parents can be pressured into terminating a pregnancy. It is being left to a third party to determine the outcome – to make decisions which parents may later regret.

"Screening may also lead to unrealistic expectations about the way we control our futures."

There was a risk, he said, of screening being hijacked and contributing towards a 'designer future' which was determined by the whim of fashion.

Opposers to the motion were Sandy Raeburn, professor of clinical genetics at the University of Nottingham, and Nadeem

mention is given to the abnormalities they are looking for, or they forget to mention them because only a few women will have a negative result."

Doctors, she said, were trained to make decisions, not to be counsellors and were neither told how to offer tests nor how to tell a mother her baby had an abnormality.

"Some parents would feel under pressure to comply – either to have a termination or not. Some women will do what they are told in order not to make trouble."

Qureshi, lecturer in the Department of General Practice, University of Nottingham.

Professor Raeburn argued that stigmatisation arose from ignorance. "The fact there can be ignorance and bad counselling does not mean we should make it the norm.

"Screening can, in fact, lead to a greater knowledge in our community and that could lead to much less stigmatisation, not more."

Dr Qureshi added: "I hope all of us would agree that screening reduces the load of disabled people on society. It gives rights to people to choose their own reproductive futures."

The whole issue of pre-natal screening and the way women are told about it, together with the issue of termination, Dr Hamilton said, needed to be approached with imagination.

She said: "It is vital that obstetricians learn how to deal with it and admit that sometimes they don't know. Everyone involved in this area needs imagination and to work with interest groups so we can help women make their own decisions and support them in those decisions."

## Ask your child's school to use **UDET**

A TRAILBLAZING set of disability awareness training materials has been saved for Britain's schools. Now, says ASBAH disabled living adviser Leonie Holgate, it is up to us all to make sure they are used.

A video and teacher support notes produced by the Understanding Disability Educational Trust (UDET) have been distributed to every mainstream and special school in the country – despite the trust's closure earlier this year when it ran out of money.

Leonie, who has used the material herself, said: "It's so versatile. I have used it for lectures and it is a very good way of opening up discussions.

"You can use it in English lessons or as part of the science curriculum, and it is all very well done. My big concern is that, if we are going to make progress in this area – in helping all children at school to play and work together, and to socialise, and for disabled children to be less isolated – then it really must be used.

"I understand that, although the trust has closed, the package has been sent to every school. Every fieldworker, when they go into schools, should be asking how they are using the UDET package, so that it is not just viewed once and then left on a shelf."

The UDET material – together with UDET's 'Lifetimes' book written by Chris Davies – is now being handled by RADAR. *Inquiries to Education Officer, RADAR, 12 City Forum, 250 City Road, London EC1V 8AF.*

# Service makes clothes to suit



**DO you have difficulty finding affordable clothes which fit well, you like, are comfortable and fit your life-style?**

The National Association of Clothing Workshops (NACW) wants to ensure that people with disabilities have equal access to affordable clothes which are comfortable, fashionable and appropriate to their lives.

The aim is to establish a network of clothing services throughout the country which will offer a range of services, including: advice on clothing, what and where to buy, information on fabrics, design and style, a subsidised alteration and adaption service of a customer's existing wardrobe of clothes, and a complete bespoke tailoring service.

Research and development worker Lynn Purcell (pictured above) has the job of establishing this network of services and has been making contact with disabled living centres, disability networks and other voluntary and statutory organisations to seek their support for this work.

At present there are only three areas in the whole of the UK where this type of clothing service is available – Baildon, near Bradford in Yorkshire; Retford in Nottinghamshire and Semington, near Swindon in Wiltshire.

Two new services are due to open later this year, in Bristol and Manchester. Three further services are at the development stage.

However, with a possible eight services up and running, the vast majority of people who could benefit from this type of service –

estimated to be somewhere between 150,000 and 600,000 people throughout the UK – will continue to be unable to access one.

Lynn said: "This is very frustrating for people. At the moment it depends on where you live, not on your need, as to whether you can have this service or not."

One satisfied customer of a recently closed clothing service in Gloucester said: "An invitation to be best man at my brother's wedding filled me with horror. I am aged 22, the size of an average four-year-old and with a pronounced scoliosis. Wearing anything other than loose shirts and T-shirts was very difficult.

"The suit was such a success, I worked with the staff to make me a complete wardrobe of clothes that not only fit me, but also enable me to enjoy an active social life with my able-bodied friends."

Lynn said: "It is hard to believe, but in Britain in the 1990s there are



*Irene Ramsey, from Belfast, in an outfit specially made by a clothing service*

still many disabled people who stay at home because they are unable to access affordable, comfortable, fashionable and appropriate clothing."

Lynn is keen to work with anyone interested in assessing the need for a clothing service in their area, and discussing ways of establishing such a service.

**Contact: Lynn Purcell, Research & Development Worker, National Association of Clothing Workshops, 104 Park Lane, Poynton, Cheshire, SK12 1RG. Tel: 01625-850321.**

## Your nearest clothing service

THE following centres are all members of the National Association of Clothing Workshops (NACW) and offer a range of services:

■ **Bassetlaw Fashion Services for People with Disabilities, Unit 7, Canalside Workshops, Leverton Road, Retford, Nottinghamshire, DN22 0DR. Tel: 01777-860206. Contact: Mrs Pat Spurr.**

■ **Clothing Matters, West Wiltshire Disabled Living Centre, St George's Hospital, Semington, Wiltshire, BA14 6JQ. Tel: 01380-871781. Contact: Mrs Diana Vickers.**

■ **Fashion Services for People with Disabilities, Greenfield Centre, Green Lane, Baildon, Bradford, BD17 5JS. Tel: 01274-597487. Contact: Mrs Hazel Howard.**

Two new services, in Manchester and Bristol, are due to open during 1995, and several other initiatives are at the development stage.

The Department of Health has recently provided funding for the NACW to develop a national network of clothing services.

# WHEN BABY COMES



**ASBAH staff  
talk to Liz  
Cawthorne  
about how  
they help  
the happy  
event go as  
smoothly as  
possible**

**FOR** many women pregnancy and childbirth represents a sense of personal fulfilment and these days women with disabilities, quite rightly, want to share in this enriching experience.

An increasing number of young women with spina bifida and/or hydrocephalus are coming to ASBAH for reassurance and advice either when planning to have a baby or during pregnancy.

They want to know whether there will be any difficulties with conception, pregnancy, labour and childcare due to the fact they are a wheelchair user or because they have a hydrocephalus shunt.

Staff, including fieldworkers, disabled living advisers (DLA) or our DLA co-ordinator, based at national centre, can offer support and advice at this physically and emotionally challenging time.

The following list is the type of advice ASBAH staff would give:

- Folic acid supplement – where to obtain and how much to take, preferably 2-3 months before conception and the first three months of pregnancy.
- Go for a pre-conceptual check-up with her GP to check on the kidneys, blood pressure, etc.
- Goes for genetic counselling, if the waiting list at the local hospital is not too long, in order to find out the risk of having a baby born with a neural tube defect.
- If overweight, see a dietitian.
- See a continence adviser because it may become difficult to self-catheterise during pregnancy.
- Make sure the obstetrician is happy about looking after someone with disabilities. Visit him, preferably before getting pregnant.
- See if the obstetric unit is accessible, for example, for getting in and out of bed and showering.
- Referral to other organisations such as ParentAbility (part of the National Childbirth Trust) and Maternity Alliance.
- Send ASBAH information sheets numbers 3, 4 and 5 on ante-natal screening, genetic counselling and folic acid.

Rosemary Batchelor, ASBAH's DLA co-ordinator, said: "The woman needs to be as fit as she can be before getting pregnant. Women on anti-convulsant drugs should go to their neurologist for advice before planning a pregnancy because of possible problems taking a folic acid supplement. We are receiving a lot of calls from GPs, health visitors and midwives on pre-conceptual care which is very pleasing."

As well as advice, however, ASBAH fieldworkers have an important role in "just being there" for expectant mothers, as well as providing information to midwives and health visitors.

Elizabeth Lawlor, who covers Cheshire, North Staffs and the Wirral, said: "Women can often ask a fieldworker a question which they feel they can't ask an obstetrician because we have a relaxed relationship."

Debbie Simms, mother of two-year-old Ellie, appreciated having Elizabeth to talk to and someone to accompany her to ante-natal clinics. After having the baby, she has received more practical help because the fieldworker is able to pass on information from mum to mum. Debbie, aged 28, from The Wirral, said: "Elizabeth knows other mums and has picked up things from them like putting the baby in dungarees so it is easy to grab from a wheelchair when it crawls off."

**A** KEY job in British sports journalism – how to upgrade the image of disability sports in the eyes of the competitors – has been given to former *Your Voice in ASBAH* member Marshall Thomas.

Marshall has been appointed editor-designate of *Challenge*, a new subscription-only monthly magazine catering for disabled sports people, which appears for the first time in August.

It will be Marshall's first real job in journalism after getting a degree in economics and sociology and then completing a year's magazine journalism training. And the job means a move back to Reading, familiar territory where he was at university.

"I saw the job advertised in *UK Press Gazette* and applied, although I felt I was really too inexperienced," said 24-year-old Marshall, from his home in Finsbury Park, North London.

His boldness paid off. After an interview in which it became clear to his new employer, Knightswood Publishing, that what Marshall lacked in grey hairs he more than made up in knowledge, enthusiasm and desktop publishing skills, the job offer arrived in the post.

"I was staggered, delighted. The job's right up my street and I beat several more experienced journalists to it," he said. The new job started on 7 August and, if all goes well, he will be given the editor's chair at the end of the year.

It will not be an easy ride. In the eyes of many in the world of able-bodied, elite sport – particularly old guard administrators – disability sports and elite able-bodied sports do not mix. Remember Arthur Tunstall's outburst at the Commonwealth Games in Canada last year when he claimed that bringing disability sports to the games caused embarrassment to the other competitors?

## The LINK diary This and That!

Plans for next year's Paralympics in Atlanta have also bought the argument about whether you can pitch athletes with physical disabilities against those with learning disabilities into sharp focus. The Atlanta organising committee has been warned that, if it fails to include athletes with learning disabilities, the paralympics will be called off.

Some of the rules of disability sports competitions are also so labyrinthine as to be unfathomable to outsiders.

"There are obvious minefields but there is also a lot of enjoyment to be had just in taking part. We shall aim to put all sides of the arguments," said Marshall, obviously anxious not to become a hostage to the fortune of any faction.

Marshall finds his own sporting pleasure in horse-riding. He has joined a Riding for the Disabled group in 'Birds of a Feather' country at Chigwell, and what he doesn't know about horse-racing probably is not worth knowing.

His new job not only takes him back to Reading but to the lush gallops of Lamborne just down the road. He added: "It's heaven down there!"

● *Challenge* has a launch offer. For £15, readers may obtain the first 15 copies for the price of 12. Send cheques (payable to Knightswood Publishing) to *Challenge*, FREEPOST (RG3260), Reading RG1 8ZZ.

A COLLEAGUE of mine has become as obsessed with winning votes as John Major was in July. John Williams, who runs our appeals department, is urging *Link* readers to vote for ASBAH to

benefit from the proceeds of a major pro-snooker tournament. At stake is a donation of at least £8,000 to ASBAH.

For ASBAH to benefit from the Liverpool Victoria Charity Challenge, you must read the voting details in *The Daily Star* on **Tuesday, 22 August**. Please buy the paper that day, and then vote for us to go forward to the tournament proper.

Readers will be invited to vote by phone when the newspaper publishes a list of 64 charities (in groups of eight) together with brief statements from each charity. It will be up to the readers to select two charities from each group to go forward to the tournament proper, when they will be teamed up with the snooker players. The winning player will collect £100,000 for his selected charity.

Big money is at stake, so it is clear why John Williams is so assiduously lobbying for our support. So, please, watch that space in *The Daily Star* on **22 August**, and vote to support us.

*AFTER waiting with bated breath to find out whether the big marketing push for our START assessment and training initiative has worked among social and health services professionals, we are relieved to be able to report that it has.*

*Inquiries since the Westminster launch in May are building up and there is also a demand for copies of our START information pack. There may be further success to report in a future issue about a European award for START; the scheme has been accepted as the only UK entry in a competition run by the HELIOS independence for disabled people programme.*

# DATES FOR YOUR DIARY

## Tuesday, 22 August

*Under Milk Wood* by Dylan Thomas, audio-described performance at the Royal National Theatre (Olivier Theatre), London, 7.15pm. Box office: 0171-928 2252, minicom: 0171-620 0741.

## 3 - 9 September

ASBAH driving course at Nell Bank, Ilkley, West Yorkshire. Seven-day course including 10 hours driving instruction. Details: Joan Pheasant, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorks LS29 8BD, tel: 01943-609468.

## 9 - 10 September

British Sports Association for the Disabled bowls competition, Grantham Indoor Bowls Centre, Dysart Road, Grantham, Lincs. Event and entry fee details: Norman Slater, 30 Morley Close, Melton Mowbray, Leics LE13 OLG, tel: 01664-500158.

## 14 - 16 September

'Fast Forward into the Future', 8th International Congress of the International Federation for Hydrocephalus and Spina Bifida, The Collary Centre, Sydney, Australia. Details: HSB Conference

Secretariat, GPO Box 128, Sydney, NSW 2001, Australia.

## Saturday, 16 September

ASBAH AGM, Peterborough.

## 19 - 21 September

International Naidex, Wembley Exhibition and Conference Centre, London.

## 17- 27 September

Project Phoenix trip to Andalucia, overseas study tour for disabled people. Cost about £780. Helpers eligible for some sponsorship but must make a contribution towards own costs. Details: 31a St Vincents Road, Westcliff-on-Sea, Essex SS0 7PP.

## 23 - 24 September

Parachuting for ASBAH at centres in Maidstone, Ipswich, Peterborough and Brackley (Northants). Details of how to take part: Elissa Lowder, ASBAH Appeals, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988.

## Sunday, 24 September

Family fun day, Buile Hill Park, Beccles Old Road, Salford, 10am - 4pm, organised by Trafford and Salford ASBAH in association with

Salford City Council. Details: Tammi Gaynor, tel: 0161-865 0222 (mornings only).

## Saturday, 30 September

Hydrocephalus Study Day, organised by Isle of Wight ASBAH, Riverside Centre, The Quay, Newport, IOW. 9.30am-4pm. Speakers: paediatric registrar Mr Ian Sugarman and ASBAH disabled living adviser Leonie Holgate. £5 per person. Transport may be available for visitors from mainland. Mr D J S Sprake, 01983-551234.

## Tuesday 10 October

Sex Education Schools conference, organised by the National Children's Bureau, Holiday Inn, Sheffield. For details, tel NCB conference office, 0171-843 6041/6042.

## Saturday 21 October

Surrey ASBAH Study Day, Banstead Mobility Centre, Carshalton, 9am - 4pm. Speakers include Mr Steve Capps FRCS, Moyna Gilbertson, disabled living advisers Caroline Berkley and Leonie Holgate. £6 families, £10 professionals, to include buffet lunch. Creche available. Alan Twyford, tel: 0181-390 0853.

## 13-17 November

ASBAH Lifeskills Course, five-day course, venue to be decided. Details: Joan Pheasant, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorkshire LS29 8BD, tel: 01943-609468.

## March 1996

ASBAH understanding behaviour course, three-day midweek course to help families where a child with spina bifida and/or hydrocephalus is displaying behavioural problems. Details: Joan Pheasant, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorks, tel: 01943-609468.

## Special date for Sharon



NEW mum Sharon Bellamy, a member of ASBAH's fund-raising telesales team, received a double delight with the birth of twins, Cara and Tamsin (pictured left). They were born on 11 May 1995 at Peterborough District Hospital.

National centre staff contributed to a whip-round and bought Sharon a twin buggy, some Boots vouchers and a photo album.

Colleague, Maureen Mitchell, said: "They are beautiful babies. We've all given them hugs and kisses."

## HOLIDAY ACCOMMODATION

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

### ISLE OF WIGHT ASBAH

Fully-equipped two-bedroom holiday bungalow, sleeps six plus cot. Clubhouse, indoor heated pool, shop, etc. Site overlooks sea. Own transport advisable. *Details: Mrs P Burden, 36 Sherbourne Avenue, Binstead, Ryde, IOW PO33 3PX, tel: 0983-564604.*

### STAFFORDSHIRE, ALTON

Wheelchair-accessible holiday accommodation in country cottage, B-B or H-B. *Details: Jean Ditchfield, tel: 01538-702189.*

### SELSEY, SUSSEX (ASBAH)

Purpose-designed mobile home for wheelchairs. Sleeps six, colour TV, midi stereo system, payphone, ramp and veranda. Clubhouse, indoor swimming pool. *Details: Mrs B Nunn, tel: 01903-763473.*

### 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: Margaret Humphreys, tel: 01494-714270 (Bucks & E Berks ASBAH).*

## The Learner Driver with Spina Bifida and Hydrocephalus

by Barbara Simms BSc, MSc and Warren Nichols DipDI, DTpADI  
28 pages, £1.75 (inc p & p)

Reliable information for driving instructors and others involved with L-drivers. Advice about driving licences, tests for people with disabilities, car adaptations, and learning difficulties which could affect progress during tuition.

Please send cheque with order to:  
Information Department, ASBAH, 42 Park Road, Peterborough PE1 2UQ.



### TENERIFE

Wheelchair accessible apartments. Heated pool with hoist. Restaurant, poolside bar, equipment hire. Ring today for video and cheapest prices on flights and accommodation.

### ALGARVE, PORTUGAL

Wheelchair friendly luxury villas with swimming pools or friendly hotel with adapted rooms.

*Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX, tel: 01753-685718.*

### MEMBERSHIP

INDIVIDUAL ASBAH membership – receive publications as well as voting rights at twice-yearly Council meetings. £17.50 a year (waived for those on benefit).

*Application form from: Company Secretary, ASBAH, 42 Park Road, Peterborough PE1 2UQ.*

### TRAVEL PLANNING

PLAN your holiday, coach tour or trip abroad with Lincs Travel. 2% of value of business donated to ASBAH. *Pam Forster, Lincs Travel, 9 Stenner Road, Coningsby, Lincs LN4 4RP, tel: 01507-523833.*

*Please say you saw the ad in LINK.*

# LINK Rates

Editor: Liz Cawthorne  
Published by ASBAH,  
ASBAH House,  
42 Park Road,  
Peterborough PE1 2UQ  
Telephone: 01733 555988.

### LINK SUBSCRIPTION 6 EDITIONS – 12 MONTHS

UK ..... £4.80  
Europe and Overseas Surface Mail ..... £7.50  
Air Mail ..... £15.00

All payments should be made in Sterling.

Classified Rates: £3 for 30 words max;  
£4.25 for 30-45 words;  
£5.50 for 45-60 words.

Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of LINK (October) should be submitted by Wednesday, 13 September. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

**AFFILIATED ASSOCIATIONS**

**BARNSELY**

Mr Geoff Jenkinson  
12 St Leonard's Way  
Ardley, Barnsley  
S Yorks S71 5BS  
Tel: 01226-292546

**BEDFORD**

Miss C Merry  
6 Thurne Way, Brickhill  
Bedford MK41 7XD  
Tel: 01234-346344

**BOURNEMOUTH, CHRISTCHURCH & DISTRICT**

Mrs G Lanning  
23 Seaway Avenue  
Christchurch, Dorset  
Tel: 01425 273 255

**BRISTOL & DISTRICT**

Mr G Egan  
64 Rookery Road  
Knowle, Bristol  
Tel: 0117 9777942

**BUCKS & EAST BERKS**

Mrs Margaret Humphreys  
15 Brackley Road  
Hazlemere, High Wycombe  
Bucks HP15 7EW

**BURY & BOLTON**

Mr David Clyne  
51 Cuckoo Lane, Whitefield  
Manchester M25 5WQ  
Tel: 0161 798 7804 (after 4pm)

**CAMBRIDGESHIRE**

Mrs D Thorn  
58 Howland  
Orton Goldhay  
Peterborough PE2 5QY  
Tel: 01733 235139

**CHESTER & DISTRICT**

Mrs P Ithell  
34 King Edward Street  
Shotton, Deeside  
Tel: 01244 811074

**COVENTRY**

Mrs N Newman  
11 The Earls Court  
Cheylesmere  
Coventry CV3 5ES

**DERBY & DISTRICT**

Mrs A Hewitt  
St Merryn  
20 Burley Hill  
Allestree, Derby DE3 2ET  
Tel: 01332 841893

**DUDLEY & WOLVERHAMPTON**

Mrs Lorna J Wootton  
14 Leveson Road  
Wednesfield, Wolverhampton  
West Midlands WV11 2HF  
Tel: 01902 738724

**GRANTHAM**

Mrs J Asken  
88 Goodliffe Road  
Grantham, Lincs NG31 7QB  
Tel: 01476 60679

**GREENWICH & DISTRICT**

Mrs M Mears  
29 Wellmeadow Road  
London SE13 6SY  
Tel: 0181 244 3526

**HAMPSHIRE NORTH, W SURREY & S BERKS**

Mrs Liz Selby  
Buryfields House, Buryfields  
Guildford, Surrey GU2 5AZ  
Tel: 01483 571736

**HAMPSHIRE SOUTH**

Mrs Joan Searle  
68 Windmill Grove  
Portchester  
Fareham, Hants, PO16 9HH

**HERTS & S BEDS**

Mrs S Riseborough  
45 Frankland Road  
Croxley Green  
Herts WD3 3AS

**HUDDERSFIELD**

Mr Steven Bolton  
41 Fieldsway  
Kirkheaton, Huddersfield

**HULL & DISTRICT**

Mr Philip Brown  
233 Cranbook Avenue  
Hull HU6 7TX  
Tel: 01482 857 165

**JERSEY, Channel Islands**

Mrs Mollie Buesnel  
Villa Acacia  
Sunshine Avenue  
Five Oaks, St Saviours  
Jersey, CI

**KENT**

Mrs S Stevens  
6 Croftside, Vigo Village  
Meopham, Kent DA13 0SH  
Tel: 01732 822985

**LEEDS & BRADFORD**

Anna Waddington  
Mullion Cottage  
Main Street  
Hawthornthwaite, Guiseley  
West Yorks LF20 8NX

**LEICESTERSHIRE**

Mrs A Twomlow  
29 The Crescent  
Market Harborough  
Leicestershire LE16 7JJ  
Tel: 01858 432967

**LINCOLN & MID LINCS**

Mrs P Malson  
"Pinfold", Chapel Lane  
North Scarle, Lincoln LN6 9EX

**LINCOLNSHIRE SOUTH**

Mrs P Mason  
67 Boston Road  
Heckington, Sleaford, Lincs

**LONDON N WEST**

Mrs H Prentice  
37 Milton Road  
Hanwell, London W7 1LQ  
Tel: 0181 579 4685

**LONDON SOUTH**

Mrs S Cudd  
15 Woodvale Walk, Elder Road  
W Norwood, London SE27  
Tel: 0181 761 2400

**MIDLAND**

Mrs Diane Britt  
Stanton House  
54 Stratford Road, Shirley  
Solihull, West Midlands B90 3LS  
Tel: 0121 733 7810

**NORTHAMPTONSHIRE**

Mrs J Cockings  
45 Grafton Road  
Rushden, Northants

**OXFORDSHIRE**

Mrs Shirley Dale  
14 South Row  
Chilton, Didcot, Oxon

**PRESTON**

Mrs S Thompson  
34 Beatty Road  
Southport, Merseyside PR8 6LB

**ROTHERHAM & DONCASTER**

Mrs Katie Hemmings  
40 Bentley Road  
Bentley, Doncaster DN5 9TA

**St HELENS & DISTRICT**

Mrs N Maddocks  
236 Rainhill Road  
Prescot, Merseyside L35 4LD  
Tel: 0151 426 3921

**SALISBURY & DISTRICT**

Mrs J Renshaw  
1 Phillip Court, Coronation Rd  
Salisbury SP2 9DA

**SHEFFIELD**

Mrs Celia Nicholson  
104 Townend Lane, Deepcar  
Sheffield S30 5TS  
Tel: 0114 884131

**SOMERSET**

Mrs J Eastley  
46 Hamilton Road, Taunton  
Somerset TA1 2ER

**SOUTH THAMES**

Miss S Davies  
18 Gordon Road, Beckenham  
Kent BR3 3QF  
Tel: 0181 402 1739

**SOUTHAMPTON & DISTRICT**

Mr S J Fitzgerald  
32 Ellis Road, Thornhill  
Southampton SO2 6ER  
Tel: 01703 402644

**STAFFORDSHIRE**

Mrs J Davies  
8 Oakhill Avenue  
Oakhill, Stoke on Trent ST4 5NJ  
Tel: 01782 45365

**STAINES, HOUNSLOW & DISTRICT**

Mrs Pamela Page  
237 Upper Halliford Road  
Shepperton, Middx TW17 8SP

**STOCKPORT**

Mrs J Roberts  
9 Highcroft Road, Romiley  
Stockport, Cheshire SK6 4PS  
Tel: 0161 430 4869

**SUNDERLAND**

Mr J Pounder  
42 Gowanburn, Sunderland  
Tel: 0191 415 1725

**SURREY**

Mr Alan Twyford  
86 Tolworth Park Road  
Tolworth, Surbiton  
Surrey KT6 7RK  
Tel: 0181 390 0853

**SUSSEX**

Mrs M White  
Averys, Rusper  
Horsham, W Sussex RH12 4PR  
Tel: 01293 871217

**TRAFFORD & SALFORD**

Mrs T Gaynor  
Davis Court, Cyprus Street,  
Stretford, Manchester M32 8AX  
Tel: 0161 865 0222 (A.M. only)

**WARRINGTON & DISTRICT**

Mrs S Lawless  
4 Astley Close, Warrington  
Cheshire WA4 6RB  
Tel: 01925 573708

**WESSEX**

Mr T Poole  
123 Gerrards Green  
Beaminster, Dorset DT8 3EA  
Tel: 01308 862614

**WIGAN, LEIGH & DISTRICT**

Mrs Pat Stridgeon  
24 Greendale Crescent  
Leigh WN7 2LQ  
Tel: 01942 676091

**WIRRAL**

Mrs M Appleyard  
28 Stavordale Road  
Moreton  
Wirral, Cheshire L46 9PR

**WORCESTERSHIRE**

Mrs F Bourne  
20 Grafson Place, Droitwich  
Worcestershire WR9 8NQ  
Tel: 01905 776809

**YORKSHIRE NORTH**

Miss Faith Seward MBE BA  
45 The Paddock, York YO2 6AW  
Tel: 01904 798653

**WALES**

**Llanelli**

Mrs Anthea James  
61 Westland Close  
Loughor, Swansea SA4 2JT

**Mid Wales**

Mrs J Carter  
12 Lambeth Close, Craven Arms  
Shropshire SY7 9QY

**North Wales**

Mrs L D Morris  
Penrhyn Arms  
Pendre Road, Penrhynside  
Llandudno LL30 3BY

**South Wales**

Mrs Brenda Sharp  
4 Lakeside, Barry  
S Glamorgan CF62 8SS  
Tel: 01446 735714

**NORTHERN IRELAND**

Mr J Rippey  
Long Eaves  
24 Tulleywiggan Road  
Cookstown, Co Tyrone  
Tel: 0164 87 62290

**NON AFFILIATED ASSOCIATIONS**

**Blackpool & Fylde**

Mr John Dewhurst  
40 Edmonton Place  
Bispham, Blackpool FY2 0VT  
Tel: 01253 592807

**Calderdale**

Mr A L Crowther  
12 Elm View  
Huddersfield Road  
Halifax HX3 0AE  
Tel: 01422 341497

**Cannock & Walsall**

Mr Ken Hall  
17 Wallhouse Street  
Cannock, Staffs  
Tel: 01543 504847

**Chesterfield**

Mrs K Tomlinson  
23 Hathern Close,  
Birmingham Common  
Chesterfield, Derbys

**Cornwall**

Helen Youngman  
26 Penalverne Avenue  
Penzance, Cornwall TR18 2RL  
Tel: 01736 51962

**East Anglia**

Mrs Sylvia Frost  
97 Gaywood Road  
King's Lynn, Norfolk PE30 2PU

**Essex**

Mrs R McCarthy  
26 Brixham Gardens  
Ilford, Essex IG3 9AX  
Tel: 0181 594 1852

**Gainsborough & District**

Mr M Hawkes  
10 Turpin Close, Gainsborough  
Lincs DN21 1PA  
Tel: 01427 616807

**Isle of Wight**

Mr D J S Sprake  
Springfield, Town Lane  
Chale Green, Ventnor  
I W PO38 2JS  
Tel: 01983 551234

**Lancaster, Morcambe & District**

Mrs Dyson  
25 Royds Avenue  
Heysham, Morcambe LA3 1PA

**Nottinghamshire**

Mrs W Purseglove  
122 Chesterfield Road  
Huthwaite, Sutton-in-Ashfield  
Notts NG17 2QF

**Rochdale**

Mrs Anne Lawton  
20 Spencer Street, Chadderton  
Oldham, Lancs  
Tel: 0161 6524487

**Teeside**

Mr J Gray  
148 Lingfield Ash  
Coulby, Newham  
Middlesbrough, Cleveland

**Whitchurch (Salop)**

Mrs E Calder  
Southfork  
Sedgeford, Whitchurch  
Salop SY13 1EX

**OTHER ASSOCIATIONS**

**SCOTTISH SBA**

Executive Officer:  
Mr Andrew Wynd  
190 Queensferry Road  
Edinburgh EH4 2BW  
Tel: 0131 332 0743

**IRISH ASBAH**

Ms Claire Gill  
Hon Secretary, Irish ASBAH  
Old Nangor Road  
Clondalkin, Dublin 22  
Tel: Dublin 0103531 4572326

Association secretaries requiring changes to this list should contact: **LINK EDITOR, ASBAH, 42 PARK ROAD, PETERBOROUGH PE1 2UQ Tel: 01733 555988 Fax: 01733 555985.**