

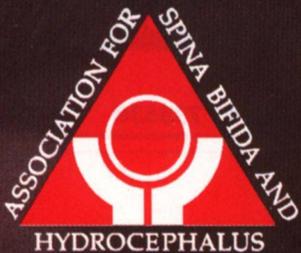
ANNIVERSARY
30TH

Link

The magazine for people with
Spina Bifida and/or Hydrocephalus

February/March 1996

Issue No 162 Price 80p





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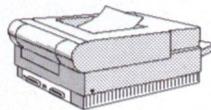
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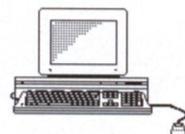
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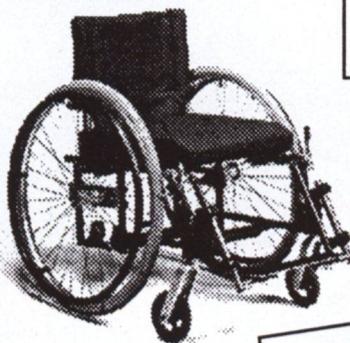
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ANOTHER good way to see in ASBAH's 30th anniversary year – fundraiser Donna Treanor with the £20,000 cheque we received from the organisers of pigeon racing's 'Show of the Year' at Blackpool in mid-January.

The show has contributed many hundreds of thousands of pounds to all sorts of charities since it was inaugurated in 1973. Organiser Major Edward Camilleri said the proud total now stood at over £829,000.

ASBAH has been a major beneficiary for many years, and we are always at Blackpool for the big event.

30th anniversary plans



ASBAH is 30 years old this year and to mark the event we shall be holding a special conference in

central London on Thursday 6 June.

The main theme will concern some things which we do rather well – involving disabled people in the running of their own associations, and empowering them to take on the challenges and rewards of independence.

The conference will also be showing a fascinating and revealing presentation of disability by the media, offering some concrete ideas on how things can be improved.

Among those who have accepted invitations to speak are Minister for Disabled People Alistair Burt MP, Sue MacGregor, presenter of BBC Radio's *Today* programme, our own vice-president Claire Rayner OBE, wheelchair marathon and Paralympic champion Tanni Grey, BBC disability correspondent Peter White and Richard Gutch, chief executive of Arthritis Care

and chair of ACENVO (Association of Chief Executives of National Voluntary Organisations).

We have invited our patron, HRH The Duchess of Gloucester, and hope she will be able to join us on the day.

To register your interest in attending, please contact: Tony Britton, ASBAH, tel: 01733-555988.

★ Top TV presenter Anthea Turner will front a fundraising appeal for ASBAH during our anniversary. She also appears on the cover of a new brochure, and on the front of this issue of *Link*.

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ASBAH is a registered charity

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Cover: Anthea Turner, of National Lottery TV fame, graces the front of our 30th Anniversary Brochure.

First class support from East Coast



Britain's Fastest Railway

A FRIENDLY chat between neighbours has led to on-going fundraising support for ASBAH by British Rail workers.

Our senior services manager, Teresa Cole, told a BR manager, who lived nearby, about the work ASBAH does and how hard it can be raising money.

He then went away and agreed with a group of InterCity East



Teresa Cole (left) and John Williams (right) from ASBAH are presented with a cheque from Peter Tasker on behalf of InterCity East Coast employees

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Coast employees to adopt us as one of two charities to benefit from a marathon go-kart afternoon, supported by family and friends, with Teresa and ASBAH senior appeals manager, John Williams, in attendance.

The result, so far, has been a cheque for £360, but staff will be donating more money to ASBAH in 1996 from another go-karting event and a raft race. The ladies have decided to form their own team for the next go-kart marathon.

Teresa and John attended a special cheque presentation – with free first class travel thrown in – at Bounds Green in North London. They were given a grand tour of the major repair depot for the East of England and saw the record-breaking loco, which last June beat all speed records.

The cheque was presented by Teresa's neighbour, Peter Tasker, who is production manager at InterCity East Coast Ltd, Bounds Green.

John Williams said: "This is a wonderful fundraising opportunity for ASBAH this year. We are delighted to have been chosen as one of the lucky recipients of money raised through East Coast's staff's efforts and enthusiasm."

The other charity with which ASBAH is to share funds is the Sickle Cell Thalassaemia Society.

Local association news on pages 21-22

Obituary: LAVINIA, DUCHESS OF NORFOLK ASBAH Vice-President and President of Sussex ASBAH

LAVINIA, Duchess of Norfolk, aged 79 years, was very much a friend to SASBAH. Officially she was a vice-president of ASBAH and president of SASBAH, but she was very much more than this.

After much hunting through the old minute books I have found that she very graciously agreed to become president of SASBAH back in 1973 – this was announced at the AGM in March of that year, though she was already involved and had agreed to front an appeal letter two years previously.

My own first memories of her were at our annual SASBAH market, held in the servants hall at Arundel Castle.

She would always come and visit all the stalls, chatting to members, buying items and very generously providing the coffee and the staff to serve it.

Although she was very busy, involved with more than 150 charities at one time, she dealt with them all personally. The phone would ring, and the voice at the other end would say 'Duchess

By Margaret White County Organiser for Sussex ASBAH

here'. Notes and letters were handwritten, Christmas cards arrived each year, again handwritten, and invitations to her cocktail parties at Arundel Park in the summer. SASBAH members, as well as committee, would attend and she made sure everyone felt really welcome.

She again led an appeal for SASBAH when we were setting up 5 Grand Avenue, and it was her suggestion that Princess Diana officially open the house 10 years ago. Each Christmas she came to the house to see everyone, bringing gifts. It was when she was on her way to this annual visit that she had the car crash two or three years ago, which set off a train of ill health.

I know that she always read *Link* and SASBAH's monthly newsletter and took a very real interest in all our doings.

Her last visit to us was the



The Duchess of Norfolk

presentation of our Lord's Taverners bus, presided over by Leslie Crowther, whose jokes bound together the Duchess, our new friends from CNA insurance, SASBAH members and staff.

Although we had not seen her for a year or so, due to ill health, she was very much in our thoughts here in Sussex and we shall really miss her.

She didn't want to be just a figurehead, she wanted to be of real use to the charities with which she was involved – and she did just that.

Officers & Staff

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HRH The Duchess of Gloucester, GCVO

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Joan Pheasant, NNC

Disabled Living Services Co-ordinator:
Rosemary Batchelor SRN FETC

Publicity Manager:
Tony Britton

Research and Information Officer:
Gill Winfield Cert Ed

ASBAH

● STAFF MOVES



● LORNA Johnston is our new part-time education adviser for Northern Ireland.

Her appointment follows the departure of Karen Sharma who had been in the post two and a half years.

Lorna, aged 48, will be based at home in the middle of the Ards Peninsula, working 17 and a half hours a week for the region. Her background is special needs education which should equip her well for the job.

She started teaching in 1969 at a mainstream comprehensive school before taking a post graduate course in education at Bristol University.

From 1972, she was a remedial teacher until in 1990 she was seconded to Belfast Education Library Board working for a special project to raise literacy and numerary skills in deprived areas of the city. Lorna then transferred to the N E Board doing similar work at two secondary and three primary schools.

She then taught for a year at a special school, followed by a year's research on transition and continuity of education at Queen's University, Belfast.

● INTERVIEWS for a new fieldworker for North West London were due to take place on 8 February.

The post is being re-filled by South East Region following the departure of David Austin.



● A NEW part-time post of disabled living adviser (DLA) – funded after money was released

from continence adviser Mary White going part-time – has been filled.

Paula Thompson has a nursing background and worked for two years with children and young adults with spina bifida and hydrocephalus in a genitourological ward at Newcastle's Royal Victoria Infirmary.

She is combining efforts with continence adviser Julie Llewelyn, who already splits her full-time job between Eastern Region and national, so giving full-time national cover.

Paula, aged 32, trained as an enrolled nurse at Peterborough District Hospital in 1985 before moving to Newcastle.

From Newcastle she went to Ely in Cambridgeshire where she

was employed by the RAF as a civil servant, working with sick children at the Princess of Wales Hospital. When this ward closed, she continued at the base hospital for a further 18 months in orthopaedics.

Paula said: "I was with the RAF during the Gulf War so it was very exciting."

From this, she went to a nursing home in Bourne, Lincolnshire, where she worked for three and a half years – taking six months off to have a baby.

She now lives in Wittering near Stamford, Lincolnshire, with her Post Office manager husband and their seven-month-old baby.

She was attracted to the ASBAH job because of her previous experience of spina bifida and hydrocephalus and because the job was 'totally different to what she had done before.'

Paula is based at ASBAH's national centre in Peterborough and works two and a half days a week.

● THE SEARCH started in January for new premises for ASBAH's Northern Region and START after a potential buyer for Five Oaks came forward.

Northern Region co-ordinator and START manager, Joan Pheasant, began to look for new premises in the Leeds, Bradford and Ilkley area.

Joan said: "Any new premises will need to be accessible to wheelchairs, with some car parking."

ASBAH's former training and residential centre has been on the market since November 1994.

The potential buyer was interested in acquiring the 1930s building and some of the grounds to convert into a private family residence.

The Denton View and Wharfedale flats, together with a separate activity centre, will

continue to be run by a three-way management agreement between Bradford Social Services, Sanctuary Housing Association and a voluntary organisation (which at present is ASBAH).

New car parking arrangements and access will have to be made available before the sale of Five Oaks can go ahead.

The flats will continue to be staffed by housing support worker Mark Best and two part-time assistants, Nuala Bolser and Michaela Dennis.

Joan said: "Their role is to offer advice and support and deal with emergencies."

ASBAH is responsible for the day-to-day running of Denton View and Wharfedale while Bradford Social Services fills the tenant vacancies, which are open to people with any type of physical disability.

Name change for clothing service

THE NATIONAL Association of Clothing Workshops (NACW), which is supported by ASBAH and featured in the August/September issue of *Link*, has changed its name and the address of its headquarters.

Now known as 'awear', the organisation aims to ensure that people with disabilities have direct and full access to fashionable, affordable clothes of their choice which fit well and are appropriate to the lives they lead.

The new headquarters of 'awear' are at: **Redbank House, 4 St Chad's Street, Cheetham, Manchester, M8 8QA. Tel/fax: 0161-839 7399.**

The group's research and development officer, Lynn Purcell, is now based at this office.

Mrs Purcell commented: "At awear we recognise that disabled people experience discrimination

Congratulations Claire!

ONE of ASBAH's vice-presidents, Claire Rayner, was recognised in Her Majesty the Queen's New Year's Honours List with an OBE.

Claire, writer and broadcaster who has been involved with ASBAH from our early days, received the award for her services to women's issues and health issues.

Congratulations from all at ASBAH for receiving this great honour. Claire has been a vice-president of ASBAH since 1985.



Claire Rayner OBE

when trying to find clothes that they like."

A list is available of voluntary sector organisations providing comprehensive clothing services and customised training on all issues to do with clothing for disabled people and those with special clothing needs.

See August/September issue of *Link* for details of where to find your nearest clothing service.

Suffolk's award

AN AWARD for integrating children with learning difficulties into mainstream schools has gone to Suffolk County Council. It was presented by the European action programme, HELIOS II, which promotes opportunities for, and full integration of, disabled people across the European Union. The integration project was piloted in Lowestoft.

National Spina Bifida Week this year will take place from 2 - 8 September (inclusive)

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.

Your help is needed to find out about hospital car park charges

ASBAH wants to hear from *Link* readers about whether you are charged for using hospital car parks.

Our Services Committee has asked that we publish the following questionnaire for you to complete so that we can find out the extent of charging for car parking at NHS Trust/general hospitals.

We want as many people as possible to fill out the survey form

below – it may be photocopied if you prefer – so that a full picture as possible may be obtained.

If the response shows widespread concerns, ASBAH will approach the NHS Executive to complain.

Please send in your completed questionnaires as soon as possible to: Tony Britton, Publicity Manager, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.

Boots catalogue

BOOTS has launched an Argos-style catalogue of daily living aids in conjunction with Coopers Health Care. A total of 450 products, small items to wheelchairs, will be available through mail order. Catalogues, costing £1 each, and order forms will be on display in 350 stores. Pharmacists will be able to give advice.

Readers are advised to check first whether their social services department or hospital can help from their stocks of loaned equipment.

ASBAH Hospital Car Parking Survey

1. Full name(s) and address(es) of the NHS hospital(s) you most frequently visit.

.....
.....
.....
.....
.....
.....

2. How often to you visit hospital?

3. Are you charged for car parking?

4. If you are charged, how much does it cost?

5. When (approximately) were these charges introduced?

6. What do you think about the car parking charges?

.....
.....
.....

7. Your name, address and telephone number

.....
.....
.....
.....

ASBAH'S MAIN INTERNET WEB SITE IS AT <<http://www.demon.co.uk/citygate>>

A man for all sports

BRITAIN'S disabled sportsmen and women have at last found a media man to fight their corner – none other than Marshall Thomas, a former member of *Your Voice in ASBAH*.

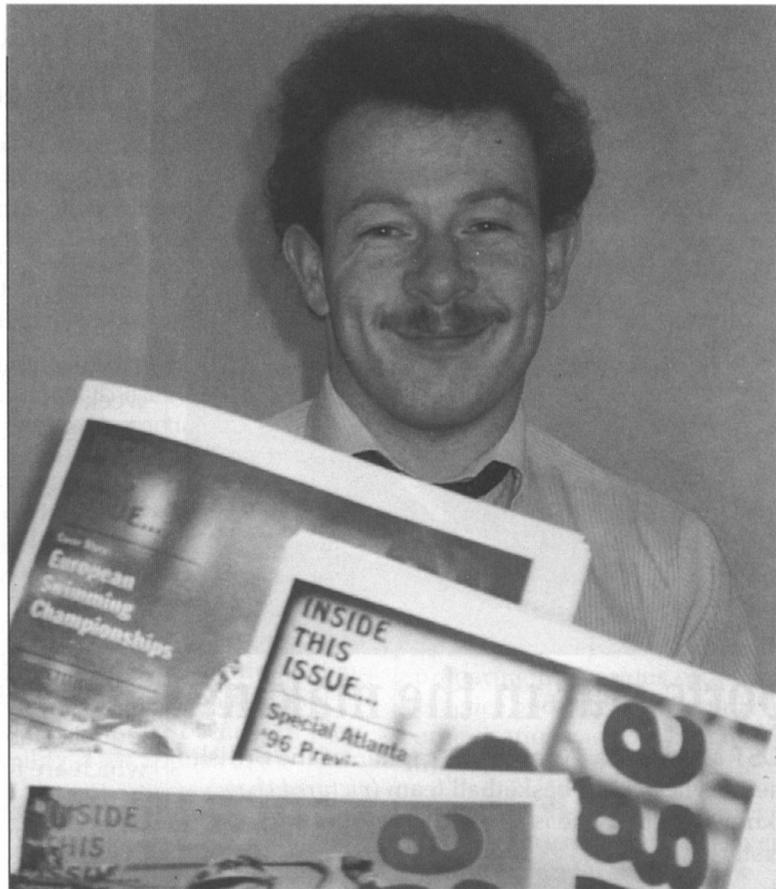
Marshall has become first editor of *Challenge*, which bills itself as the national newspaper reporting disability sport. The fifth issue of this monthly tabloid came out in January.

There are reputed to be a million disabled people taking part in all sorts of sport, everything from archery to yachting, most weeks of the year. The energy they put in would match the output of a small-size nuclear power station.

The rewards they have got so far in terms of regular recognition on television and in the Press of all this intensely competitive activity is almost zilch. Disability sport is lucky if it gets a downpage mention once a month in one of the heavier broadsheets.

That's where 25-year-old Marshall and his subscription-only sports paper from Knightwood Publishing at Reading, Berkshire, come in.

They've homed into a reality that, outside some major set piece events like the Paralympics or a



Former *Your Voice* member, Marshall Thomas, with some back issues of *Challenge*, the disability sports newspaper of which he is now the proud editor.

major wheelchair marathon where TV cameras are already gathered to film elite able-bodied athletes, the mass media of this country could not really care less about disability sport.

"There's a huge gap in the market, and we aim to fill it," said Marshall, interviewed after putting his Christmas issue to bed. "*Challenge* covers all sports enjoyed by disabled sports men and women, whether they are learning, physically or sensory impaired."

"We are not involved on any side of the arguments in politics or disability politics. We report what is happening impartially, and cover all sides of the argument on controversial matters."

It just happens to be a good news time for disability sport, even though the rest of the world mostly ignores it. The Atlanta Paralympics take place in August, immediately after the Olympics,

and competitors planning to prove their world-class credentials are battling for their places in the sun.

The first controversies have also been aired – including the hoary old chestnut of whether or not people with learning disabilities should be allowed into the Paralympics. The organisers have at last decided that you can and you should.

"It wasn't until Seoul in 1988 that the Paralympics became widely recognised and Britain is one of the major sporting nations. At Barcelona, for instance, we came third in the medal table with something like 40 gold, 47 silver and 41 bronze medals. Obviously, this year we shall be looking for more," said Marshall.

● *If you have any ideas for editorial items for Challenge, Marshall would be delighted to hear from you on 01734-612233.*



Sports star in the making

IN JUST six months, Ann Wild – captain of the British women's wheelchair basketball team (pictured above) – will know whether she is a world-class sporting superstar!

She hit the European heights when she won a bronze medal in the European championships held in The Netherlands in November. It was this third place which qualified the team for the Paralympics, which take place in Atlanta next August immediately after the Olympics.

"It was the first time I had won a medal, and it was a fantastic feeling. Lots of wine flowed that night. There were quite a few hang-overs the following morning," said 22-year-old Ann, who is our national mobility adviser, based at our regional centre for the South East in New Barnet, Hertfordshire.

Her 12-member squad also came away from the five-day championship with the fair play award, and that pleased Ann no end. But don't get the idea that women's wheelchair basketball is soft and drippy.

"While the women's game might be more brains and less brawn than men's basketball, it's still very aggressive," said Ann.

"And, because we had Atlanta to play for, there was absolutely no compromise. Basketball is said not to be a contact sport. Tell me about it – I'm still nursing the bruises!"

Ann, who lives at Barkingside, Essex, has been playing basketball since she was 10 years old and joined the Great Britain squad when she was 13. She has only ever missed one of their international matches – in 1988, when she needed a spinal fusion operation.

Proposal to cut mobility allowance for people in long hospital stays

PLANS have been announced by the Government to cut Disability Living Allowance mobility component for people in hospital for long stays.

As part of the Budget, Secretary of State for Social Security, Peter Lilley, outlined Government plans to reduce expenditure by cutting benefit income.

The mobility component will be withdrawn after four weeks in hospital for adults and 12 weeks for children.

Mr Lilley stated that "Hospital patients, especially acute patients, have little scope to be independently mobile whilst in hospital and most of their needs are met by the NHS."

He added that the proposal would bring the component into line with other benefits which are reduced following a long spell in hospital.

Only Motability agreements, for a car or wheelchair, which are funded by the mobility component and which are current when a person enters hospital will continue for the full term of the agreement. It will not be possible to renew a Motability agreement when in hospital.

Anyone who has been in hospital for 12 months or more at the point of change will have the benefit cut from £31.20 down to the lower rate, currently £12.40. People who are in hospital under part III of the Mental Health Act will not retain any benefit since, according to Mr Lilley, "for security reasons, they do not have the same opportunity for independent mobility."

Volunteers needed for jobs survey

READERS who can help with a GCSE sociology course project on 'Disabled People and Employment' by filling in a questionnaire about their own experiences of looking for work or as an employer or a service provider should contact: **Kirsten Battle, 17 Mallard Drive, Cippenham, Slough SL1 5BW.**

Kirsten's own experience of sending off 2,000 job applications before finding a job was reported in December *Link*. She wants completed questionnaires as soon as possible so that she can finish the project.

Bereaved parents' helpline

BEREAVED parents can talk to someone who has been in a similar situation by calling the Child Death Helpline. The confidential helpline is operated from Great Ormond Street and Alder Hey Children's Hospitals. It is open every evening from 7-10pm and Wednesday from 10am-1pm. The freephone number is 0800-282986.

READ DAVID FULFORD-BROWN, LINK'S ENTERTAINING NEW COLUMNIST, ON PAGE 26

Disability Discrimination Act – Protection at last?



Background

The Government-sponsored Disability Discrimination Bill received Royal Assent in November 1995.

This has been hailed as one of the most important pieces of legislation ever, in relation to protecting the rights of disabled people, but how much direct affect will it have in reality?

The answer in the short term is probably very little, as none of the main aspects of the Act will be enforced until November this year, after a number of guidelines and codes of practice have been produced.

The picture in the longer term is a little more optimistic, as more and more of the Act becomes enforceable. However, with 10-year time scales being talked about for some sections, disabled people in the United Kingdom are going to have to wait a fair amount of time yet, before they receive comprehensive rights to a wide range of services and other facilities.

Having said this, the Act will have far reaching implications for the voluntary sector over the next couple of years. We hope to be providing training and support sessions for voluntary organisations in relation to new responsibilities under the legislation this year. In the meantime there are a number of issues that groups should be aware of now, so that you can be prepared for when the legislation does come into force.

One of the biggest issues within the development of the legislation has been the definition used to identify disabled people covered by protection within the new law.

After many heated and complicated discussions, it was agreed that anyone with a physical, sensory or mental impairment would be covered but that this should be substantial and have a

By Jonathon Burke

long-term effect (ie over 12 months). Impairments that are slight at first, but are expected to worsen in time, are also covered.

Rights and responsibilities

There are basically four parts to the legislation. These relate to employment practices and procedures, the supply of goods and services, renting or selling property and monitoring and evaluation of the legislation.

Part 1 – Employment

Under this section it will be against the law for an employer to treat a disabled person less favourably than someone else because of their disability. This applies to all employment issues including recruitment and selection, training, promotion and dismissal. Employers will also have to make any reasonable adjustments to their workplaces to ensure that adequate access and facilities are available for disabled employees. Although organisations with less than 20 employees will be exempt, they will be encouraged to follow good practice guidelines that will be drawn up in line with the legislation. It is expected that this will be the first section of the legislation to be enforced, probably by November this year.

Part 2 – Goods and services

This will basically make it illegal to refuse to offer a service to a disabled person purely on grounds of their disability and in particular it will make it unlawful to provide a service to a disabled person on terms which are different to a non-disabled person. Again people and organisations providing any services will be asked to make *reasonable* changes to ensure that a disabled person is able to receive the service in question.

Part 3 – Selling land or property

It will be illegal for anyone who sells or lets property to discriminate against a disabled person. So, for example, a landlord

could not charge a higher rent to a disabled person than someone who is not disabled.

However, the legislation does not require property to be made accessible for a disabled person to purchase it.

Part 4 – Monitoring and evaluation

A body called the National Disability Council will be set up to advise the Government on how successful the legislation is (or not, as the case may be!) in combating discrimination against disabled people. It is also this organisation that will be responsible for preparing the various codes of practice and offering support to organisations as how best to implement the legislation.

As well as these main areas of the act there are also sections covering education and transport. The education section will force schools, colleges and universities to produce public documents explaining what services and facilities they have to offer to disabled pupils. The transport section will put minimum standards into place for public transport, so ensuring a basic level of access is available to all.

Further consultation and implementation

From December 1995 until May 1996, various consultation exercises will take place which will inform some of the detailed development of the codes of practice and detailed guidelines necessary to enforce the Act. When this exercise has been completed, the implementation process will begin with the first section on employment protection being in force by November 1996 and the rest of the Act being phased in from 1997 onwards.

The author, a member of Your Voice in ASBAH, wrote this piece for Voluntary Action, Leeds, for which he works.

A 'living' centre

EVERYTHING from height-adjustable sinks to toilet seats and from easy-hold cutlery to tap turners, trowels and a tipable kettle is on display at a new resource, helping disabled people become more independent in their daily lives.

The Disabled Living Centre in Stamford, South Lincolnshire – has special adaptations and equipment on view for bathrooms, kitchens, bedrooms and sitting rooms.

The new centre has been set up by Lincolnshire Social Services in partnership with the Red Cross.

The service is combined with the Red Cross Medical Loans scheme which loans out equipment like commodes, wheelchairs, crutches and cradles.

Centre manager, Lynne Hames, an enrolled nurse, says the centre is

available for people to see the equipment or find out suppliers of equipment not on display.

As well as the demonstration areas, there is an information room with details of manufacturers and distributors.

Lynne said: "People can visit us or we can send information through the post. They can purchase from here or we can put them in touch with the major retailers."

The centre works with community occupational therapists who can give in-depth assessments to maintain people in the home.

Lynne said: "Disabled living centres are becoming a way of life. People can try things out here rather than sending for the wrong thing from a catalogue."



Lynne Hames tries out some specially adapted cutlery and crockery at the new disabled living centre

The centre – in St George's Avenue, off the A6121 Ryhall Road, close to Stamford Hospital – is open Monday, Wednesday and Friday from 10am-4pm. Tel: 01780-480599. There is car parking and the building has easy access.

YOUR nearest Disabled Living Centre is ...

Aberdeen – Hillylands Disabled Living Centre – 01224-685247.

Aylesbury – Independent Living Exhibition – 01296-315066.

Belfast – The Disabled Living Centre – 01232-669501 ext 2708.

Birmingham – The Disabled Living Centre – 0121-643 0980.

Bodelwyddan – North Wales Resource Centre for Disabled People – 01745-583910 ext 4706.

Bristol – Avon Disabled Living Centre – 0117-965 3651.

Bromley – Lewis House – 0181-663 3345.

Cardiff – Disabled Living Centre – 01222-566281 ext 3751.

Carmarthen – Cwm Disability Centre for Independent Living – 01267-241743.

Colchester – Disabled Living Centre – 01206-832172.

Edinburgh – Lothian Disabled Living Centre – 0131-537 9190.

Elgin – Moray Resource Centre – 01343-551339.

Exeter – Independent Living Centre – 01392-59260.

Grangemouth – Dundas Resource Centre – 01324-665546.

Hillingdon – Independent Living Centre – 01895-233691.

Huddersfield – Level Best – 01484-453000.

Hull – National Demonstration Centre – 01482-225034.

Inverness – Disabled Living Centre – 01463-704000 ext 5477.

Leeds – The William Merritt Disabled Living Centre – 0113-279 3140.

Leicester – Leicestershire Disabled Living Centre – 0116-2700515.

Lewes – East Sussex Disabled Living Centre – 01273-472860.

Liverpool – Liverpool Disabled Living Centre – 0151-298 2055.

London – The Disabled Living Foundation – 0171-289 6111.

Lowestoft – Waveney Centre for Independent Living – 01502-538571.

Macclesfield – Disabled Living Centre – 01625-661740.

Manchester – Regional Disabled Living Centre – 0161-832 3678.

Middlesbrough – Independent Living

Centre – 01642-827471.

Newcastle Upon Tyne – Disability North, The Dene Centre – 0191-284 0480.

Nottingham – Disabilities Living Centre (Notts) – 0115-942 0391.

Paisley – Disability Centre for Independent Living – 0141-887 0597.

Papworth – Papworth Disability Resource Centre – 01480-830495.

Portsmouth – The Frank Sorrell Centre – 01705-737174.

Shrewsbury – Shropshire Disability Resource Centre – 01743-444599.

Southampton – Southampton Aid and Equipment Centre – 01703-796631.

Stockport – Disabled Living Centre – 0161-419 4476.

Swansea – Disabled Living Assessment Centre – 01792-580161.

Swindon – Options Plus – 01793-643966.

Welwyn Garden City – Herts Association for the Disabled, The Woodside Centre – 01707-324581.

West Wiltshire & Bath – Independent Living Centre – 01380-871007.

Direct payments for Community Care

NEW legislation to allow local authorities to give people cash payments as an alternative to Community Care services has been published.

Welcoming the publication of the Community Care (Direct Payments) Bill, Stephen Dorrell, Secretary of State for Health, said: "This is an exciting step forward for Community Care. Direct payments will give people more choice and control over their lives, and so more independence. I am aware that disabled people have been asking the Government to legislate in this area for some time and we have spoken to a wide range of representatives of local authorities and disabled people in preparing this Bill.

"We are keen to involve people who use the services in the process and the next stage will be a consultation document. This will set out proposals for regulations."

The Bill

Clause 1 of the Bill gives the local authority the power to make direct payments to someone they have assessed as needing Community Care services. It allows the local authority to take into account the individual's financial circumstances when calculating the level of a direct payment.

It creates powers to specify in regulations who may receive direct

payments, categories of people who may not be paid to provide a service using direct payments, and a maximum period for which direct payments may be used to purchase residential accommodation. The local authority may require repayment of all or part of any direct payments under circumstances which will be defined in regulations.

Clause 2 ensures that a local authority no longer has responsibility to provide someone who is receiving direct payments with the service to which the payments relate if they are satisfied that his needs are being met through his own arrangements. The local authority will retain its overall duty of care to the client and will have a duty to provide services if his needs are not met, for whatever reason, by means of the direct payments.

Clause 3 adds direct payments to the list of social services functions under the Local Authority Social Services Act 1970, and so enables the Secretary of State to issue guidance and directions and to order an inquiry. It also ensures that direct payments recipients can have the same access as service recipients to the complaints procedure under that Act.

Clauses 4 to 6 cover the corresponding arrangements for Scotland and Northern Ireland.

New driving guide

A NEW guide for disabled drivers has just been published by the Mobility Information Service. *Adaptations for the Disabled Driver* is said to be the only definite listing of driver adaptations and specialist suppliers of its kind.

Written by David Griffiths MBE, director of the service and himself a motorist with a disability, the publication outlines the basic types of disabled driver adaptations available and explains in basic terms how they operate.

Over 60 companies offering vehicle modification facilities are listed together with details of the services and equipment offered. There are sections giving advice on vehicle choice and a quick-reference adaptation/disability matching table.

The guide, with over 30 illustrations, costs £1.50 (in p&tp) from: *Mobility Information Service, National Mobility Centre, Unit 2a, Atcham Estate, Shrewsbury, SY4 4UG.*

Home swap scheme

HOME-swapping in a two-way or one-way exchange for holidays or breaks throughout the year is the subject of a new register for people with physical disabilities of all ages.

The quarterly register lists homes all over the country, with full details of the differing facilities each can offer.

For a small fee subscribers can see which homes are on offer, or put their own home up for swap with someone else.

For more details contact: *Special Families Homeswap Register (RB), Freepost, PY2077, Plymouth, PL7 3BR.*

New book on home adaptations

TIPS on improving and adapting property are contained in an updated version of a handbook published by The Disability Information Trust.

The guide is fully illustrated with photographs and provides information and comment on equipment including kitchen appliances, cleaning and laundry equipment, food preparation

and utensils; door and electrical fittings; alarms and intercoms; kitchens and dining furniture.

Home Management and Housing – Equipment for Disabled People costs £10 (including p&tp) from: *The Disability Information Trust, Mary Marlborough Centre, Nuffield Orthopaedic Centre, Headington, Oxford, OX3 7LD. Tel: 01865-227592.*

ASBAH to fund new folate study

ASBAH has agreed to back a one-year research project at Leeds University looking at the types of folates in the bloodstream.

The study, which will cost £14,995, will be conducted by a research team with an international reputation both for folic acid research and for developing specific screening tests.

ASBAH's Advisory Committee and independent referees recommended the study and our Finance and General Purposes Committee agreed ASBAH should fund it at a meeting in December.

The study, by Dr M D Lucock, Dr C J Schorah, Professor M I Levene, is titled *The Character of Intraerythrocyte Folate Species: Implications for Prevention of Neural Tube Defects*.

It is known that complex forms of folate exist in food and react differently in the digestive process and in the bloodstream.

It is important to understand what these compounds are, and whether there are significant differences in body chemistry between women who have experienced NTD pregnancies and a control group.

Ultimately, it may be possible to develop a blood screening test to identify women at risk of an NTD pregnancy.

£3,000 raised in Radio 4 appeal

AROUND £3,000 was raised for ASBAH in a BBC radio appeal early in the New Year.

Jill Dando, newscaster and presenter of TV's *Crimewatch* programme, asked listeners to support the work of our new assessment, rehabilitation and training service, START, on *The Week's Good Cause* at 8.50am on Sunday, 7 January.

Fundraising: we get to the top of a super shortlist

STAFF at News International – publishers of *The Sun*, *The Times*, *Sunday Times* and *News of the World* – picked ASBAH in preference to three other organisations as their charity of the year.

Representatives on the Employee Consultative Council sub-committee voted for ASBAH after a presentation by Sarah and Steve Baker, backed by our executive director Andrew Russell and disabled living adviser Caroline Berkley.

Sarah experienced a neural tube defect in pregnancy in 1995 and so the Bakers know at first hand the impact and distress this causes.

Steve works for News International, and the couple pressed ASBAH's case during discussion of the Staff Charity of the Year.

"All four charities were very worthwhile and all had strong arguments in their favour," said sub-committee chairman Andrew Whyte, the firm's deputy director of corporate affairs.

"With ASBAH, we were impressed about the passion and bravery of Sarah and the professionalism of your organisation.

"We liked your entry because you were not one of the big, big charities. You were big enough for our money to make a difference, but not too large for it to be lost in a great big pit.

"We thought our donation would make a material difference to the

work you are doing," he added.

ASBAH executive director Andrew Russell said: "We are absolutely delighted that our research project will be funded in this way. It is very important to get a better understanding of how and why spina bifida occurs, and it is very encouraging that the News International committee agreed with this.

"I am particularly grateful to Steve and Sarah for giving ASBAH this opportunity."

The money will go to an important research study into how folic acid prevents occurrence of spina bifida and other neural tube defects, in most cases.

It is hoped to develop a blood-screening test to tell women whether or not they are at risk.

The three other charities placed with ASBAH in the final shortlist were: a local scout group project bringing disabled and able-bodied children together; the Multiple Sclerosis Society; and the British Kidney Patients' Association.

Every charity nominated by a News International staff member benefited by receiving £250.

In 1995, the News International Staff Charity of the Year raised £10,000 for Leukaemia Busters.

This year the total amount of money raised by staff will be matched pound for pound by the company.

So at the end of 1996, ASBAH could be in line to receive an amount up to £20,000.



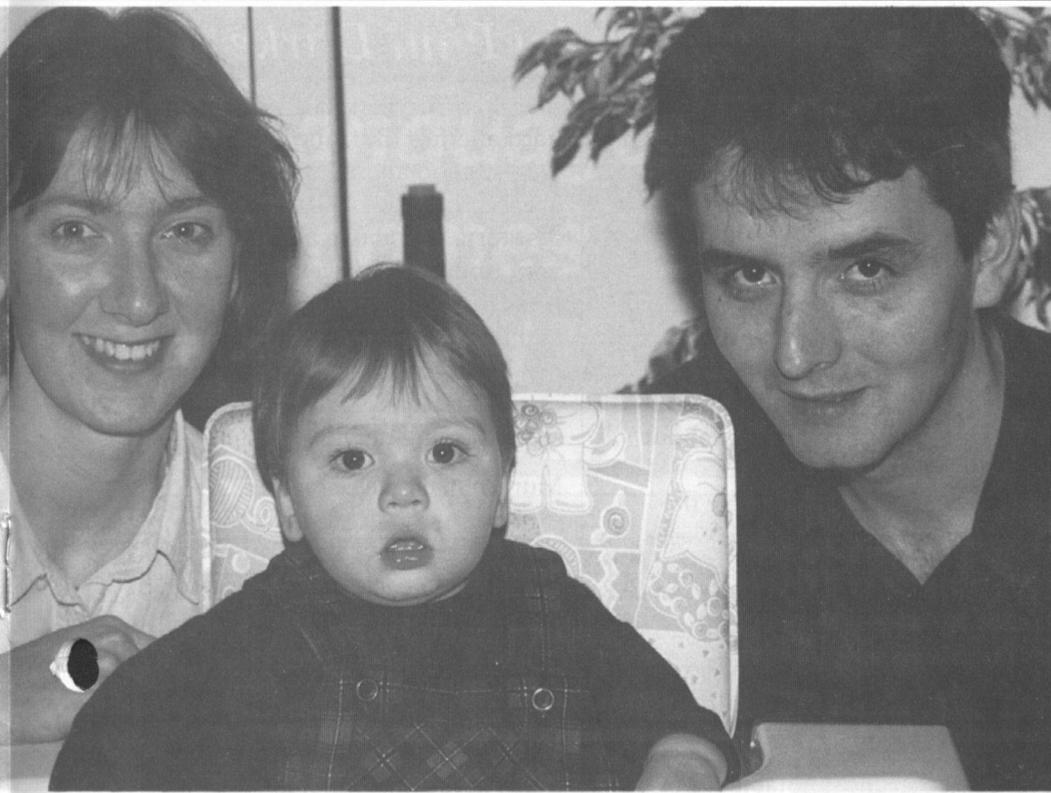
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Why I back ASBAH'

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ld Link: "I think we
few heart-strings
e told the News

International staff sub-
committee how absolutely
excellent ASBAH was."

She had been confused after
the termination.

"I received such conflicting
advice from doctors, nurses
and consultants about why it
had happened to us, whether
we had done anything
wrong, the chances of it
happening again and what
we could do to prevent it."

About a month after the
termination, the couple were
handed a booklet about
SATFA – Support Around
Termination for Abnormality.
It was through this group
that they finally learnt about
ASBAH.

"Some of the leaflets sent by
SATFA were from ASBAH so
I got in touch with you and
got through to a disabled
living adviser, who spent 20
minutes giving me inform-
ation on the research that had

been done on neural tube
defects and what conclusions
had been reached. She then
talked about folic acid and
how taking it reduces the risk
of spina bifida in pregnancy."

Sarah, a nurse, had taken folic
acid for her first child which
was 'normal'. The second
pregnancy which was
terminated was, however,
unplanned.

What really impressed Sarah
was the specific information
she was given by ASBAH
about the chances of it
happening again and how
much the chances would be
reduced by taking folic acid.

Sarah said: "We could have
got more help from ASBAH
but I was quite happy with
the information I received.
We feel we have as much

***"We feel
we have as
much
support as
we need
at the
moment
but we
know the
door is
always
open."***

support as we need at the
moment, but we know the
door is always open.

"Both ASBAH and SATFA
have been a great help to us.
We know that charities are
finding it difficult to survive
and we know they need to
keep going in order to help
parents like ourselves.

"We had already decided to
donate some money to
ASBAH at Christmas, then
this staff charity thing came
up at Steve's work and I
wrote a heart-rending letter
saying how wonderful
ASBAH had been for me.

"The scan and termination
was an awful thing – I
wouldn't wish the experience
on my worst enemy. It's a
very sad thing to happen to
anyone."

News International





Darke at the cinema by Paul Darke

IN November I attended, as a juror, the First International Short Film Festival *Wie wir leben* (translated as *The Way We Live*) in Munich. It was an interesting experience to say the least.

As a film festival there were a lot of television programmes entered, which was a shame as it highlighted the lack of disabled film makers out there at present.

And most of the entries were very much of the inspirational kind. But some gems were to be found amongst the ordinary: the winner (which won a prize of £4,000), a German film called *Be Aware of Trudchen Luescher* was an extraordinary study of loneliness and despair in the face of old age and visual impairment, made with commensurate skill and humour.

That virtually all the films submitted were made by able-bodied people was another great disappointment.

The winner of the special UNESCO prize was an English animation film called *A is for Autism*, directed by Tim Webb and produced by Channel 4, which explored through the drawings of people with autism their world. It was clearly a work of imagination and in no sense exploitative of its subjects. In a film festival supposedly about disability where few films were made by disabled people the question of exploitation was a central criteria. Another English animation which narrowly missed out on a prize was *Disability Is ...* made by a group of young disabled people from Manchester.

The other most notable film was the one which came second, a documentary about a stand-up comedian, who couldn't stand up, called *Fred*. The subject of the documentary was a guy called Fred Burns, whose impairment was spina bifida. Fred is a guy who lives on the seedier side of life. He lives his life like he drives: a little too fast. He also

likes his beer, fags and women hard and fast. But, and this is what was so good about *Fred*, there is a great sense of joy and pleasure in his story, and above all else, he is very funny. There were no other films that covered spina bifida, and this was a disappointment to me, but there is always the second festival in a couple of years time, so get filming now!

Munich itself was a bizarre experience (and extremely expensive) as it ranged from being exceptionally accessible (the underground system was the best I have ever seen and was fully wheelchair accessible if you had a helper to help you cross the four-inch gap between platform and train) to routinely inaccessible (all shops had steps due to the snow). The stares and looks of disdain from the locals were like I have never experienced before. Bavaria, and Munich in particular, are the richest parts of Germany and as such they do not tolerate deviation from the norm very much, but hopefully the festival will play a key part in changing that.

New holiday guide to 'accessible' Wales

THE FIRST of a new generation of holiday guides for people with disabilities will be available from the Wales Tourist Board this spring.

Discovering Accessible Wales will offer objective access information to would-be visitors who are disabled.

The guide covers the whole range of accommodation, holiday attractions and activities in Wales, from sports and leisure facilities, arts venues and heritage sites, to beaches, nature trails, cafes, restaurants, pubs and public amenities.

More than 400 locations in Wales were reviewed by the Wales Tourist Board's adviser on the provision of disabled facilities, Bob Donaldson, who is himself a wheelchair user.

Nearly 80% of the locations had

some level of overall access but, more importantly, the different elements within the site were individually assessed and graded for the guide.

Bob said: "We looked at the parking, toilet provision, the features and rides, the on-site transport, everything that affects the visitor's enjoyment.

"The result is a guide that enables the would-be visitor with disabilities to make an informed choice, given their own preferences and those of their family and friends."

Bob's own experiences of planning day trips and holidays with his family and friends were that most guides did not

recognise the different requirements, wishes and expectations of the individual members of the group of which he was a member.

Discovering Accessible Wales seeks to treat the visitor with disabilities as a holiday maker and individual with certain access requirements.

It recognises that any individual on holiday is looking for new experiences, the out of the way place, the happy surprise, the chance meeting or discovery that makes for a lasting holiday memory.

Discovering Accessible Wales is available from: **Brunel House, 2 Fitzalan Road, Cardiff, CF2 1UY. Tel: 01222-499909.**

Language comes first

Fazed by complex accounts of language difficulties? Elizabeth Sisson suggests a simple model to explain the problems likely to be encountered in reception classes and some practical first steps to help children succeed.

IT is a sad fact that most local education authorities do not have the necessary provision to address the special educational needs of children with spoken language difficulties in mainstream schools. In many areas the opportunity for in-class support by the nursery nurse or learning support teacher is becoming quite rare. As the support services are cut and resources dwindle, the burden of the responsibility for children with special needs often falls on the shoulders of the class teacher. In mainstream schools this can mean someone without any training or experience of such children and their difficulties, or any knowledge of how to address them. It is also a fact that there are now more children than ever before in mainstream schools who have speech and language difficulties: estimates vary from 2-5% of children.

Complex

Many of these communication difficulties are very complex and prevent the child from making inroads in other curriculum areas. Almost every educational task requires a certain level of understanding and use of language. As Ann Lock points

out: 'Language is the basic educational skill and children who have difficulty with language are liable to have difficulty with almost everything else. Whatever else they may need to learn or be taught, they will need to learn language first.'

The area of receptive language difficulties is a very complex one with many facets and presenting problems. Difficulties can be very difficult to detect – the class teacher is often only aware that the child is not coping with the school work: that some of his responses are 'bizarre', or that the child is not understanding what is said to him. The opportunity of speech and language therapy assessment is not always available and there are usually very long waiting lists for mainstream school assessments.

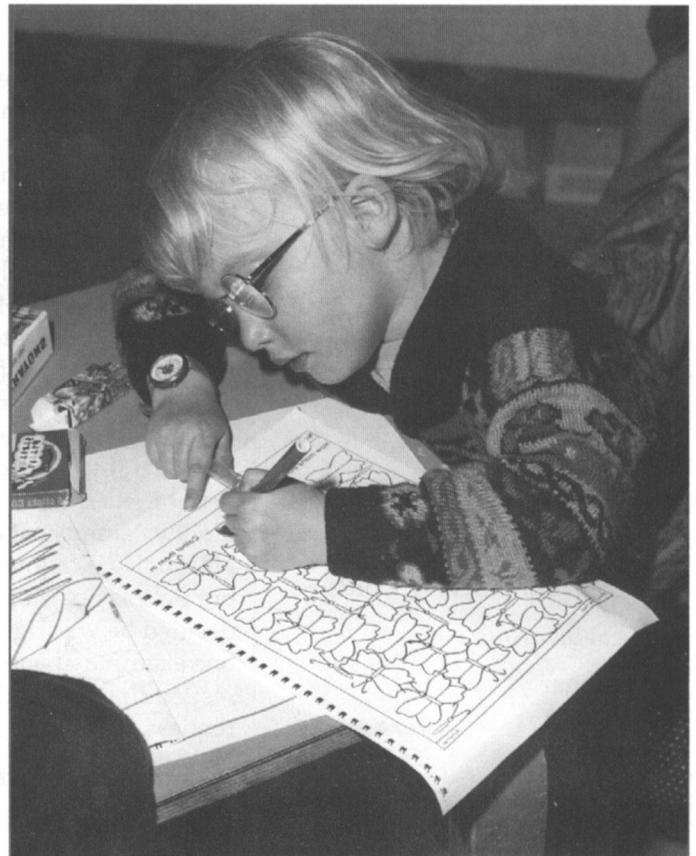
Even if a speech and language therapist has assessed the child to confirm that he has a receptive language delay or disorder it means little. The teacher can be totally fazed by the enormity of the problem which leads to feelings of

stress, frustration and isolation.

With other difficulties colleagues can usually advise or help: with spoken language difficulties this is often not the case. Text books are complicated and do not always provide practical, time-efficient strategies. It became clear to our service that a simple model was necessary to explain receptive language difficulties – to breakdown the complexity into manageable chunks, initially for the speech and language therapist herself! The model also needed to provide some simple initial aims of therapy or language work. It would certainly not address all the issues or be a total explanation but it would be a practical first step.

The model

Instead of discussing receptive and expressive language the terms input and output were used. Obviously the main problem is one of input but this necessarily leads to output problems.



Family Weekend at Meldreth Manor last summer

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Input

There are seven factors involved:

- Attention and listening skills.
- Auditory memory.
- Information carrying words.
- Vocabulary.
- Grammar.
- Reasoning.
- Sequencing.

■ Attention/listening skills

As many class teachers would confirm, today's children generally have poor attention and listening skills, but children with speech and language problems have difficulties over and above this. To learn anything one needs to be able to listen, yet children are not born with this ability. If a child's attention span is short, learning is more difficult and, since the ability to communicate is one of the most complex things we learn to do, a vicious circle is often set up.

It is generally agreed that children go through six levels of attention from fleeting to intermediate which is well controlled and sustained and can be focused on more than one thing at a time (Cooper, Moodley and Raynel 1976). Many of the children with language difficulties have single channelled attention so that they cannot perform a task and listen to the teacher at the same time.

■ Auditory memory

This relates to pure short-term memory and the number of 'slots' that the child has available to use.

Children in reception classes need to be able to receive four items in the correct sequence to be able to function well, yet many of the children could only recall one to two items and not necessarily in the correct sequence. This had massive implications for understanding teacher instructions, eg ... Mark, six years of age, had an auditory memory of two items so when faced with the instructions 'It's home time, go and get your coats and bags, go to the toilet if you need to, be quiet about it, then come and sit down quietly,' simply sat down quietly. Normally he followed the others but on this occasion he had decided he was right. This is just one example of one child responding to a fairly routine request.

■ Information carrying words

Related to the issue of auditory memory is the number of information carrying words that the child can cope with (Derbyshire Language Scheme). It must be remembered that each concept may be an information carrying word. Often when the child has learned concepts, eg colour, shape, size, he fails to carry out 'simple commands' because there are too many concepts for the number of 'slots' he has available. Fay, age 5.2, has been taught the above mentioned concepts and was given the instructions 'Colour all the squares green' from a choice of squares, rectangles and circles and a pot of colours. As her auditory memory or slots available was only two items she coloured everything red because she only processed 'all' and 'colour'.

■ Vocabulary

Obviously if a child has delayed language then the vocabulary will be delayed. However the pattern of vocabulary may not be straightforward because the child may not have acquired the basics early on. He perhaps needs to be taught vocabulary rather than picking it up as normally happens.

For example, twins Paul and Lee, age six years 10 months, did not know elbow and ankle but did know and could use tubular, circular, and cylindrical because they had been taught these items at school.

■ Grammar

Related to the issue of auditory memory, information carrying words, and vocabulary, is the child's ability to decode sentences for grammatical information. Developmentally children acquire nouns, verbs and adjectives first in very general terms before they understand negatives, prepositions, pronouns, tense or other more complex configurations. It is often assumed that the child knows more than he does and many of the resulting errors may be labelled as naughty, eg Jamie, age five years, four months, did not understand negatives unless not or 'nt' was accompanied by a gesture such as a wag of the finger or shake of the head or appropriate tone of voice. Therefore, when told 'Don't go in the mud' – well, you can imagine!

Other less obvious grammatical confusions which lead to odd responses, eg 'What did you do this morning?' to a child who does not understand the past tense of the verb would probably lead to him telling you what he is doing right now.

■ Reasoning

Children with delayed language have very poor skills of verbal reasoning. As a consequence they function in a very concrete manner, for example when required to process information so as to make responses, inferences, predictions, associations, etc. They cannot, for example, answer 'Why' questions, 'What would you do,' 'What happens next,' 'What if,' so they give the answer they think you want. This is usually a response to a 'What' question since this usually requires a concrete

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**Language
comes
first
from p18**

response. In addition most question words begin with 'wh', so as the child sees the adult round his lips to ask the question this can add to the confusion. The responses can be very bizarre!

■ Sequencing

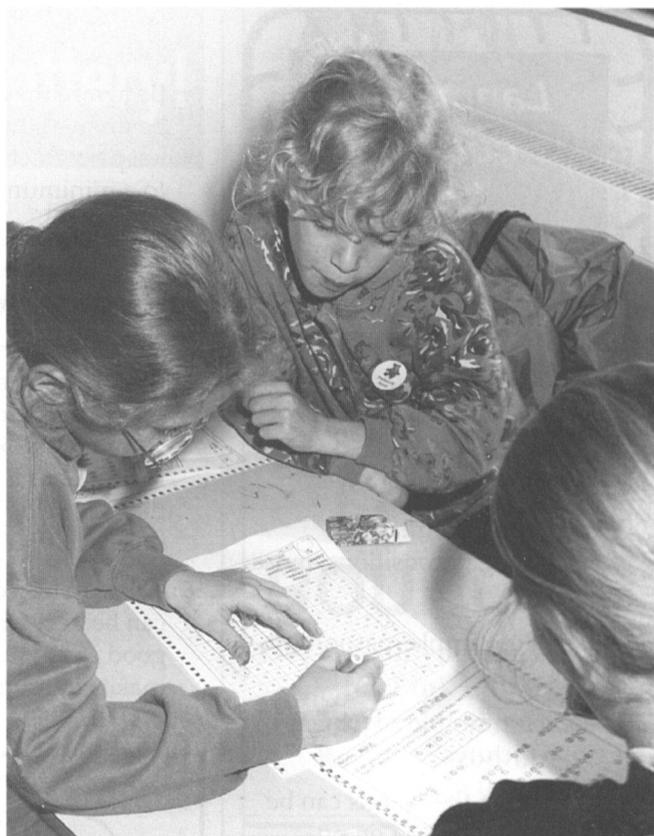
Many of the necessary terms to do with sequencing are very abstract, for example before, after, next, last, yesterday, tomorrow etc. There is no concrete reference for these words. Children will often have difficulty with this area in that they cannot sequence a two-picture story or take in a simple two-part instruction in the correct order – eg, 'Go to the toilet and wash your hands' or 'Take your coat off and sit down' – even with appropriate auditory memory.

Output

Given the input problems listed the children are naturally going to have output problems. These are usually fairly easy to detect and describe. Vocabulary may be immature or inappropriate, sentences may be poorly constructed, telegram-like or stereotypical. Ideas may be sequenced in a very odd fashion. These features will probably also be accompanied by poor social use of language so that the child is not aware of the 'rules' of communication, eg how to initiate conversations or what is appropriate to discuss.

Often the most distinctive part of the child's output language is the way they 'go off at a tangent' even if only simple and often unrelated responses were required. This is probably due to an awareness on

Children doing a written language exercise at ASBAH's Family Weekend at Meldreth Manor last summer



the part of the child that he did not comprehend the adult, knows the adult wants a response and is therefore attempting to satisfy that need as best as he can.

Additional factors

● Sieve-like learning

The child may appear to have learnt something one minute or day only to have forgotten it the next. This makes for a great deal of frustration on the part of the teacher.

● Visual performance

Sometimes the child's visual skills are better so they pick up on clues and cues to aid understanding, for example, using gesture or tone of voice to interpret the meaning or following other children in PE. This often makes the problem harder to detect especially if the child is quiet or sits at the back of the class.

This sometimes also means that the child can 'read' but fails when the understanding is required.

● Confidence

The child may or may not be

aware of difficulties. No one likes to try something difficult only to fail. Therefore confidence can be a very big problem. Being nervous or anxious adversely affects the ability to understand.

● Diversion tactics

The child can be very skilled at 'diverting' the adult. Two forms of these behaviour may be observed: verbal and physical. Verbal techniques may include 'going off on a tangent' as mentioned above or manipulating the adult on to a different topic of conversation. Physical strategies often include behaviour which is designed to imitate the adult so that the topic or question in hand may be avoided. The extreme end of the spectrum is behaviour designed to exclude him from the classroom.

Aims for language work

All of these problems can become target areas for language work which aims:

- To increase attention and listening skills.
- To develop auditory memory.

continued on page 20



- To increase the number of information carrying words.
- To develop vocabulary.
- To develop grammatical concepts, eg prepositions, tense, pronouns.
- To develop simple reasoning skills.
- To develop simple sequencing eg two pictures.

One or more of these aims can be highlighted or worked on by support staff or a class teacher. By breaking the child's difficulty down into these chunks the class teacher is more aware of the nature of the child's predicament. It is then possible to make simple changes which will usually benefit the child enormously. Related to the input problem are additional factors:

1. Make sure that the child is looking at you and that you have his full attention before giving an instruction.
2. Keep the command short and simple. Take care not to overload the child's auditory memory capacity so that they can cope with the number of information carrying words. Break up a complex instruction into several smaller commands.
3. Make sure the instruction uses vocabulary that the child knows.
4. Make sure the instruction uses grammatical information that the child knows.
5. Keep your utterances to the 'here and now' and use more concrete language rather than

terms such as 'if' and 'when' etc.

6. Be aware that things may not be done in the correct sequence, keep abstract sequencing terms to a minimum.
7. Use as much gestures and tone of voice as possible to add cues and clues to what you want.
8. Set the child in a suitable position in the classroom, ie, at the front so that you can see what he is doing and he can follow your lead but slightly to the side so he can follow the other children as well.
9. Build up his confidence. This can be very difficult if he is not good at anything, but try to make communicating pleasurable.

10. Remember it is not the child's fault that he cannot retain the information.

Conclusion

The model does not take away the problem of the class teacher who is responsible for a further 30 or so other children but it is felt that it adds a little insight and gives practical pointers into comprehension difficulties.

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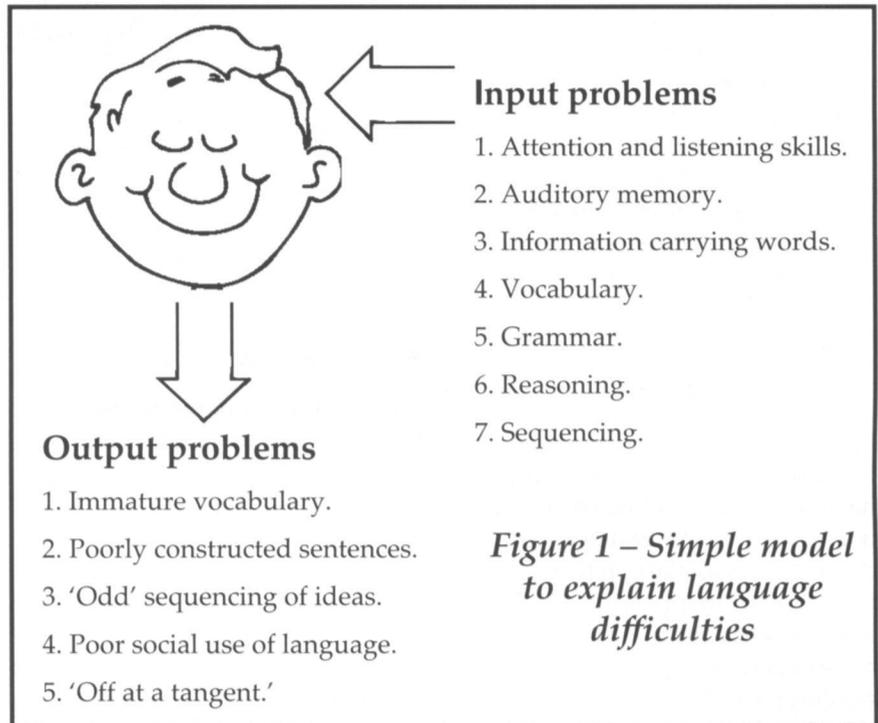


Figure 1 – Simple model to explain language difficulties

● Elizabeth Sisson is the chief speech and language therapist at Glebefields Health Centre, part of Sandwell Hospital and Community Health Services.

● This article first appeared in the magazine *Special Children* in January 1994 (issue number 71). It was ASBAH disabled living adviser, Leonie Holgate, who asked for it to be re-printed in *Link*. Leonie commented: "This article itemises so many of the problems our children have and is very relevant in schools."

North Wales wins the Lottery!

A PROGRAMME of independent living training which will benefit many people with spina bifida and hydrocephalus has been given a major boost – with an award of almost £12,000 to North Wales ASBAH by the National Lottery.

Members of the association were cock-a-hoop about the award when it was announced just before Christmas. It will allow them to respond more readily to individual needs as they become apparent, and tailor-make training and courses to individuals and groups.

The National Lottery money will be spent in the counties of Clwyd and Gwynedd. It is believed to be the only amount won by any ASBAH association in the first round of National Lottery Charity Board grants, which concentrated on alleviating poverty.

"We worked very hard for the lottery money and the assessment was extremely thorough, with lots of penetrating questions asked," said Carol Buxton, administrative assistant for North Wales ASBAH who worked on the successful application.

To help meet the lottery first-round requirement that applications focus on low income groups, Carol cited an academic study, as yet not officially published, on lifestyles in rural Wales. Reports circulated in the Press showed that between 25 and 30% of the population of north Wales, including the geographical area served by North Wales ASBAH, were living in or on the margins of poverty.

Carol's association is being given £11,970 of National Lottery money over three years. It will let them develop their independent living training beyond their

existing programmes for the under-18s, which in the past have been largely funded by the BBC Children in Need Appeal.

"The lottery money means that in future we can respond much more quickly to the individual needs of people over the age of 18," said Carol.

The money will be spent on a flexible range of learning options including mobility and wheelchair skills, driving lessons, self-confidence and awareness training, and using counselling or other means to secure sexual and emotional growth. The work will be done both one-to-one and in groups.



LOCAL ROUND-UP

Please send your news items to: Link Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ

James Wilson, of Orpington, Kent, aged seven, working on the computer bought for him by local and national fundraising efforts, watched by Margaret Holmes, honorary secretary of South Thames ASBAH.



Cash for computer

A LONDON local association raised more than £2,000 towards a computer for seven-year-old James Wilson – helping him to pass statutory school tests.

The fundraising bid was the last major project undertaken by Margaret Holmes before she retired a year ago as ASBAH fieldworker for South London.

Mrs Holmes, now honorary secretary for South Thames ASBAH, said: "Over £2,000 was

raised through the generosity of various organisations both national and local.

"National and South Thames ASBAH contributed, as did a local primary school which held a 'no uniform day' when all the children paid for the privilege of not wearing uniform and the proceeds were donated for the benefit of James. The congregation of a local church also held a special collection."



LOCAL ROUND-UP

Catherine McKissick presents ASBAH Greater Manchester fieldworker, Jean Black, with a cheque for £3,200 which was raised at a charity gala ball.



Having a ball for hydrocephalus research

A HIGH spot in the Christmas calendar at Lytham St Ann's was the charity gala ball organised by the Raynor family – following the recovery of their relative Catherine McKissick from a shunt revision operation.

"Catherine went through a terrible ordeal in the summer and

we were very worried about her," said her aunt, retired hotelier Mrs Pat Raynor, after almost 150 revellers had enjoyed the ball gown and black tie event at the Lowther Pavilion, Lytham.

"But she looked a new woman at the charity gala and gave a lovely speech."

"You can't believe the response we had – everyone was so generous, particularly when ASBAH is hardly known round here outside the immediate families."

Music by the 14-piece John Towers Big Band, a buffet catered for by a former chef of the Raynor's and a raffle headed by the prize of a weekend for two in London – including a meal at Langan's Restaurant – set the scene for the event.

It was described as 'a great launch for the season's festivities' by ASBAH fieldworker Jean Black, after attending with husband Brian, who is president of Trafford & Salford ASBAH.

Over £3,200 was raised for ASBAH, with the cheque being presented by Catherine McKissick to Jean Black. The family has asked that the money be spent on research work linked to hydrocephalus.

Mrs Raynor thanked all her family for their support, paying tribute in particular to daughter Deborah who lives in London but took the lead in winning the support of the local community.

Welcome Diane!

BLACKPOOL and Fylde ASBAH held its AGM in November at the Welcome pub, Blackpool, where Diane O'Hagan was elected secretary to succeed John Dewhurst.

Diane, who is 31 years old and has been a member for five years, writes: "I also do voluntary work three days a week at the Rock Rehabilitation and Occupational Therapy Centre. This has been open since 1983.

"This is where I met Chris. We went out for two years and got married in June 1994, and we are now expecting our first baby in April. Chris is a wonderful and loving husband who took my

disability in his stride. I am also sure that he will make a loving and devoted father.

"I feel honoured to have been elected as secretary of my local branch and feel sure I will enjoy my time in this position. I will also do my best for the Blackpool & Fylde ASBAH group."

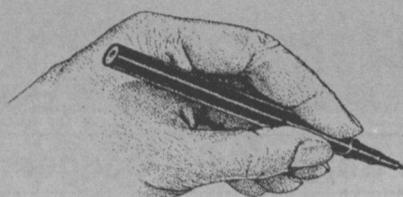
Outgoing secretary John Dewhurst added that the AGM and hot pot supper was a relaxed affair. "The comment was passed that everyone was laughing and joking instead of the depression of the last couple of years after the death of two members, Sue and little Emma."

Benefits up-rating

A look at how benefits were affected in the Chancellor's Budget

<u>Main benefits</u>	<u>Now</u> <u>(£/week)</u>	<u>April '96</u> <u>(£/week)</u>	<u>Main benefits</u>	<u>Now</u> <u>(£/week)</u>	<u>April '96</u> <u>(£/week)</u>
Attendance allowance			Invalidity Allowance <i>(transitional)</i>		
Higher	46.70	48.50	Higher	12.40	12.90
Lower	31.20	32.40	Middle	7.80	8.10
Child benefit			Lower	3.90	4.05
First child	10.40	10.80	Retirement Pension		
Each other child	8.45	8.80		58.85	61.15
Disability Living Allowance			Statutory sick pay		
Care component:			Earnings threshold	58.00	61.00
Higher	46.70	48.50	Standard	52.50	54.55
Middle	31.20	32.40	War Disablement Pension (100%)		
Lower	12.40	12.90	Private or equivalent	101.10	105.00
Mobility Component:			Industrial Disablement Pension		
Higher	32.65	33.90	Over 18	95.30	99.00
Lower	12.40	12.90	Under 18	58.35	60.65
Disability Working Allowance			Widow's pension		
Single adults	46.85	48.25		58.85	61.15
Couples/lone parents	73.40	75.60	INCOME SUPPORT		
<i>Applicable amount</i>			Residential care homes		
<i>(ie taper threshold)</i>			Very dependent elderly	227.00	234.00
Single adults	54.75	56.40	Physical disablement:		
Couples/lone parents	73.00	75.20	Under pension age	267.00	276.00
Family Credit			Over pension age	197.00	203.00
Adult	45.10	46.45	Mental handicap	237.00	244.00
Severe Disablement Allowance			Max Greater London increase	34.00	38.00
Basic rate	35.55	36.95	Nursing homes		
<i>Age-related addition:</i>			Physical disablement		
Higher	12.40	12.90	Under pension age	331.00	341.00
Middle	7.80	8.10	Over pension age	295.00	303.00
Lower	3.90	4.05	Mental handicap	301.00	310.00
Invalid Care Allowance			Terminal illness	295.00	303.00
	35.25	36.60	Max Greater London increase	39.00	43.00
Incapacity Benefit			Personal allowances		
Long term	58.85	61.15	Single, under 18 usual rate	28.00	28.85
<i>Short term (under pension age)</i>			Single, under 18 higher rate	36.80	37.90
Lower	44.40	46.15	Single, 18-24	36.80	37.90
Higher	52.50	54.55	Single, 25 or over	46.50	47.90
<i>Short term (over pension age)</i>			Couple, both under 18	55.55	57.20
Lower	56.45	58.65	Couple, one or both under 18	73.00	75.20
Higher	56.45	58.65			

A look at how benefits were affected in the Chancellor's Budget



Letters

I work voluntarily for ParentAbility, running its 'Practical Helpline' to give advice and support to parents who are themselves disabled. One of the things I am trying to do is to improve the information which is available on the suitability of standard items of baby/nursery equipment to parents with disabilities.

ParentAbility has recently been awarded a grant from the Viscount Nuffield Auxiliary Fund to research and produce a 'buyers' guide to baby slings/backpacks from the perspective of disabled parents.' I have agreed to co-ordinate this project and hoped you may be able to publicise this work.

The project will involve parents with disabilities trialling currently available slings, gaining information from parents who have used them in the past and seeking advice from professionals.

We are looking for parents who have physical/sensory impairments and have very young children to join a focus group which will trial a selection of baby slings/backpacks in the spring or early summer of 1996. Obviously parents need to consider whether they would be safe to trial slings, not likely to fall, etc.

We are also looking for information from parents who have used these items in the past and also for one or two interested

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.

OTs or physios to give their professional advice. Funding is available to enable people to participate in this project; to cover the costs of child care, travelling, postage, telephone etc.

If anyone is interested in participating, please could they contact me.

Lisa Nichols
ParentAbility Practical Helpline
22 Grooms Drive
Eastcote
Pinner
Middx HA5 2HU

DATES FOR YOUR DIARY

Monday 25 March

Southwark Council education and leisure department, conference for parents of children with special educational needs, Education Resource Centre, Cator Street, Peckham, 10am - 3pm. *Details from: Laura Baldock, Pupil support and SEN service, tel: 0171-525 2746.*

Thursday 28 March

Information Enables South Regional Conference, London Voluntary Sector Resource Centre. Day of training workshops for people working in disability and advice. Workshops on: incapacity benefit, taking cases to disability appeal tribunals, training new workers, fundraising, advocacy, access & access regulations. Organised by Alliance of Disability and Information Providers (ADAIP). Cost £10. *Mark R Hall, tel/minicom (please use voice announcer) 01302-310123.*

Tuesday 23 April

Information Enables Midlands Regional Conference, Queen Alexandra College, Birmingham. *Details as above.*

21- 23 May

Midlands Naidex, National Exhibition Centre, Birmingham.

24- 26 May

Scottish Mobility Roadshow, The Royal Highland Centre, Ingliston, Edinburgh, 10am-5pm daily. Free entry. *Tel: 0131-229 8632.*

31 May - 1 June

Northern Ireland Mobility Roadshow, King's Hall, Belfast. *Disability Action, tel: 01232-491011.*

Thursday, 6 June

30 Years and Counting, ASBAH conference to celebrate our 30th anniversary, Queen Elizabeth II Conference Centre, Westminster. 10.30am - 3.30pm. Themes include

empowering people with disabilities, and the depiction of disability by the media. See page 3 of this issue for more details. *Tony Britton, ASBAH, tel: 01733-555988.*

Saturday 22 June

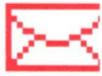
Reunion for ex-pupils of Exhall Grange School in Coventry. *Details: David Moss 01476-70373.*

24- 26 May

ASBAH Family Weekend 1996 for families which have a child with a disability under five years old. Kings Park Conference and Sports Centre, Northampton (note change of venue). *Lynn Thomas, National ASBAH, tel: 01733-555988.*

22 - 26 July

Towards Womanhood, a four-day conference organised by ASBAH for young women aged 16-25 (approx), plus carer/husband/boyfriend/mother. University of Nottingham, Rutland Hall. *Lynn Thomas, tel: 01733-555988.*



IN *HN News* (Autumn 1995), I read the poem by Liz Galfskiy, about

having an MRI scan. As I was reading the poem, it made me realise that I am not the only person who is scared stiff of having scans.

The reason why I had to have these scans is that I have got hydrocephalus. I know that these scans are extremely necessary but it never really made up for the fact that I was scared stiff all the time that I was having them done.

I hadn't actually had a scan since I was four years old (I am 15 now) but a couple of months ago I had to have an updated one to be on the safe side, because of a small scare that I had on holiday in July/August. It was just to see what the problem was, so it could be 'cured.'

It seemed to take ages. I was petrified because of all the noise and the fact that I was sure that they would never be able to get me back out of the scanner again. These feelings had stayed with me, ever since the scans that I'd had when I was very young.

It was the strong claustrophobic feeling and the fact that I was holding a buzzer (something that I hadn't had to do when I was four years old) and that, any time I wanted, I could have made contact with the outside world. I didn't want to press the button, because I wanted to say to people how brave I'd been and how I had been able to 'restrain myself' so I didn't. At the time, this feeling made me feel quite ill.

At the end of the scan, it had seemed like a year, not only 45 minutes as some people had said to me!

I was very glad to hear that I am not the only person who is scared of these MRI scans. It was reassuring to know I am not alone.

Kelly Jenno
Brantham, Manningtree
Essex



I WAS interested to read the article 'Fighting for the rights of your unborn child' in the December/January issue of *Link*, and it was refreshing to see some thought being given to the rights of pre-born children. However I was very disappointed by the language used in the article.

I was surprised, for instance, to read that 'Carol learned that Poppy was ... perfect.' By using the word 'perfect' to mean 'able bodied' you strongly imply that disabled people are, uniquely, imperfect, a rather extraordinary assertion for a magazine which is devoted to promoting a more positive attitude towards people disabled by spina bifida.

I know, of course, that I am not perfect, but neither is anyone else I know. Being able-bodied does not render one 'perfect'. Likewise the term 'perfectly normal' is misleading if, in fact, it means anything at all. What, after all, is 'normal,' let alone 'perfectly normal'?

Similarly it was reported that through screening errors a 'beautiful' baby like Poppy might have been aborted. This clearly implies that 'beautiful' and 'able bodied' are synonymous.

Although Carol herself had a very positive attitude towards her baby and was determined not to abort even if Poppy did have a disability, the tone of the

article seemed very much to favour the view that one ought to think carefully about pre-natal screening solely because the results might be wrong, and one might, in error, abort a non-disabled baby.

In my view aborting a disabled baby is just as much a tragedy as aborting an able bodied child. *Link* does a disservice to those (like me - I have spina bifida) it is supposed to support by using such negative language.

Alison Davies
Blandford Forum
Dorset

Editor's note: The simple intention of the article was to express the views of a woman who refused to follow doctor's advice to abort based on the results of a pre-natal scan.

Every woman is different and, in the same situation, would have reacted differently. For those interested in the editor's view of Carol's dilemma - I wrote the article as an expectant mother who had herself recently refused an ultrasound scan for various reasons including being repulsed by the idea of possibly having to choose between the life and death of a baby which was disabled.

The use of the word 'perfect' was perhaps unfortunate by implication but was merely a 'short-hand' way of describing a baby which was, by the majority of people, considered 'normal' or 'average.'



ON 20 December Bass Taverns sponsored 80 disabled children for a

day in Lapland to meet Father Christmas.

My little girl Kylie, who has hydrocephalus, was one of the children nominated and had a fantastic day.

Kylie had a reindeer ride, met the 'real' Father Christmas and

wrapped up very warmly for the minus 27 degrees temperatures.

Please say a huge thank you from us to everyone who made the day possible. The trip was 'When You Wish Upon a Star'.

Gill Pratten
Green Hill
Cleethorpes
South Humberside



Dave's diary

This issue of Link welcomes new columnist David Fulford-Brown who will offer his own very personal view of disability and society

I'M BACK from hospital and (thankfully) all went well. This was confirmed when I went to Sheffield for a check-up. Usually my check-up consists of a couple of scans and the usual admonishment to lose a couple of hundred pounds. This time, the doctor and I had something more important to talk about: – an article in *The Sunday Times*.

On page 9 of the main section, there was a story about a man with Down's Syndrome who was refused heart surgery as a child ('Mother to sue over Down's son'). It is a shocking story in itself, but that's not all.

As well as Down's Syndrome, the boy had spina bifida (although the doctor didn't diagnose it). When the article got to SB, it described it as 'a disorder progressively destroying his spine,' I had never heard of this effect and was rather concerned! I showed the article to my doctor. He reassured me that the spine does not progressively degenerate and that the story was another example of the media getting their facts wrong (again!)

I am sick and tired of the ill-informed media publishing blatant cobblers about spina bifida! It is not just that they are wrong, but that the (usually negative) announcements can have very detrimental effects on my nerves, work and social life! They always seem to be pronouncing the end of my life, or that something major is about to go wrong with my innards!

If the media must get stuff wrong, it's a pity it isn't on the plus side of life. I wish they'd write about people with SB having a great

capacity for or being immune to, alcohol! Or what about 'People with SB are great story tellers?' 'People with hydrocephalus can tune into next week's lottery numbers?' 'Motability to give Ferraris to people with spina bifida?' (My insurance agent would die of shock!)

Here's my suggestion to combat the problem: *A Journalist's Guide to Spina Bifida and Hydrocephalus*. This could be a small booklet, sent to the major media organisations, highlighting all the old wives' tales and falsehoods perpetrated by the ignorant. It could have a 'top 10' of popular misconceptions. One that comes to my immediate attention is that the oldest person with SB is 23! That gave me a fright at 21!

As well as common misunderstandings, the booklet could also talk about the origins of spina bifida, the screening programmes and folic acid. I'm sure ASBAH's press people have already sent this information to the major media. I just wonder if collecting all the information on SB into a compact, easy-to-understand booklet might improve the situation.

As I've got a computer and time on my hands, I would be happy to type up a booklet. All I'd need is the relevant technical info and details of any old wives' tales you, the reader, have heard. Write to me c/o *Link*.

Failing the above, I suggest we go round to Fleet Street, Docklands, etc, armed with baseball bats and 'explain' the situation to a few p***ed old hacks baffled by new technology (to paraphrase *Private Eye*).

Great escapes in 1996

A RANGE of outdoor courses for disabled people during 1996 can now be booked by contacting the Calvert Trust Keswick.

Each course is custom-designed

for each group and can include rock climbing and abseiling, water activities, riding and trap driving, hill walking, orienteering, paragliding, mountain biking, camping,

archery and hockey.

For further information contact John Crosbie, The Calvert Trust, Little Crossthwaite, Keswick, Cumbria, CA12 4QD. Tel: 017687-72254.

HOLIDAY ACCOMMODATION

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



Mar Y Sol – Tenerife

Wheelchair accessible apartments. Heated pool with hoist. Restaurant, poolside bar. Equipment hire. Ring today for cheapest summer and winter prices.

Algarve – Portugal

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

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)

Fully equipped purpose-designed for wheelchair access mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. Details from Mrs B Nunn, tel: 01903-763473.

SUSSEX BEACH HOLIDAY VILLAGE, Bracklesham Bay, near Chichester.

Wheelchair accessible chalet, sleeps six. Full use of all facilities, outdoor pool, children's club, full entertainment programme. Details telephone Mrs Rawlings, 01703-368278.

FOR SALE

MOVEABLE seat (driver or passenger), suitable most makes of cars. Electronically controlled to go up, down and sideways. £300 ono. Dr J Gray, 66 School Road, Hall Green, Birmingham B28 8JA.

PACESAVER Eclipse four-wheel electric scooter and charger, puncture proofed. Cost: £2,015

January 1994. Very good condition, hardly used. £1,195 ono. Tel: 01622-698043.

MEDISCUS Air Bed, a self-contained bed to relieve pressure sores, complete with heaters, tilts and push-button control, free to deserving home. Three years old, very good condition. Tel: 01623-860652.

WANTED

JASON ROBERTS is looking for a cheap, small automatic car complete with hand controls to gain extra practice prior to attempting his driving test. Can you help him or make some useful suggestions to him? He can be contacted on 01352-713425 (North Wales).

LINK Rates

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Small adverts for the next issue of *Link* (April) should be submitted by **Friday, 6 March**. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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