Link

The magazine for people with Spina Bifida and/or Hydrocephalus

August/September 1996

Issue No 165 Price 80p

30th ANNIVERSARY

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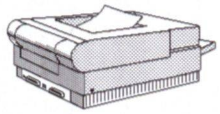

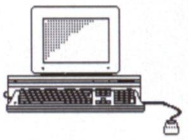

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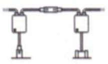

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Tribute to Professor John Lorber, one of ASBAH's founding members

by Miss Mary E Oughtred
ASBAH General Secretary 1969-76

PROFESSOR John Lorber MD FRCP died on 2 July in the Cotswolds, to which he retired in 1986, though even then he continued to travel back to Sheffield to see patients who asked for his help. His name is almost a household word to those who have been in contact with ASBAH since it was formed in 1966. He was a founder member, on the Executive Committee from its inception and the first Chairman of the Medical Committee, in which capacity he served for 10 years.

The time and support he has given to the Association over the years has been tireless, extra to his many commitments to the Children's Hospital and Sheffield University.

It is to Professor Lorber that we owe the two booklets *Your Child with Spina Bifida* and *Your Child with Hydrocephalus*. They meant so much to all involved with what were, at that time, not very well understood severe conditions. Members and readers are much in Prof Lorber's debt for the many articles about various aspects of treatment and care which he contributed in *Link* over the years.

Through his chairmanship of the Medical Committee, his wide contacts and membership of the Research Society for Hydrocephalus and Spina Bifida, the research programme has been furthered by his expertise and guidance.

Professor Lorber travelled widely, lecturing and training, and wrote extensively for learned journals and the *BMJ* on many aspects of child health.

He will, however, best be remembered not only for what he *did*, but for what he *was* – a man of integrity, generous of his time, skilful, careful and compassionate to his patients and their parents and fearless in saying what he believed to be in their best interests.

John Lorber, we remember you proudly and with gratitude.

Our appeal for Dr Bayston: update

MORE than £2,000 has been sent in by following our request for money to help important research by Dr Roger Bayston – a senior microbiologist at Nottingham University and ASBAH's Honorary Consultant on Hydrocephalus. ASBAH is committed to raising £10,000 to support this research, which continues to show up new ways to improve the treatment of people with shunts.

A special mention is given to the Irish Association for Spina Bifida and Hydrocephalus (Dublih branch) which contributed £200.

In the last issue of *Link* (June/July), we reported that national ASBAH had already raised half the amount, and had committed itself to raising the balance this year. ***To make a donation, please send it to Andrew Russell, Executive Director at ASBAH, clearly marking your gift 'for Dr Bayston's research.' Cheques should be made payable to ASBAH.***

A RANGE of new ASBAH Christmas cards – our first new collection for seven years – is now available. There are 13 different designs to choose from and 33% of the money collected goes to ASBAH.

To obtain a copy of the order form, please phone:
Elissa Lowder at ASBAH House. Tel: 01733-555988.

Contents

ASBAH is a registered charity

Cover: ASBAH's patron HRH The Duchess of Gloucester pictured at our 30th Anniversary Conference in London in June. Inset photo: Kirsten Battle and baby Abigail, see story on page 6.

STAFF NEWS

YOUNG people are set to reap the benefits of a grant worth £50,000 over two years which has been awarded to Northern Ireland ASBAH.

The money will be used to fund a new staff member 25 hours a week to deliver tailor-made courses for ASBAH young people on mobility and social skills.

The post will fill a gap in provision for young people with spina bifida and/or hydrocephalus in Northern Ireland, giving then ability and confidence in handling a wheelchair and all the social skills needed for adulthood.

The age range of those benefiting could be 0 to mid-20s but in practice is likely to be from eight years old and upwards.

The grant, three-quarters of which comes from the European Union Special Support Programme for Peace and Reconcilation, and one quarter from the Department of Health and Social Services, was awarded by the Northern Ireland Voluntary Trust.

The aim of the funding is to help people with disabilities take an equal place in society by building up their experience, knowledge and skills.

The Northern Ireland Association and the Northern Ireland Region of national ASBAH worked together on the application. The money was awarded to the Association and will be operated by ASBAH's regional staff.

Northern Ireland Region co-ordinator Margaret Young said: "We are delighted to have been awarded this grant. We applied for the grant in response to a need identified by Northern Ireland staff. As a result, a number of courses on mobility and social skills will be organised a year. There is an emphasis on user-involvement so we'll be asking people what they need."

It is expected that there will be a demand for courses to cover the whole range of mobility – not just wheelchair skills, but advice on driving and transport. For the courses on social skills, residential weeks are anticipated for 14-18 year olds with a weekend or two days follow-up. For 19-25 year olds the social skills courses will probably run over three weekends.

General awareness days for parents are also planned over the two-year scheme.

The new post-holder will be responsible for assessing the needs and how those needs can be translated into courses and where the courses should be held. Ideally, s/he will have some occupational therapy training as well as experience of spina bifida and hydrocephalus.

The post will be advertised at the end of the summer.

◆ SUSAN Mason is the new fieldworker for Lincolnshire.

It is the first time ASBAH has had fieldwork cover solely for this county.

The new part-time post is 100% funded by Lincolnshire County Council's Health and Social Services departments.

ASBAH East Region co-ordinator Mary Malcolm said: "Lincolnshire is a very rural county and people with physical disabilities are very isolated. This new post will help more than 150 people with spina bifida and/or hydrocephalus."

Five Oaks move delayed

NORTHERN Region and START staff were still waiting, as this issue of *Link* went to press, for confirmation that they will be moving into offices in Shipley.

The expected move had been held up while some terms of the lease were being sorted out.

An offer was made last November by a private buyer for the sale of their current premises – former ASBAH training centre Five Oaks at Ilkley, West Yorkshire (*pictured below*).

Meanwhile the Five Oaks Housing Scheme, incorporating Wharfedale and Denton View, is now up and running. ASBAH is keen to stay involved as one of three partners in this very successful scheme.

ASBAH is responsible for the day-to-day running of the flats while Bradford Social Services fills the tenant vacancies, which are open to people with any type of physical disability. The other partner in the scheme is Sanctuary Housing Association.

THE THIRD ANNUAL NATIONAL SPINA BIFIDA WEEK WILL START ON 2 SEPTEMBER

Built in a week – one family with a girl in a wheelchair get a fully-accessible home!

Sarah's dream home

LUCKY Sarah Smith had the double delight of a new electric wheelchair and a tailor-made bungalow built in just one week!

She gained the wheelchair from the Blue Peter Whizz Kidz Appeal and the £55,000 four-bedroom home in a challenge taken up by her local council for National Housing Week.

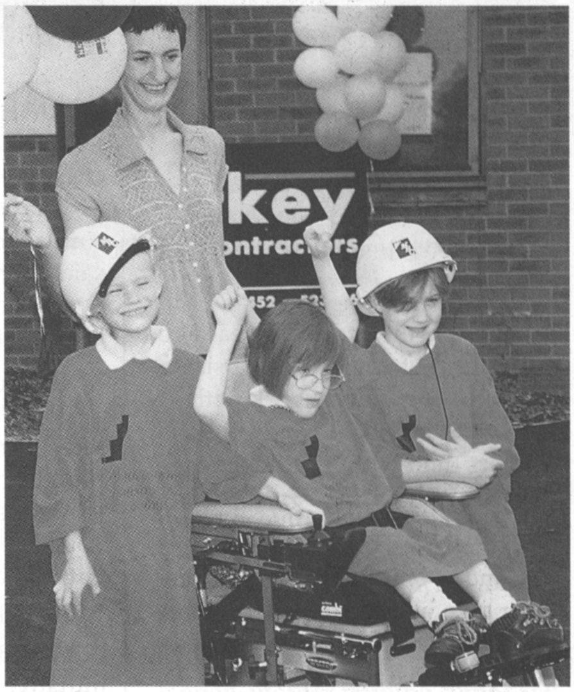
The dream home ended a nightmare three years in private rented accommodation for the Smith family – divorced mum Kate and three children, including wheelchair-user Sarah who has spina bifida.

In their old house, mum had to carry Sarah upstairs every time the seven-year-old wanted to go to the bathroom or bedroom. Mrs Smith, aged 36, said: "This is going to completely transform our lives. It's a dream come true after years of quite hard struggle.

"We really thought Sarah would have to go into a home last year because I couldn't cope with lifting her all the time.

"We both nearly broke our necks when I fell down the steep stairs inside our house while I was carrying Sarah on one occasion.

"There were eight steep steps just to get into our old house."



The Smith family celebrate as they move into their new purpose-built bungalow

Sarah helped the architects design the lay-out of the bungalow which includes wheelchair access to all the rooms, low light switches and heating controls.

Sarah said with a smile: "I am really looking forward to getting into the kitchen to help mum with the cooking which I have never been able to do before."

Stroud District Council donated the land and Gloucestershire Housing Association built the timber-framed bungalow in Ebley through the services of a local building company. Other companies donated services and materials for the project.

Officers & Staff

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Well aware – now for the shy ones in middle school

A PIONEERING schools visiting project to promote disability awareness among pupils and teachers has turned into a runaway success in one of the English shire counties.

But the scheme, started a year ago by a group of ASBAH enthusiasts, is finding it easier to work with less inhibited juniors and sixth formers than with middle school pupils.

"Juniors and sixth formers have responded better than the middle age-range where self-conscousness has tended to block spontaneous questions," said group co-ordinator Carole Armour.

"The answer appears to lie in better preparation by teachers and more awareness by them of what they wish to achieve from the sessions. We intend to focus on better briefing of teachers next year."

The project, run by members of Leicestershire ASBAH, has received a number of invitations to visit new schools and also plans some repeat visits.

In the first year, 10 schools and colleges received just under 40 visits. Another 12 schools and colleges want visits next academic year – so 1996/97 looks like being even busier.

The first year stamina award goes to group member Gary Farnsworth, who made an amazing 17 visits to one school in two weeks just before Christmas. Runners-up were husband and wife team David and Lucie Rixon, who also made many visits during the year – including six to a single community college.

The voluntary scheme has been largely self-financing as most of the schools pay travel expenses.

"ASBAH welcomes initiatives like this and hopes it will encourage other members of local associations to consider starting similar schemes in their areas," said Carole, who is also active in our Your Voice in ASBAH user-group forum.

If you are inspired to attempt such a project yourself but would like advice on what to do, and the pitfalls to avoid, then Carole would be pleased to hear from you. She will be happy to talk, without any obligation on the reader's part.

But she does stress that the initiative must not come from those "volunteered" by their association. To stand a real chance of success, initiatives must come from enthusiastic disabled members who feel able to share their experiences with able-bodied children.

Carole can be contacted through Teresa Cole, our senior services manager, at ASBAH, 42 Park Road, Peterborough PE1 2UQ. tel 01733-555988.

COVER STORY

COVER girl Kirsten Battle vowed that, if she was ever lucky enough to have a daughter, the little girl would be named Abigail Louise – like her own younger sister.

The chance came when Kirsten, who has spina bifida, gave birth to her first child earlier this year.

"Everybody says she looks like her dad. She's got his blue eyes, they're massive", said Kirsten from her home near Slough.

After Kirsten married Mark last year, the story of her determination to walk down the aisle was told in *Link*. So was her hunt to get a job – with 2,000 job bids going out in the post.

ASBAH fieldworker Liz Clayton almost played midwife. She paid a visit when Kirsten started her labour.

Full story in the summer issue of *Lift*, ASBAH's free magazine for young disabled service-users – out now.

Another lucky lottery winner!

TENANTS of an ASBAH housing scheme in Greater Manchester will benefit from a £4,000 grant from the National Lottery Charities Board. The money will go towards the refurnishing of the four flats at Davis Court, Stretford, which is managed by Trafford & Salford ASBAH. The flats were opened in 1988.

The refurnishing was one of only two schemes in Trafford which received money from the NLCB's second round of grants. Grants of £159.1m to 2,229 groups were divided almost equally between organisations working with youth issues and those with low income.

"Although the flats are let as unfurnished, we provide most of the furniture. We have a rolling programme of renewal and this lottery grant will help up get on with this job," said Tammi Gaynor, of Trafford & Salford ASBAH, which selects all the tenants.

"I was assessed on the telephone for an hour and a half – it felt a bit like doing a GCSE exam," said Tammi. "We argued that generally tenants at Davis Court cannot afford to furnish the flats themselves."

OUR COVERAGE OF ASBAH'S THIRTIETH ANNIVERSARY CONFERENCE STARTS ON PAGE 9

Leonie retires after 17 years

ONE of ASBAH's most experienced and respected staff members is to retire in October after 17.5 years' service.

Leonie Holgate is a disabled living adviser whose job has evolved as her experience has grown, and whose wide-ranging expertise has defied a job description.

Originally trained as a physiotherapist, she has built up knowledge in a variety of fields including mobility and education.

She started working for ASBAH in 1979 when she was asked by the then executive director Moyna Gilbertson to carry out a retrospective survey of children she had known at Queen Mary's Children's Hospital, Carshalton. This was followed by a three-year research project on the problems encountered by school leavers.

Over the years Leonie moved away from physiotherapy to teaching, learning, psychology and general function. She has done a lot of general advisory work, helping ASBAH fieldworkers all over the country. She has also worked very closely with the Five Oaks team. She was responsible for setting up the driving courses at Five Oaks.

A highlight came in 1991 when she was asked to speak at the annual conference of the Australian association, followed by a five-week tour of the continent. She has also done work in Southern Ireland.

Leonie is pleased when a parent or individual is reassured by her advice that a problem is part of the disability and not them being silly or lazy. And she gains satisfaction when she gets through to another professional. "My knowledge has come purely from experience, observation, meeting parents and professionals, reading, listening and discussions with colleagues," she says.

She has written various sets of ASBAH guidelines and worked with publicity manager Tony Britton on the film *Hydrocephalus – A Guide to Education.*

Although retiring as an ASBAH part-time employee, Leonie hopes to stay involved. She says she will miss colleagues at head office and her contacts all over the country.

She will continue to run a group of adults with mixed disabilities one afternoon a week for the Queen Elizabeth Foundation at Dorincourt, Leatherhead.

Her hopes for ASBAH are that we open another training centre and that there is good fieldwork cover across the country. "It is good that some of our young people are taking responsibility but ASBAH is there for people who need help making decisions, who can't hold a job down and who are struggling with independent living."

Help & Advice

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

London, Surrey, Kent, West and East Sussex

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

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

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

Northern Ireland

ASBAH Northern Ireland, 73 New Row, Coleraine, Northern Ireland
BT52 1EJ. Tel: (01265) 51522 Regional Co-ordinator: Margaret Young.

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

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

Rest of England and Wales

ASBAH 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 introductory Freepost envelope. Prescriptions for drugs or medicines should not be sent to AlphaMed.*

Darke at the Cinema *by Paul Darke*

THE CANNES Film Festival awarded a variety of awards this year to films that feature disability as both central and peripheral to their narratives; the most interesting of which, one suspects, will cause the most offence: *Crash*. The runner's up prize to Golden Palm winner (the British film by Mike Leigh, *Secrets and Lies*) was a film called *Breaking the Waves*. Set in Scotland, it tells the tale of the wife who wishes that her husband did not keep going to the North Sea oil rigs as an off-shore worker. Her wish is answered as an accident happens that paralyses the husband so that he can no longer work. The wife then has to endure a form of sexual degradation so that her husband is cured. Sounds like a barrel of laughs from beginning to end! Made by Lars von Trier, a Dane, with a largely Scottish cast, it sounds like Art House fodder that is unlikely to hit your multiplex.

A Belgian film, *The Eighth Day*, about two brothers, one of whom has Downs Syndrome, took the best actor award; awarded jointly to the two actors who played the brothers, one of whom is actually an actor with Downs Syndrome. Though called another *Rain Man* by the British press and assumed to be a patronising recognition of the actor with Downs Syndrome, it none the less looks like a film to look out for in the next year or two (if we are lucky) hitting a local, though probably inaccessible, Art House cinema near you.

Crash, on the other hand, made by a Canadian director David Cronenberg, will hit a multiplex near you – however much they are criticised they are usually accessible – as it is full of sex and stars (Holly Hunter, Rosanna Arquette and James Spader) – supposedly bizarre sex at that. The Rosanna Arquette character has to wear callipers due to a road accident which makes her an ideal partner for sexual activity (with her callipers on and with her wounds!). It is set to create a stir, if not a stink, just like the novel of the same name on which it is based, by J G Ballard, did when it was published. I am looking forward to this film – as I am ex-calliper wearer myself, though slightly less attractive than Rosanna Arquette in callipers – as it does seem that it will push the boundaries of disability imagery that little further away from the quaintness or archetypal nature that currently exists. I am sure it will offend many but at least it will challenge and instigate debate about sexuality and disability in the context of how it is falsely, and usually, unseen: as an act of perversity.

•NEWS IN BRIEF •NEWS IN BRIEF •NEWS IN BRIEF •

RAILWAY CAR PARKS

ORANGE BADGE drivers who have been charged for parking at railway stations, where previously they have been able to park free, are asked to give details to Bert Massie at RADAR, 12 City Forum, 250 City Road, London EC1V 8AF. RADAR is following the matter up after complaints to the Railways Working Group of the Disabled Persons Transport Advisory Committee.

RELEASE ME VIDEO

THE VIDEO, *Release Me* – a love story acted by adults with learning disabilities, looking at their rights to have sexual and independent relationships – can be hired or purchased (£10 and £50). *Frances Lea, tel/fax: 0181-340 3814.*

QUARTERLY INCONTACT

A QUARTERLY newspaper and pen pals scheme have been launched by inconTact, the self-help group for people with bladder and bowel problems. The aim is to break down the barriers of isolation.

Membership is £5 per year to join. Send cheque to inconTact, The Basement, 2 Doughty Street, London WC1N 2PH.

CHOOSING A WHEELCHAIR

RADAR's new guide to this subject, called surprisingly enough *Choosing a Wheelchair*, was published at the end of May and costs £7 (inc p+p) from: RADAR, 12 City Road, London EC1V 8AF. Besides info on available models, the guide explains NHS provision.

HOLIDAY WHEELCHAIR HIRE

A WHEELCHAIR hire service for visitors to the Pembrokeshire coast is being run from a base near the tourist office in Haverfordwest. Self-propelling models are not available because of difficulties in obtaining insurance cover. Hire charges are £1.50 for 24 hours or £10 a week. Booking, advised during peak holiday periods, can be made. *Tel: 01437-760665 (PIPPA – Physically Impaired People of Pembrokeshire Association).*

CASH CRISIS FORCES CLOSURE

THE NATIONAL Music and Disability Information Service – which handled 1,300 inquiries a year from students, therapists and the public – has closed because of a cash crisis.

DAVE'S DIARY OFFERS SOME PERSONAL THOUGHTS ON THE FOLIC ACID SAGA – SEE PAGE 25

30 YEARS AND COUNTING!

THE MAIN event of ASBAH's 30th anniversary year brought 13 top-notch speakers to the Queen Elizabeth II Conference Centre opposite Westminster Abbey. Before an audience of 250 people, they spent the day talking about the achievements of disabled people and how the media image of disability can be improved.

Opening the conference, THE DUCHESS OF GLOUCESTER said that she felt a special attachment to the charity. "ASBAH is an organisation close to my heart as it was the first charity of which I became patron some 23 years ago." (Former general secretary Mary Oughtred who invited Her Royal Highness to become patron of ASBAH shortly after the Duchess's marriage. She was then known as Princess Richard).

The Duchess set the scene for the day's events by sketching in the medical background. While the number of spina bifida births in the UK had fallen dramatically in the last 30 years, she said the figures showed a rise in the number of children surviving with hydrocephalus because of the better medical care of premature babies.

"Three decades ago, life expectancy for a child with spina bifida was very limited and expectations of life were generally poor. Today, we have moved on from purely medical improvements, important though these are, to working to bring opportunities to the largest group of adults with spina bifida and hydrocephalus that has ever existed in the country", said the Duchess.

"These opportunities are to develop individual talents, to achieve educational qualifications, to form relationships, get a job, get married and bring up a family – in fact to participate fully in society." The constraints of an inaccessible environment and the prejudice of many able-bodied people remained to be overcome.

"Thirty years have shown that, given the chance, people with spina bifida and hydrocephalus can achieve success in professional life, sports, cultural activities and, of course, in personal life.

"Local ASBAH associations have played a great part acting as a voluntary focus for information and for friendship for families bringing up a disabled child. ASBAH has always meant local concern and local action, as well as a national influence for change", said the Duchess.

She concluded: "A significant part of the work of ASBAH is now played by disabled people themselves, as well as by parents and professionals and this positive trend will go on steadily in the coming years."

Six pages on ASBAH's 30th anniversary conference, celebrating the empowerment of disabled people

Q E II CENTRE, LONDON – 6 JUNE 1996

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PICTURE: The Duchess is welcomed by Godfrey Bowles (right) and Andrew Russell

ONE of the best-known speakers was writer and broadcaster CLAIRE RAYNER, who urged greater understanding and tolerance – particularly over abortion and the inclusion of disabled pupils and students in mainstream education.

On the difficult issue of abortion, Mrs Rayner said: "I ask this audience today, even while they celebrate the achievements and the great progress made by people with spina bifida and hydrocephalus, to extend friendship and acceptance to those others who choose not to give birth to a baby with one of these problems".

"They too are part of our community, your community, and I believe they are concerned as we all are to improve the quality of life of people dealing with these conditions. Rejecting them is unjust, cruel and does the disabled movement no good at all. I am quite convinced of this."

Mrs Rayner, a vice-president of ASBAH for the past 11 years, said education of disabled children remained a major issue.

"I believe that we need far fewer special schools. In fact, I would like to get rid of all special schools and have all children in mainstream schooling, with special services bolted on for those who need them.

"The point the Minister made that you can't legislate against people's feelings – of course, you can't. You can't make people accept but you can as sure as hell teach them. And the easiest way, the quickest way, is to teach at school.

"If children from the age of four of five onwards take it for granted that some of the people they meet at school are going to be in wheelchairs, some are going to be deaf, some are going to be wearing helmets in case they fall, and that some are going to be on crutches or whatever, they will grow up taking it for granted that these are people just like themselves.

"I think we need to remember that we had an even bigger problem of racial intolerance in this country and have still got it, but it has been greatly reduced by the fact that the vast majority of white children and black children now grow up together in school. That's how you get rid of discrimination.

"It is quite difficult to discriminate against people you fought with when you were a five-year-old."

CONFERENCE SPEAKERS

11am	Opening by **the Patron of ASBAH, HRH The Duchess of Gloucester GCVO**
11.05	**The Minister of State for Social Security & Disabled People, Alistair Burt MP**
11.30	**Claire Rayner OBE,** ASBAH vice-president
11.40	**Stefan Krusche,** ASBAH, Germany
11.55	**Richard Gutch,** Chief Exec, Arthritis Care
12.35	**Sue MacGregor OBE,** 'Today' programme
1.45	**Tanni Grey MBE,** wheelchair athlete
1.55	**Paul Darke,** film critic
2.40	**Peter White,** BBC disability affairs correspondent
2.50	**Tracey Proudlock,** ASBAH executive committee
3.05	**Alan Twyford,** vice-chair, Your Voice in ASBAH
3.15	**David Grayson OBE,** National Disability Council
3.50	**Pierre Mertens,** president, International Federation for Hydrocephalus and Spina Bifida

Due to pressure on space, reports of some of the speeches have been held over until the next issue

WORLD FAMOUS conductor JEFFREY TATE, who is president of ASBAH and has spina bifida, was working in Japan on the day of the '30 Years and Counting!' conference. But he sent this message, read out by chairman Godfrey Bowles:

"Thirty years have seen a huge progress in the quality of life and prospects for children born with spina bifida and hydrocephalus. This is in large measure due to the work of ASBAH bringing together people from all walks of life people with these disabilities, their parents, medical researchers, many professional disciplines and other people of energy and goodwill.

"ASBAH's confidence in the talent and determination of our disabled members is reflected in the theme of our conference today. This celebrates the increasing participation and achievement of disabled people in society, in raising families, in the arts, in sports and in the professions.

"I was born just too early to profit from ASBAH but fortunate to have had a back-up team of family and professions who pre-echoed the kill and care that characterise ASBAH. This can enable us, the disabled, to ignore that label and to feel totally able to enter into a full and active life".

Dr Tate added that the Duchess of Gloucester's interest in all of ASBAH's work was a source of great strength.

Civil rights – the Minister goes for persuasion, not punishment

ANNIVERSARY CONFERENCE

The Minister, Alistair Burt

THE MINISTER for Disabled People, ALISTAIR BURT, had a difficult job – explaining to the conference why government had chosen Disability Discrimination Act (DDA) as steps along the road towards full civil rights, rather than the quick fix advocated by many disability groups (including ASBAH) of a commission with powers to punish.

"We must strike a balance between the aspirations of disabled people and the responsibilities and duties of the rest of society", he said during a keynote speech called 'Rights and Opportunities for Disabled People'.

"The aims of the legislation won't be achieved if it breeds a culture of mistrust, evasion and hostility. There is little point ending discrimination against one group if the solution is just to shift an unjustifiable burden on to another. So we must develop partnerships. We must talk to each other. If we fail in this, we won't get it right."

Despite some murmurs of dissent from the 250-strong audience and highly critical questioning, the Minister stuck to patient persuasion during his 30-minute contribution. It was a style he obviously hoped will be echoed in the difficult months ahead.

He described the DDA as a milestone on the road to an enlightened and more supportive society, which will affect the work place, the high street, the sports centre, our schools, colleges and universities, our buses, trains and taxis and every single on of us.

For the first time, he said, disabled people have rights not to be discriminated against in the field of employment, in obtaining goods, facilities and services and in buying or renting land and property. The Act also introduced new provisions to improve access to transport and education.

The first part of the DDA to be implemented was the setting up at the beginning of the year of the National Disability Council (NDC) and its opposite number of Northern Ireland. Under the Act, at least half of the memberships had to have special knowledge – either as disabled people themselves or as parents or guardians of disabled people.

In fact, over half of the members appointed were disabled, including chairman David Grayson and athlete Tanni Grey, both booked to speak to the conference in the afternoon.

Mr Burt said that, while the NDC would be the lead body in advising how the DDA was working, the National Advisory Council on Employment for Disabled People would continue to advise on employment and training.

Government placed great importance on consultation as it moved to implement the Act. It had already consulted on a code of practice on employment rights, on guidance on the definition of disability, on regulations relating to the first of the rights of access to goods, facilities and services and on the timetable for introducing the remaining rights of access.

There had also been consultation on regulations relating to further and higher education and, on transport, a number of working groups involving representatives of both the manufacturing and operating industries were working closely with the Department of Transport on the detail of the regulations. More consultation with industry and consumer interests would take place as the draft regulations were prepared.

In addition, government had begun to seek tenders for an independent advice and support service will help to settle disputes over access to goods and services "without, we hope, the need to go to court."

"I am very anxious, however, to get the message over to the wider world that the Act is not a burden. It is an opportunity to tape into both a new consumer based and also for many a new source of talent. . . Legislation alone won't change attitudes, and we all have a role to play in doing that."

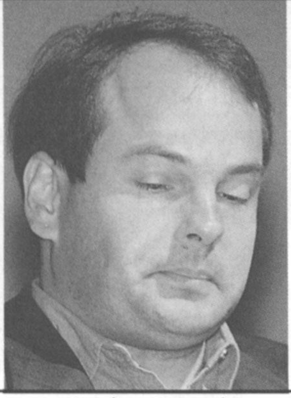
One questioner said the DDA had "got no bite to it. Is anything going to be done about that?"

Replying, the Minister said: "Don't be misled by those who say that, just because there is no commission, the Disability Discrimination Act lacks teeth. It doesn't. It is the law. It can and it will be enforced.

"Its employment provision will be

Continued on page 12

ANNIVERSARY CONFERENCE



Stefan Krusche

STEFAN KRUSCHE warned against letting doctors and scientists dictate the pace of the ethical arguments involved in the genetic engineering debate.

Mr Krusche, from German ASBAH, said that many disabled people viewed attempts to eliminate disability with grave suspicion.

Mr Krusche described an experience he has when he was invited to speak to a congress on clinical genetics in Germany last year.

"There were many, many various forms of genetical disabilities described, presented with Latin or Greek names, like bottles of wine in a catalogue. Spina bifida was one of these disabilities.

"It is not easy for myself to understand me only as a spina bifida man with scoliosis, hyphosis, bladder and bowel lesions but as the man, Stefan, who had his problems with his body of course. However, I am a personality with individual ideas of happiness, contentment and life quality."

He said he would have more respect for doctors if they treated him as an individual and not only as a man with chronic conditions. Under such conditions, it was difficult to build up self-esteem, and to have a more rounded view of one's own life.

"Often, I have the feeling I want to show to all the scientists, doctors and also to my able-bodied friends that my life is intensive, varied and has real value. Even in the improbable cases that some time only healthy, fully-developed babies will be born, the life of these children will not have more value."

Mr Krusche said it should not be an aim of society to produce only strong human-beings, resistant against illness, to provide workers for industry but he suspected this was an aim of genetic research in many industrialised societies.

"For me, it should be a much more recognised aim to change positively the life-conditions in the world so that not only the strong ones, in the sense of Darwin, can manage their lives, but also the weak ones."

And, while he recognised that it was important for women to be given early information about the health status of their unborn children, there should be adequate help available to them when deciding whether or not to end their pregnancies. Mr Krusche said part of the process should include discussions with parents of other disabled children so the pregnant woman can judge for herself "how the life of handicapped children really looks".

"Women who decide to give birth to a handicapped baby should get all medical, technical, social and legal help. There are theoretic considerations to shut out insurance benefits for women if they don't use special pre-natal investigations: this is ethically unacceptable. We must not come to the point that a cost-value analysis is enough to close out the existence of handicapped life."

THE MINISTER, from page 11

enforced like employment provisions throughout the land by industrial tribunals and its civil rights provisions will be enforced through the county courts in a very similar way."

He rejected the view that the DDA should have a commission able to take cases of discrimination to the courts, much the same as in race or sex cases. Race and sex cases were very clear-cut, but disability covered a much wider field. American experience had shown that commission cases had created logjams in the courts.

The DDA was "the iron fist", he said. "The velvet glove is to persuade all those who would even cross their mind to discriminate that it is just the wrong thing to do, and that they are working with the grain by not discriminating.

"And, if we can make people move in that direction, then we won't need a whole series of cases but, if we do, the law is there and will be used. I am quite sure of that."

One questioner drew an appreciative chuckle from the audience when he said:

"With respect, you say we have got full civil rights. Why did it take four taxis today to get one that would take my wheelchair if we have got full civil rights?"

Mr Burt replied: "We all know that access to transport is not yet good enough. The Act acknowledges that. There are changes – taxies are already changing and we will be enforcing stricter regulations in relation to taxis in the future.".

He said it will take time to get it right, but government was working to improve access to buses and trains.

The Minister added that it was wrong to tell business that its obligations under the Act were massive, must be implemented immediately and that defaulters would go to jail. This attitude would force small traders out of business and no-one was well-served by that. He remained convinced that the DDA would move disabled people's rights enormously.

Get it right – we could be 'role-models for society'

ANNIVERSARY CONFERENCE

USER INVOLVEMENT in running, staffing and volunteering for charities like ASBAH and Arthritis Care could make them "role-models for society as a whole", particularly if they involve partnerships rather than threats of takeovers.

That was the view of Richard Gutch, chief executive of Arthritis Care, in the conference's second key-note address, entitled 'Users must be stakeholders'.

He identified several key issues to be addressed in the development of successful stakeholds including what he said was probably the most important – the fear that existing trustees, staff and volunteers would be removed to make way for users.

"This is probably the most important one of all, and that's because I think it's felt rather more than it's expressed.

"It's felt often by some of those already involved in charities that users are going to displace existing trustees. They are going to displace existing staff. They are going to take the place of existing volunteers. They are going to question existing patterns of service, and suggest different ways of doing things. They are going to make demands for change and question existing attitudes", said Mr Gutch.

"In other words, they represent a challenge to the status quo and user-involvement. I think there's no escaping this: user-involvement does mean a shift of power within an organisation and it can make life difficult. Some people will feel upset and feel they they are being squeezed out in some way."

Mr Gutch said at worst breakaway groups could be formed, with bad publicity.The way round that was, with much patience and dialogue, to view the challenge of user-involvement as a partnership, rather than a 100% takeover.

"Indeed I think it becomes then a very exciting agenda because what we are actually taking about is trying to make our organisations, trying to make ASBAH, Arthritis Care and other charities, role-models for society as a whole.

"If we can successfully involve users and develop partnerships between all the different stakeholders, then we are pointing the way for other in society to do the same. It is not always going to be easy – especially for traditional charities where change can be very difficult to accept.

"If charities don't embrace the concept and if they appear to operate on the basis that they know what's best for their users rather than giving users a central stakehold in the organisation, then I think they are going to face difficulties and most of all they will lose the support- of the very people they are there to serve – their own users and beneficiaries."

Mr Gutch said users were the people with the condition that the charity was set up to support. By stakeholders, he meant allowing users a say in everything the charity did.

And they needed to feel comfortable with what the charity was doing in their name. "This is especially important in the use of images and messages in fund raising work. How would people with the condition feel if they came face to face with one of the charity's posters? If it is going to make them feel negative about themselves, then should the charity really be using images of that kind?"

Richard Gutch

Users should be involved as research subjects, both by taking part in trials and having a view on research priorities and the balance to be struck between research into managing the condition and research into future cures.

"There's a tendency for research results to be over-sensationalised for fund raising or publicity purposes and that can often leave people with the condition having their hopes raised unnecessarily or getting very confusing messages about when this wonder cure is going to be available. There have even been examples where people taking part in the research have been the last to hear about the results."

During questions, Mr Gutch was asked how users could overcome parent pressure not to get involved. Mr Gutch pointed to workshops run by Young Arthritis Care, where parents were invited to begin with to get a feel for what was going on, and then left.

"I am not pretending we have got an easy solution but that's one way to try and break down misapprehensions about what is going to happen in these workshops. I think the other thing is through trying to create opportunities where parents can hear from young people who have gained a greater independence, and hear from them how positive an experience that has been."

The day 'Today' became more than a wake-up voice

ANNIVERSARY CONFERENCE

Sue MacGregor

SUE MACGREGOR, welcomed by Godfrey Bowles as "the embodiment of a famous voice", charted her 29-year career in BBC radio from when she was one of the team on 'The World at One' to her present position as a presenter on the 'Today' programme.

And she let slip perhaps the real reason why she accepted, without payment, ASBAH's invitation.

"I am one of the lucky ones. My parents tell me that I was born with a mild case of hydrocephalus. Luckily, medical skills managed to put that right and to drain the extra fluid off my brain, and it has left me with nothing more than a mildly uncomfortable lower back occasionally because there was a tiny bit of spina bifida remaining in my system.

"So I'm particularly honoured to be here in hour of your ASBAH organisation which has done so much for people who are deeply disabled today."

In her early career, 'The World at One' broke the broadcasting mould by encouraging ordinary people, including disabled people, take about themselves unrehearsed and unescorted, and often it was hard work.

"I don't wish to group people in great clusters, I know you don't like that, but disabled people weren't on the whole used to speaking for themselves and we were amongst the programmes that actually pioneered their doing that and I met some extraordinarily remarkable people.

"We tried not do do what we called in the business 'zoo jobs' – in other words looking at people who were different from us, saying "Gosh, you know this is a new species. . ."

Among disabled people who left marks on her memory were: Mary Greave, who fought for wheelchair access and a decent income income for people with disabilities; and Lin Berwick, blind with cerebral palsy who now a Methodist lay preacher and raising money build a holiday home for disabled people in East Anglia.

She also greeted Bert Massie, in the audience. "He runs RADAR with a sort of unbeatable mixture of heavy persuasion and charm, and is not above a bit of flirtation."

She recalled the running story sparked when former Minister for the Disabled Nicholas Scott scuppered the private member's Disabled Persons Bill and then had to apologise for misleading the House of Commons after denying that his department had provided material for his backbenchers to talk it out. His daughter, Victoria, who works for RADAR, then called for her father's resignation.

"It was the stuff of headlines for many days and I remember even the dear old Times, which has changed a lot I admit, having a headline about it. . . 'The day I denounced Daddy'."

Ms MacGregor revealed that a 'Today' programme reporter, 29-year-old Gary Donoghue, is the only totally blind person on a daily national network radio show. He became blind at the age of eight but travels the world for the programme, tape-recorder in hand.

"He writes his own material, edits it and I said to him 'How do you describe?', because radio is all about pictures in the mind and conveying those pictures to other people. 'How do you describe the people that you are talking to, to make them come alive as you do?' And he said: 'Well, sometimes, I just make it up. It seems to work!'

"As somebody who works in the media, we cannot and mustn't take sides on disability issues. But I hope we can reflect their importance and throw light onto the issues in an impartial way. Do tell us if we are doing it right, and if there are ways in which we can do it better", said Ms MacGregor.

"We still have to be vigilant about attitudes. That story just yesterday about people on the plane who refused to fly with a little girl with meningitis, although it was perfectly safe to so so, should remind us of how vigilant we have to be."

Hydrocephalus Network
News
AUTUMN 1996
ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS
ASBAH, 42 Park Road, Peterborough PE1 2UQ
Tel: 01733 555988 Fax: 01733 555985
Reg Charity Number 249338
Network Co-ordinator: Rosemary Batchelor

Request for information

READERS knowing of anyone who has hydrocephalus with a shunt who has served in the Armed Forces are asked to pass details on to our Disabled Living Services department. Please write to Lynn Thomas, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

More on blood donors

OUR report on a member, who was told he could not give blood due to having a shunt, roused a lot of interest.

Several people have contacted ASBAH saying they have been refused as blood donors because they have spina bifida or hydrocephalus. The reasons given were related to the presence of a shunt and this was confirmed in a letter from a consultant in transfusion medicine.

The National Guidelines state that if someone has a shunt they are permanently excluded from donation.

ASBAH's Medical Advisory Committee is reviewing the situation with a view to taking up the problem with the authorities, and will keep members informed.

Medical Advisory Committee Chairman, Dr Martin Bax, said: "I have been in correspondence with the National Blood Transfusion Service to see why they made this decision. The ban seems to be a blanket one in relation to the risk of infection. There's always a worry that a valve is infected but this risk is very, very low. We are continuing to look into it."

ASBAH throws down the gauntlet on behaviour problems

A POSTER on behaviour problems was presented at an international conference by ASBAH staff in July.

They hope someone at the Research Society for Hydrocephalus and Spina Bifida will take up the gauntlet and do some more research into this area.

The poster was presented in Utrecht, Holland by ASBAH disabled living services co-ordinator Rosemary Batchelor and disabled living adviser Leonie Holgate. It is the result of an audit into the field of behaviour disturbances.

Boost to hydrocephalus research

CROWDS of people who paid their last respects to former Peterborough District Hospital plastercast maker Gerry Betts are helping to push forward the boundaries of knowledge about hydrocephalus.

Mr Betts, who worked in the hospital plaster room for almost 40 years until his retirement five years ago, died in March after a heart attack and a stroke. He was 65.

In June, £600 given in place of flowers at the funeral was handed over to ASBAH by his widow, Mrs Jo Betts, daughter Sue Mitchell, sons Simon and Tim and grandson Charlie – with the request that the money be earmarked for hydrocephalus research.

Five-year-old Charlie Mitchell is fitted with a shunt to control his hydrocephalus and his family use ASBAH's services.

continued on page iv

THE GROWING PAINS OF A YOUNG MAN WITH HYDROCEPHALUS

NOW WE know so many young (and not so young) people who have hydrocephalus, for a variety of reasons, we are in the privileged situation of learning from them. It is crucial that we listen attentively and accept their observations. This is of great value in terms of increasing our sensitivity and awareness, writes LEONIE HOLGATE, our specialist hydrocephalus and education adviser. This, in turn, will enable a realistic approach to be considered which will meet the needs and aspirations of these young people and allow them to develop their potential. The following list was written quite spontaneously by a young man who wishes to remain anonymous and it really reaches to the heart of the matter for many. The comments on the opposite page, made by BRIAN WILSON, endorse the anonymous contribution.

A PERSONAL VIEW OF WHAT HYDROCEPHALUS MEANS TO A YOUNG MAN

1 I have difficulty filtering out relevant information.

2 I get distracted, lose my train of thought – I get caught up in irrelevant details.

3 I get intense panic attacks.

4 I have difficulty in working out appropriate social responses.

5 I feel 'left out,' 'left behind.' I don't fit in. I feel something is missing.

6 I have difficulty with eye contact and vocal communication – lazy eye gets worse under stress. (People aren't aware that I am addressing them and look over their shoulder).

7 I am afraid of other people's expectations of me.

8 I'm afraid of commitment – I have an intense fear of doing things wrong.

9 If I make a mistake I have an impulse to rip it all up and start over again, or worse, rip it up and do nothing.

10 I go through drastic mood swings – easily depressed, fear of failure, insecurity, isolation, anxiety. Fear of punishment.

11 I have difficulty making positive active decisions.

12 I have difficulty developing a consistent routine, and following it through. Acting on plans is difficult.

13 I have a lack of self confidence.

14 Difficulty in following a conversation – memory/ attention fades in and out:

I lose track of what I've said/other people say;

Can't stick to one idea and follow it through.

15 Not quite hearing what people say – distracted by other noises in an area.

16 Learning is a difficult process for me:

If shown how, I can cope for a short period of time, until something unexpected occurs;

Afraid to repair something myself, in case I do more damage;

I need things explained very carefully, preferably with writing so that I can refer back;

Hate feeling inferior or being patronised;

I get impatient and frustrated easily. I feel limited.

17 I miss-hear words ' tuning in and out'.

18 I'm clumsy – not very aware of the space I use.

19 I forget where I put things.

20 I day dream and fantasise a lot.

21 People, in general, seem to think that I can pull myself together but I don't know how to start.

22 Difficulty in sustaining relationships – I can't seem to provide the support and depth that other people need.

BRIAN WILSON SAYS, LIKE THE YOUNG MAN OPPOSITE, HE TOO CAN FEEL A SOCIAL MISFIT

The following is an endorsement by BRIAN WILSON, who has spina bifida and hydrocephalus, of the list on the previous page.

I had been feeling 'unwell', 'not myself' over a considerable period of time with no specific symptoms of illness.

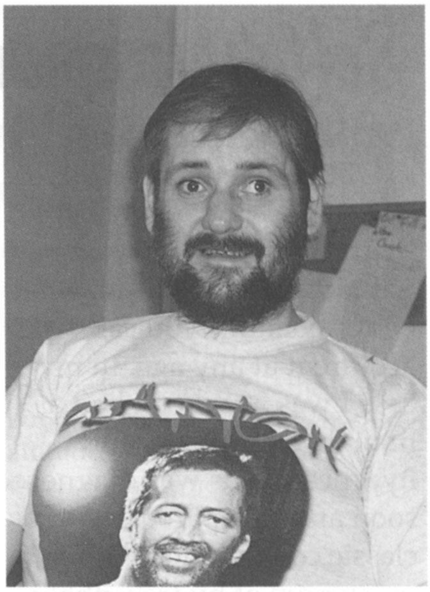
During this period I had a change of shunt mechanism and this helped for a while or, rather, spasmodically. These below par feelings, initially, influenced my responses to several of the statements in the above list and had I been really on top form may have provoked a different answer. However, I am now much better and I still am very much in agreement with the 'young man's' insight.

Some of the items mentioned by the young man can induce feelings of anger because, as will be seen on considering some of the other aspects, I feel I am misjudged which seems unjust when many of these sensations are outside my control.

It is not always easy for me to work out the correct social responses, unless I have been briefed, and occasionally I feel left out or a social misfit. This influences my response to other people's demands partly because I fear getting things wrong and partly because I anticipate not being able to meet expectations.

The initiation of action is hard and this may influence my ability to make a decision and follow a routine. It helps to be shown what to do but if something interrupts the smooth running of this or I am distracted, I feel frustrated.

I have a real fear of being asked to do something beyond my capabilities although it may be that, if I had a little support, the task could be successful. Some of this fear may stem from misinterpreting what has been said combined with a certain amount of clumsiness (not deliberate) and forgetting, pro tem, where articles, essential to the task have been put.



Sometimes the physical aspect of being in a wheelchair and not being able to look someone in the eye proves a stumbling block. It can make me feel inferior and even worse, patronised, and this produces definite feelings of anger. A similar reaction occurs when I am expected to 'pull myself together' or 'snap out of it.' The problems are not self induced.

Finally, sustaining relationships can be quite difficult as I am not sure how much support is required from me or how deep the commitment has to be.

Being able to compare my reactions and feelings with someone else, in this way, has given me encouragement and taken away some isolation. It would be interesting to know how others react to this.

New contact mum for Dandy Walker group

A NEW mum has taken over the running of the Dandy Walker Support Group. She hopes more families will come forward who are affected by this rare condition often linked with hydrocephalus.

Julie McKeown has been running a group for Liverpool since February and was asked by Contact-A-Family if she would co-ordinate the national group. She has so far got in touch with five families that have children with a Dandy Walker cyst.

Julie's youngest daughter Samantha, aged two, has a Dandy Walker cyst. Julie said: "For us, problems have included baby not eating, physical problems of getting Samantha to stand up and finding baby sitters to look after the other children while we've taken her to hospital."

◆ *Contact Julie c/o ASBAH's DLS Co-ordinator, 42 Park Road, Peterborough, PE1 2UQ.*

Self-help group for acquired hydrocephalus

I haven't seen the figures, but I bet the majority of ASBAH people with hydrocephalus were born with it. But it doesn't have to be congenital – you can acquire it at any age. In my case I was 39 when I had a brain haemorrhage, and hydrocephalus was diagnosed soon after. Apparently, it's a classic combination! Other precursors of hydrocephalus – tumours, severe infection such as meningitis and head injuries – are all conditions that, thanks to advances in technology and treatment, more and more people now survive.

So, as the years roll by, the numbers of people with acquired hydrocephalus (late-onset hydrocephalus – call it what you will) are going to increase. Add the people who develop hydrocephalus spontaneously in later life, and you have quite a group.

Acquired hydrocephalus brings it's own problems, worries and difficulties that you have to learn to live with; and who better to give help and information than others in the same position? Sadly, when I left hospital I was told I couldn't contact other patients as so few of us survive(!). I was told about ASBAH (thank goodness) but as an afterthought. Then I was sent off to cope on my own. Last March I was fed up of being told to "Put it all behind you and get on with your life" so I wrote to various national papers asking others to get in touch. Only *The Observer* printed my letter, but I got quite a response. The message from nearly everyone has been the same – the surgery and the nursing were wonderful, but the after-care is awful. Some people feel abandoned; most don't know anyone else with the condition; most have very little information. People wrote saying how much better they felt being able to write to someone.

Having found no self-help group for adults, there is only one answer – to set one up ourselves. At the moment we're a small, scattered group, so regular meetings are not appropriate (though someone has suggested a summer get-together). So the first step is to circulate a contact list, then everyone has someone at the end of a phone or someone to write to. Step two will be a newsletter, spreading information and stories around, letting people keep in touch. And there will be steps three and four as we grow!

One very important aim is to make sure that everyone leaving hospital with hydrocephalus has ASBAH's address as a matter of course. Our self-help group is certainly not in competition with ASBAH; it's more an extension of what the Association has to offer. After all, children with spina bifida and congenital hydrocephalus have ASBAH and their parents fighting for them. We grown-ups only have ASBAH, so we're in great need of their knowledge and support. And, I hope, in return we can add something to the Association.

If anyone wants to get in contact with me and join the group, do write to: ***Jane Franklin, Greenways, Ashbrittle, Wellington, Somerset, TA12 0LE.*** It's early days, but I'm sure we've got a great future!

Boost to hydrocephalus research, from page i

"My husband, who worried a lot about Charlie, would have wanted the money to go to ASBAH," said Mrs Betts, who lives in Peterborough.

"You've helped my daughter and her family understand Charlie's condition."

The donations were received by ASBAH education adviser Peter Walker, who is working closely with Charlie's school at Edmonton, North London, to make sure the five-year-old gets the support he needs and that teachers there also know more about the disability.

At the moment, Charlie attends school in the mornings only as he becomes too tired and distractible in the afternoon. He lives within a stone's throw of the Lee Valley Regional Park, the long green lung which helps north and east London breathe; dad Paul is the park's access officer.

Help us find out how the 'named person' is working in special needs education

by Mike Dodd, Education Adviser, ASBAH

IF YOUR child is being assessed for statementing or in receipt of a statement under the 1993 Education Act, do you have a 'named person'? Have you been offered a 'named person' by the local education authority? Do you know what the role of a 'named person' is?

A 'named person' is someone who can give parents advice and information about a child's educational needs.

He or she should know enough about your child's needs to give accurate information and advice about them. The person should know enough about the assessment, statementing and review processes to be able to enable you to take your full part in the process. The 'named person' should be able to support you in meetings and negotiations with the school, the local education authority and other professionals, including psychologists.

Above all, the person should be independent of the local education authority.

This year, the government has funded local education authorities to support the training of people to work as 'named persons.' This scheme is being run under a system called 'Parent Partnerships'. This has been undertaken in a variety of ways. Some LEAs have used voluntary organisations and funded the training through them, giving active support in providing venues and materials. Other LEAs have used their School Psychological Services to recruit and train people from voluntary organisations, others who are interested and some who are themselves parents of children with disabilities. Some LEAs have established their own 'Parent Partnerships,' employing people to work for them and yet to remain independent of them.

Each of these approaches has advantages and disadvantages. For example, where one voluntary organisation is used, that organisation may have an in-depth knowledge of one disability but very little knowledge of other disabilities, and yet it is obviously independent of the LEA.

Where parents and other volunteers are used, the statementing process is so legalistic and complex that they will take time to build up a knowledge and may not only be independent of the LEA but may have very negative attitudes towards it which in themselves are not helpful to the negotiations.

Where an authority employs people to serve as named persons, try as they might to be independent the LEA is their paymaster and, even if they are independent, many parents view them with a degree of suspicion, believing they are working to the LEA line. In fairness, most such people work hard to give independent advice and they do have the advantage of knowing who to contact and what is available in their own authority.

Can you help ASBAH by letting us know of any good or bad experiences which you have had with 'named persons' or, if you are involved in the training of 'named persons,' any parts which you have found particularly valuable and which you think we could use to our benefit?

•NEWS IN BRIEF •NEWS IN BRIEF •NEWS IN BRIEF •

Reserve your Appeal Rights

MIKE DODD, who wrote the article above, has discovered an alarming anomaly which can affect a parent's right of appeal to the Special Education Needs Tribunal.

In recent case work, he was told that a pupil had been assessed by the local education authority and the parents were then told the pupil did not require any special educational provision. They were told that SEN Tribunal had no power to take an appeal from them as it was the school which had asked for the assessment.

Unfortunately, ites Mike after checking with the tribunal, this is so. In order to appeal, it must be the parents or guardians who ask for the assessment.

He adds: "In view of this, parents should write to the LEA asking for a full statutory assessment of the educational needs of their children as is their right under Section 173 of the 1993 Education Act. Should the LEA refuse to make an assessment, parents then have a right of appeal to the tribunal."

Action In Churches

FORMER mobility adviser John Naudé, who left ASBAH after seven years last summer to train to be a vicar, has become Chair of Church Action on Disability, the non-denominational charitable trust.

John will be studying at Ridley Hall, Cambridge, for another year before his ordination.

New Baby Bath Seat

A new baby seat, which frees both hands to wash the baby and is suitable from birth to at least six months, is being made by Cheeky Rascals. *Obtain details by telephoning 01428-682489.* The seat costs £15.95, plus £2.50 p+p.

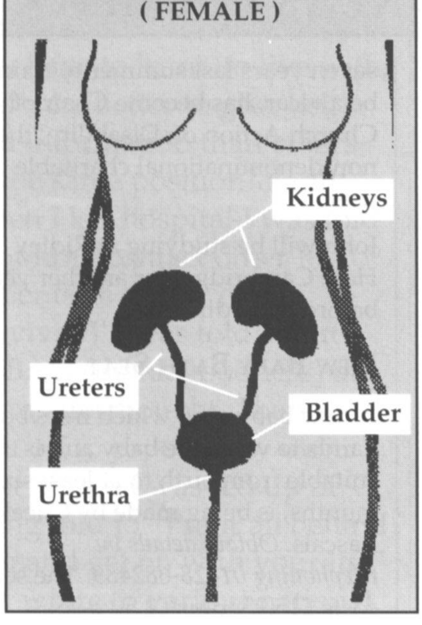
Urinary Tract Infections

URINARY tract infections are quite common in the general population. They can be mild when they only affect the bladder (cystitis) or more serious if they affect the kidneys (pyelonephritis).

When able-bodied people have cystitis, they generally need to pass urine more often than usual and they may have to hurry to the lavatory (urgency). Passing urine hurts or scalds and leaves them feeling sore and uncomfortable afterwards. The urine looks cloudy instead of clear and may smell different from usual. Because of the discomfort and inconvenience, they soon go to their doctor for advice. They are told to drink extra fluids and take the antibiotics prescribed and they get better within a day or two.

Cystitis is the commonest kind of urinary tract infection and it does not usually make the person ill. A much more serious situation arises in pyelonephritis in which the infection affects the kidneys causing a high temperature, tummy ache, backache, and sickness. Fortunately pyelonephritis rarely occurs in people who can empty their bladders normally and so have good drainage from the kidneys.

URINARY SYSTEMS (FEMALE)



But, in people with spina bifida who cannot empty their bladders well, it is quite a different story. . .

Why urinary tract infections are a problem in people with spina bifida

People with spina bifida often lack feeling and control of their bladder and bowel in the same way as they may lack feeling and control of their feet and legs. This is because the nerves in the spine connecting the brain to the bladder (or bowel or legs) have been interrupted, or disconnected, by the spina bifida. The result is that they cannot usually feel when their bladder is full, nor can they empty it properly. The bladder still contains urine (the residual urine) after they have tried to empty it. The stagnant pool or residual urine left in the bladder gets smelly and easily becomes infected and sometimes develops stones (urinary calculi) as well. Infections may spread to the kidneys causing pyelonephritis and kidney damage making the person ill. This happens because the bladder does not empty out the infected urine. It may also happen in children with reflux in whom the infected urine travels up towards the kidneys.

Many people with spina bifida do not know when they have a urinary infection. Because they lack feeling they do not suffer from the scalding pain which other people feel when they get cystitis, nor do they know their bladder is not emptying properly. Treating someone with spina bifida for a urinary infection with antibiotics and extra fluids works more slowly if the bladder is not emptying. The best way to prevent urinary infections damaging the kidneys is to be sure that the bladder empties regularly and completely. One way of doing this is by clean intermittent catheterisation.

How clean intermittent catheterisation improves urinary infections

Intermittent catheterisation means inserting a narrow tube (catheter) along the usual passage (urethra) into the bladder. The urine flows out of the bladder through the catheter into the lavatory, or into a container, until the bladder is completely empty and then the catheter is removed. By doing this several times a day the person is kept much drier, or even completely dry. Provided the bladder is not allowed to remain full, urinary infections are most unlikely to spread to the kidneys. People should catheterise at least four times a day but those who have a smaller bladder or who drink a lot may need to catheterise six or even eight times. With practice catheterisation becomes quite easy and may take less than five minutes.

Before starting intermittent catheterisation some people may have needed several courses of antibiotics for their urinary infections. But, after they start using catheterisation, their urine becomes quite clear once catheterisation has removed the stagnant pool of residual urine. They cease to get attacks of pyelonephritis even though, when their urine samples are examined, they often show a mild infection. These mild infections are better left untreated: they do not spread to the kidneys so long as the bladder is not allowed to remain full. Twenty-five years of experience of intermittent catheterisation has shown that it actually prevents damage to the kidneys as well as improving those already damaged.

How to prevent urinary infections

Fluids

It is always important to drink fluids to "flush out the kidneys," but this is less effective if the bladder is not emptying properly. It does however work very well in those who use intermittent catheterisation and do it frequently enough.

Bowels

People with spina bifida are often constipated and pressure from an overfull bowel may add to the difficulty of emptying the bladder. They may also have poor control over their bowel in the same way as they have over the bladder. Since most urinary infections are caused by bacteria which normally live in the bowel, it is important to wash this part of the body carefully. Girls should be taught always to wipe from front to back and not from back to front.

Medicines

Antibiotics and other medicines are sometimes given in small doses for months or years to prevent urinary infections. They are mainly used for children who have reflux or for anyone with damaged kidneys to protect them from further harm. In spite of this, urinary infections may still break through and need a course of a different treatment.

Other remedies

Many remedies have been used over the years to prevent or relieve urinary infections and two of these are worth mentioning: Vitamin C (ascorbic acid) and cranberry juice. Vitamin C acts by making the urine acid and this discourages some of the bacteria which cause urinary infections. Cranberry juice helps to clear infections and debris after operations on the bladder. If enough is given, cranberry juice may also help to prevent urinary infections.

Key points:

1 **In people with spina bifida urinary tract infections are mainly due to the bladder not emptying properly.**

2 **Poor drainage from the bladder encourages infections to spread to the kidneys where they may cause damage.**

3 **Good drainage is as important as fluid intake.**

4 **Intermittent catheterisation ensures good drainage and protects the kidneys. It also makes incontinent people much drier.**

If you want to know more about intermittent catheterisation and would like a free copy of *The User's guide to Intermittent Catheterisation* (see above) send a large self-addressed envelope with a 29p stamp to: *Disabled Living Services, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.*

THE USER'S GUIDE TO INTERMITTENT CATHETERISATION

by Gillian Hunt Robert Whitaker Pippa Oakeshott

Published by Family Doctor Publications in association with the British Medical Association. This is the first authoritative book on intermittent catherisation. It is written by a physician, a urologist and a general pratictioner. Drawing on 20 years practical experience, it describes the method and discusses the difficulties and how to overcome them.

"Well illustrated ... clear and informative .... excellent"

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"A valuable contribution to clinical practice ... should be available wherever doctor's and nurses have patients requiring intermittent catherisation"

British Journal of Urology

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Which model should we use?
A SOCIAL WORK VIEW OF DISABILITY

Vicki Boll, a Child Health and Disability Social Work Team Manager, looks at attitudes to disability and their effects on families and the professionals who work with them.

SUBTLY, over the last 2000 years, disability has been associated with madness, badness or sadness. A segment of the adult disabled population has expressed that societal sadness about disability has led to two connected models of disability. One is the tragedy model: it's tragic to be disabled. This in turn leads to the 'garage repair' model: repair the disability so that it is more akin to an able-bodied model.

Successful mobility is thus interpreted as the body being upright and the legs working. Communication is seen as being vocally expressive or at least understanding vocal expression – remember the great debate about British sign language. The greatest humanitarian of all, Christ, took cripples and made them walk.

With regard to madness and badness, the more repugnant or unattractive figures of history are often ascribed as having a disabling condition. There is no factual evidence that Richard III was a hunch back, but his portraits depict him as such. George II and George III are said to have suffered from epilepsy as an explanation of their irrationality. Work can be found that states that Hitler was a victim of an undetected syndrome. Royal historians pay scant regard to Prince John, the son of George V, who was born with a disability; those who do inform us that he did not live in the main royal household and was kept hidden from the public eye.

Another linked and prevalent societal attitude is that disability serves to convince the able-bodied population of their own good fortune. How often do you hear the phrase in relationship to disability: "It makes you realise how lucky you are". Disability can give us reason to be temporarily generous or benevolent, eg contributing to a flag collection or organising a one-off event for children with a disability. Consider that detected disability in the foetus is grounds for abortion or that the birth or diagnosis of a child with a disability is cited in grief literature as a loss and therefore a reason to offer bereavement counselling.

The summation of these influences and facts can only indicate that disability is an unwanted status that is further endorsed by other twentieth century influences – particularly the promotion of physical and intellectual excellence and the notion of economic worth. How many sectors of our society have been down graded because they do not financially contribute to the well being of the state, such as the elderly, the unemployed, lone parents and teenagers.

We need to examine the word integration. To integrate one has to be set apart. One could assume a situation of apartheid and therefore of exclusion. It is a word which arguably adds to the down grading of disability. It implies perhaps that a person with a disability has to break into the world of the able-bodied to achieve the quality and parity rather than enjoy an existence and an acceptance in his or her own right. In the play *Children of the Lesser God*, one of the central characters asks: "Why do the deaf have to join the world of the hearing? Why can't the hearing join the world of the deaf?"

This is the societal culture in which parents are asked to raise a child with disability. It leads to the question: "Are the negative thoughts and feelings experienced by many families at the point of diagnosis a reflection of the personal meaning of the condition for the child or more a reflection of the socio-economic climate in which the child will grow up?"

Objectivity v Subjectivity

The next perspective to consider when understanding issues that concern parents is that of objectivity and subjectivity. Blackard and Bursch in 1982 found that there was a distinct difference between professional and parental perceptions of coping. As professionals we are trained to be objective – to see a presenting set of facts and circumstances and to offer a resolution accordingly. What hopefully is improving is our ability to add the vital extra dimension to those facts and circumstances; their meaning to each individual family and furthermore their meaning to each member of that individual family.

Most carers are women and there is a proven gender difference in how men and women perceive their personal well being and that of the family. A woman judges her own well being by her perceived state of well being of other important family members – crudely translating as I'm all right if my husband, children and other important family members are all right. The child with a disability may be physically well and academically achieving to his and her potential but, if the female carer feels that the child is unhappy, then her own sense of well being will be negatively affected. Equally, if the needs of the child with a disability (who may objectively be flourishing) are seen to have a negative effect on other family members, then the female carer may well view the disability in a negative manner.

Another self-concept influence which affects individual perception and therefore has a subjective impact on the carer, is the importance of the role of the good parent. As a teenager develops and begins to assemble a realistic forecast of adulthood, for some girls the primary status is that of a good wife and parent. If a child has a disability then it is evidenced that the self-concept is damaged. Good mothers have perfect children. Again the question is posed – Is the mother reaching to an innate female biological sense, or to the external societal reckoning of disability?

A third major influence that subjectively influences perception and coping skills is the presence and range of other life stresses such as death, divorce, legal difficulties, financial difficulties, etc. Add to these others such as the carer's learned perception of disability from his or her childhood; his or her own parenting experience; his or her acquired levels of strength or vulnerability; and family values and it becomes easy to understand that each carer or family member will have their own subjective stance on disability. This view may not be replicated by the objective stance. Lazarus argued in 1990 that, where there is a discrepancy between the professional and parental perceptions of coping, it is the perception of the person coping that is more important. It is their perception of the task of coping rather than the professional assessment which should provide the starting point for intervention.

Power and control

In working with families I think we also have to consider issues of power and control. Client partnership and parent partnership are maxims to which hopefully we professionals all aspire. But who squares the meaning and reality of such partnerships? In a true sense, partnership is indicated when a balance of power and control exists. It is not a fact that we professionals have the final say.

If one considers health appointments, they are offered mainly to suit the 9-5 day of the working professional. If a child requires for instance orthopaedics, urology, neurology, physiotherapy, speech therapy appointments on a regular basis, the appointments can be scattered across time and place with little regard to the needs and convenience of the family.

The 1981 Education Act offered parents of children with special needs the opportunity, via statementing, to make a contribution to the decision about which school the child should attend. The final decision, however, rested with the Education Authority. Schools can exclude children for challenging behaviour, even though linked to their learning disability and yet this will inevitably place the family under stress.

The Children Act empowered Social Services under Part III section 17 to place the child with a substantial and permanent disability in the forefront of statutory service provision. Schedule 2 listed specific provisions that could be made available to the child and their family. But budget considerations will ultimately control services rather than the needs of the family.

Too often the child is seen as the object of service, a social work client, a health patient, a school child, rather than the subject of service. As an object of service you take what you are given. Parents take it on behalf of their child. One of the most depressing statements still made by parents is they do not wish to upset professional X, Y or Z in case it means that a service will be reduced or withdrawn. Objectively we know that this will not be the case but the sentiment expresses the perception that professionals are most powerful and have more control.

Reluctance

The final issue that I would like to present for consideration, when working with families, is centred around reluctance – reluctance to look forward and reluctance to examine feelings engendered by having a child with a disability. When working with carers, I have always found it difficult to distinguish between pragmatism and acceptance. The pragmatic view-point may say that my child has a disability; to ponder why that is and what in this family may reveal levels of bitterness and/or guilt that could hamper the process of caring. It would not change the outcome and therefore should be avoided. The accepting view-point may say my child has a disability and that is simply how it is. We need to be careful about automatically offering counselling. Whilst very therapeutic for some carers, for others it is too painful or too late and for others it is unnecessary. Again, as professionals we need to constantly remind ourselves that each carer's attitude is unique and should be trusted as such rather than assuming a blanket approach

The reluctance of carers to look too far into the future is an issue to which we need to be very sensitive. For children with a

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physical disability or a chronic illness, carers fear there may not be an adult future for their child and sadly for some that is reality. We also need to remember that the death of a child with a certain condition impacts badly on carers of children with the same condition – for many it brings to the forefront the suppressed but constant fear that their child will die prematurely.

For children with a stable condition or learning difficulty, the major fear of the carer is not so much based on their child's future physical care or future practical matters like housing or money, it is centred more around the child's future emotional well being. They fear that their child will be lonely and vulnerable. Carers know the strain of caring. They know the physical strain of toileting, bathing, dressing etc. Not for them the protection of EEC regulations. For carers coping with physical tiredness, there is emotional exhaustion. What carers are able to do is separate the negativity of the task of caring from the very positive regard in which they hold their child. What many may not trust is that future carers, who do not have the same love and affection for the child, will not be able to prevent the negative aspects of caring from impinging on their physical or emotional handling of the adult child.

Key to Success

I am sure that I have not done justice to all the issues that professionals need to be aware of when working with families. What I hope I have done, is argued that families are products of society for which we are all responsible, irrespective of profession, and yet at the same time are unique and therefore deserving of an individual package of support, tailored to meet their needs. We as professionals make a contribution to that package of care but when it comes to the total task of caring as a valued colleague once said,"We are the pimple on the elephant's back. We are not the elephant."

As early as 1970, studies concentrating on the needs of families where there was a child with a disability were reporting that what would benefit the families was a key figure who could help co-ordinate all the services that the child required. But more important than being organisationally and administratively skilled, was the attitude of the co-ordinator. The key figure had to be someone who the family felt understood those needs and accepted their validity.

In all subsequent studies, families have constantly said that the profession or discipline of the key figure is not important.

What is important is the relationship that exists between themselves and the key figure – a relationship that is based on core conditions of trust, empathy and mutual respect. Some studies have indicated other necessary attributes for a key person. It is important to have an appropriate sense of pacing and timing, to understand that people may have to tell the same story many times in order to enable them to make internal sense of it and so begin to take both internal and external control of the situation, to further understand that carers need time to accept a proposed resolution rather than one imposed upon them. Many carers already feel inadequate or guilty. These feelings do not need to be compounded by the over competent fix-it approach. Yet carers do not need professional expertise. Studies examining the rather *laissez faire* professional approach popular in the 1980s – that is, you know more about this than me – have shown that it is not always a reassuring approach. Whilst wanting professionals to acknowledge that they have expertise, carers also want the confident and evidenced expertise of the professional.

Most carers are good people doing a difficult job in not always easy conditions. A good care co-ordinator with professional collegial co-operation can go a long way towards ameliorating those conditions and so make the difficult task of caring easier.

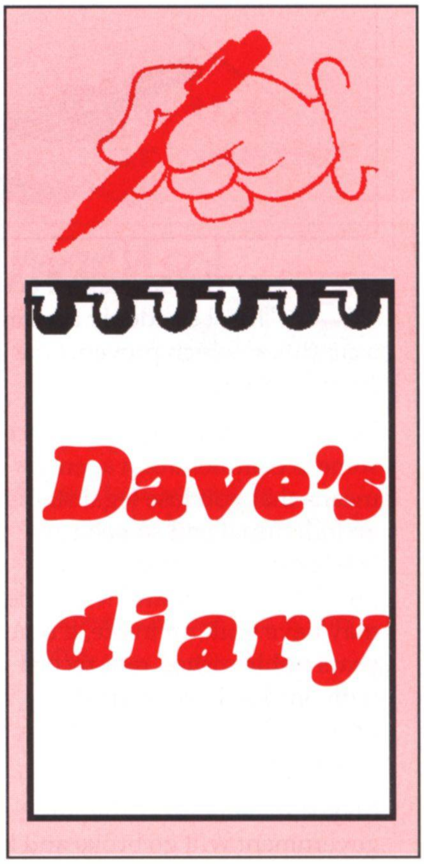
VICKI BOLL manages a divisional Child Health & Disability Social Work Team for a Social Services Department, which includes social workers working with children with disabilities and chronic illness and their families, social workers in the Child & Family Service, a Development Officer, a Senior Occupational Therapist and sessional workers. This article is based on a talk she gave in Wrexham earlier this year to care co-ordinators for children with disabilities.

Hospital Charter

HOSPITALS should be among the friendliest places for disabled people says a group which has created a charter for disabled people using hospitals.

In its newsletter – *Access & Awareness* – the working party of national disability organisations and the Royal College of Physicians of London aims to bring the Charter to the attention of hospital managers and senior staff, as well as encouraging interested groups and individuals to make contact and give details of relevant experiences. Contact: ***Jeanette Whalley, Research Unit, Royal College of Physicians, Regent's Park, London, NW1 4LE.***

A Charter for Disabled People using Hospitals (in booklet or tape format) is available from the publications dept (same address as above) price £5.00.



I HAD just crawled out of my 'pit' when I picked up the morning paper *The Independent*. I always read the paper first thing in the morning, before I do anything else. As I don't drink coffee or tea, reading the paper gives me time for my brain to wake and catch up with my body, while I pretend I'm actually doing something useful. On that day I must have been less 'with it' than usual as I was half-way through the paper before I discovered I'd been reading the previous day's issue. I was just about to chuck it away when I spotted something interesting in the 'health' section.

The Independent reported that eating foods naturally rich in folic acid is unlikely to prevent spina bifida and only a supplement or food fortified with folic acid was likely to make any difference. Well, I knew that it was better to take supplements for increased protection, but I was under the impression that eating natural foods containing folic acid did some good. I had been heartily advising female friends to keep scoffing those broccoli and brown bread sandwiches, as well as taking supplements. Now I find this idea was as much use as a proverbial chocolate tea-pot!

I was getting all confused and wound up, reading that article. The new information seemed at odds with what I'd heard about folic acid. I thought it was time to dust off my trusty base-ball bat and 'persuade' *The Independent* to get their facts right! Then I spotted the research had come from *The Lancet*, a medical journal which I wouldn't usually associate with sensationalism and inaccuracy. Not that I read such lofty publications – too many long words and not enough pictures for my tastes!

I have to say that I've always had doubts about folic acid or its absence being the cause of spina bifida. The idea that either I or my mum were somehow missing something in our diet for me to be born with spina bifida and hyrocephalus, came as a surprise. Those who know me and try to squeeze by me in the street would have a hard time believing anything could be missing from my diet! My gran is renowned for whipping up a five-course meal on the off-chance visitors might be hungry. She would be most upset at the family being described as effectively 'malnourished.' The chance that an important acid could have slipped her gastronomic 'net' seems slim indeed. Unlike me.

Even though everyone has focused on 'folic acid' as the big 'bogey man,' I'd suggest keeping an eye on other possible causes. It surely can't be a coincidence, my having SBH and the fact that mum was brought up in a heavily polluted areas of Manchester, where I was born.

In the same week as *The Independent* article, *New Scientist* (one of the few science magazines I can actually read) said that according to a recent report, "American troops exposed to the defoliant 'Agent Orange' may be at greater risk .... of having children with spina bifida." The report goes on to say there is "some evidence of a link" between exposure to the herbicide and disorders including spina bifida. I wonder what else will be discovered about such sprays. In the meantime, I shall be keeping a close eye on the morning papers.

PS: Car parking in hospitals

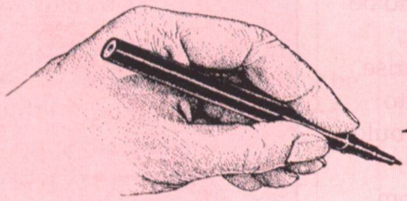
My mum points out that, when a relative is about to undergo serious surgery, the last thing on your mind is faffing about with meters and tickets. Metered parking in units dealing with long-stay patients and/or serious surgery, is one of the things which highlight a hospital's lack of care for visitors.

David Fulford-Brown

Hi-tech help for disabled jobseekers

EMPLOYERS are now able to target recruitment advertising directly at disabled people through the Internet – on a new service called *Jobsite*. Disability Access, the UK web site for disabled people, are the people behind the project. To view the site, key into: <http://www.healthworks.co.uk/da.html>.

The RNIB has launched a phone line for blind and partially-sighted jobseekers.Their *Jobsline* will help solve a basic problem facing visually-impaired jobseekers – obtaining adverts in readable formats. A pilot project has started by recording details of jobs and courses in *Physiotherapy Frontline*, the magazine of the Chartered Society of Physiotherapists. Physios can call 01829-732408 and an operator will scan adverts for them, identifying ones of interest and posting details in preferred format, ie braille, tape, large print, etc.



Letters

AFTER 56 years of active life, I suddenly acquired a condition which prevents me from working.

Living on a disability allowance to some accommodation agencies means that you lose legal status as an individual and so need an "ordinary" person to act as guarantor – no matter what one may have built up in life, a nine-years unblemished rent record with one landlord, owned property in one's own right, or whatever.

Maybe there is a fear that the government will go broke and be unable to meet the otherwise assured benefit payments.

Presumably those who implement such policies have some clairvoyance as to know for certain they will be never be so afflicted. The result for those living in the real, uncertain world is that they can so easily be excluded from decent accommodation.

R N White, Southampton

Editor's note: Mr White attended ASBAH's '30 Years and Counting!' conference, which celebrated the empowerment of disabled people. The example of discrimination he cites makes it clear that he feels the celebration was premature.

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

I AM the mother of a baby that was born with anencephaly.

Anencephaly is a maldevelopment of the brain. It occurs in the first eight weeks of pregnancy and is a failure in the neural tube which develops into the spinal cord and the brain.

For some time I have felt that there is a need for a support group for families that have had pregnancies affected by anencephaly.

The aim of the group is to provide support and information to anyone that has had a pregnancy affected by anencephaly or anyone wishing to know more about it.

If you would like to know more about the group or if you want to talk to someone that has lost a baby with anencephaly and understands how you are feeling and knows what you are going through, please contact me.

Debra Lindesay, 29 Hawkwood Close, Malvern, Worcestershire, WR14 1QU. Tel: 01684-573974 between 10am and 6pm. All calls will be treated as confidential.

DATES FOR YOUR DIARY

19 - 22 AUGUST

"Summer Experience" residential activity course for 12 -16 year olds, organised by ASBAH START service, £80 (non-returnable deposit of £20), Nell Bank, near Ilkley, West Yorkshire. *Rose Hinchliffe, tel 01943 - 609468.*

2 - 8 SEPTEMBER

Third annual National Spina Bifida Week in association with Larkhall Natural Health Group. *Tony Britton, ASBAH, tel 01733-555988.*

21 SEPTEMBER

ASBAH AGM, Peterborough.

12 OCTOBER

Joint study day on sexuality in conjunction with Leeds Young Adult Team and Bradford 16 - 30 Group Project, organised by ASBAH's START service, St Mary's Hospital, Greenhill Road, Leeds. *Rose, tel 01943-609468.*

21 - 23 OCTOBER

"Keeping Fit and Looking Great", ASBAH South East region sports and exercise event for young people aged 12 to 16, Guttman Sports Leisure Centre, Stoke Mandeville, Buckinghamshire. Families of participants will be asked to pay £25 towards the cost of this residential event. Guest appearances by Ann Wild, captain of the British women's wheelchair basketball team and 'The Rooster' (famous fitness expert Nevill Reid). Denise, ASBAH South East, tel 0181-449 0475.

16 NOVEMBER

ASBAH study day, '30 Years On - Making the Most of Life', Park Dean School,. Oldham, Greater Manchester. Speakers include consultant neurosurgeon Miss Carys Bannister FRCS, consultant paediatric neurosurgeon Michael Vloeberghs and discussion by participants on living with disability. Also welfare rights advice offered privately by an ASBAH fieldworker. *Details: Jean Black, ASBAH Fieldworker, Newbridge Resource Centre, Newbridge Lane, Stockport SK1 2NY. Tel: 0161-476 0059.*

16 NOVEMBER

Surrey ASBAH study day on education, Banstead Mobility Centre, Carshalton. Speakers: Anna Wright, head of ed psych, Surrey; Kate Evans, asst co-ord, Partnership with Parents (Kent & Surrey); from ASBAH – Peter Walker and Leonie Holgate. *Details: Alan and Margaret Twyford. tel 0181-390 0853.*

HOLIDAY ACCOMMODATION

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

WEYMOUTH BAY

Fully-equipped, wheelchair accessible caravan – sleeps five; on Haven Holiday Park, full use of all facilities – heated indoor & outdoor pools, bars, children's club & full entertainment programme. Three miles from Weymouth.

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

ISLE OF WIGHT ASBAH

Fully-equipped 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: 01983-564604.

SELSEY, WEST SUSSEX (SASBAH)

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Details from Mrs B Nunn, tel: 01903-763473.

NEW FOREST

Fully equipped caravan designed for wheelchair access throughout. Sleeps 5-6. Club house, indoor swimming pool, shop, sited at Bashley Park, New Milton, Hants.

Contact Joan Searle, tel: 01705-376816.

mar y sol

Mar Y Sol – Tenerife

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

FOR SALE

ELECTRIC wheelchair (Leigh-on-Sea, Essex) – Sunrise Medical Powertec F16 with leg extensions. Bought May 1994, sadly never used. Condition as new. Batteries recharged regularly. £1,250. Tel: 01702-558750.

LINK Rates

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Small adverts for the next issue of *LINK* (October) should be submitted by Thursday, 29 August. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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