

Link

AUGUST/SEPTEMBER 1992 NO 141

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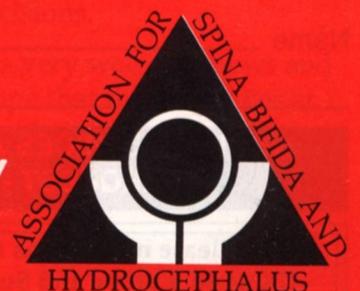
The magazine for people with
Spina Bifida and/or Hydrocephalus



IN THIS ISSUE

IT'S YOUR VOICE, YOUR ASBAH -
SPECIAL 5-PAGE REPORT ON OUR DISCUSSION DAY

A GOOD START TO A FULL LIFE





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UK £4.80, Europe and Surface Mail £7.50, Airmail £15. This is the first UK subscription rise since 1985



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Editor: Gill Winfield

Published by ASBAH,
 ASBAH House,
 42 Park Road,
 Peterborough PE1 2UQ
 Telephone: 0733 555988.

LINK SUBSCRIPTION 6 EDITIONS -
 12 MONTHS

UK£3.30

Europe and Overseas Surface Mail ..£5.60

Air Mail£12.50

All payments should be made in Sterling.

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Registered charity no. 249338.

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Getting In On The Act - a joint report by the Audit Commission and Her Majesty's Inspectorate on the provision for pupils with special needs - highlights the wide variations of support being offered by Local Education Authorities. The report points out that the production and review of statements are often given low priority and many parents are not fully involved in the Statementing process. There is a lack of clarity about what is meant by 'special needs' and the responsibility and accountability of schools and LEAs.

The recommendations of the report emphasise the need for:

- ◆ National guidelines to define the term 'special needs' and the responsibilities of ordinary schools and LEAs
- ◆ Increased accountability to parents
- ◆ Giving parents the right to choose schools
- ◆ Increasing the capacity of ordinary schools to deal with children with special needs
- ◆ Delegating resources for special needs more fully to schools.

ASBAH education adviser Peter Walker recognises the shortfall in attitudes and provisions of many LEAs and encourages parents to stand up to them and not accept less than is necessary for their child.

Baroness Blatch, the Education Minister, has announced that the Government should bring forward proposals for consultation later in the year. These will include:

- ★ Improvement in access to the present arrangement for assessments and statements
- ★ The provision of a shorter assessment process
- ★ The right of parents to express a preference for their child's school
- ★ The provision of more comprehensive rights of appeal for parents who are dissatisfied with LEA decisions.

This is very welcome news and we hope that the anomalies at present being manifested by many LEAs will be rectified.



COVER - Continence adviser Mary White with young ASBAH members. Mary is co-author of A Good Start to a Full Life - page 12



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Caring Costs

A campaign will be launched this autumn by Caring Costs - a coalition of almost 40 voluntary organisations, including ASBAH. The campaign aims to achieve an adequate income for all carers regardless of their age, sex or marital status. Caring Costs believes that carers should have an adequate independent income for basic living expenses and an allowance to cover the extra costs of caring.

The campaign will be asking politicians and others to acknowledge the extra costs facing many carers and people with disabilities, and to provide financial support to meet these costs.

For further details, send an A4 SAE to Caring Costs, 505 Charitybase, 50 Westminster Bridge Road, London SE1 7QY.

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Civil Rights - the fight continues

ASBAH vice-president Baroness Masham was able to add her personal testimony when the Civil Rights (Disabled Persons) Bill had its second reading in the House of Lords recently. Lady Masham, a wheelchair user herself, told of how she could only gain entry to her local church to attend a funeral - when a ramp was set up. And she gave another example of access problems when she recounted a trip down the M1: "I called in at a petrol station. As I tried to attract the attention of an attendant, I noticed a bell with the wheelchair sign. It had been placed by a window, high up, with a large step in front, making it totally out of reach for someone in a wheelchair or even for someone ambulant.

"I explained to the attendant that it needed to be reached by someone seated in a car, as many people cannot get out without help. Those are the people who cannot put petrol in their cars. She told me that they had only just got the bell. What is the point of giving such aids and making them totally unusable?"

The Baroness feels that Civil Rights legislation would help in these and much more serious cases of discrimination by drawing people's attention to the problems faced by disabled people.

The Bill was introduced in the Commons earlier this year by Mr Alf Morris MP but failed to get a second reading because it was 'talked out' by a Conservative MP. Mr Morris's Bill aims to confer "long awaited civil rights and freedom" to millions of people with physical, mental and sensory disabilities.

The Bill now goes into Committee in the House of Lords and Mr Morris is hoping to reintroduce it in the Commons after the summer recess though it seems unlikely to succeed without *positive* support from the Government.

★ ★ New York City Marathon Man ★ ★

Mobility adviser for ASBAH, John Naudé is poised to take place in the New York Marathon later this year. John will be entering the wheelchair-athlete section of the race and hopes to raise between £3,000 and £5,000, from sponsorship, for the Whizz-Kidz fund - which provides sophisticated wheelchairs for disabled children to improve their independence, freedom and self-respect. Last year Whizz Kidz provided more than two wheelchairs a week but they estimate the total number in need to be 60,000 - so they have a long way to go!



If you would like to help Whizz Kidz on their way, John will be delighted to send you a sponsorship form. If John can raise £2,500 by the beginning of September an airline has offered to give him a free flight to New York.

For more information contact John on 0733 555988.

New Caravan for SASBAH

Michael Checkland, Director General of the BBC, officially opened SASBAH's new mobile holiday home this summer. The caravan, which is situated at White Horse Holiday Caravan park in Selsey, Sussex, can sleep up to six people and is fully wheelchair accessible - including the shower room - and the kitchen worktops are at wheelchair-user height.

This replaces SASBAH's old caravan which they have been letting for 18 years. Costing £18,750 for the caravan alone (then there's the verandah, ramp, adaptations, site fees etc), the new holiday facility was made possible by grant of £18,000 from the BBC's Children in Need appeal and funds from three trusts.

The caravan is non-profit making and is available from April to October for members of SASBAH and other local associations, bookings are dealt with by Mrs Betty Nunn on 0903 763473.

Amnifiltration and fetal abnormalities

Amnifiltration is a screening technique which involves passing a needle into the uterus to take a sample of amniotic fluid in the same way as amniocentesis. But, instead of removing the fluid completely it is passed through a filter and returned to the amniotic sac. In this way it is possible to remove just the cells floating in the fluid whilst returning the fluid to its original place and can be performed as early as 10 weeks of pregnancy. Results are available approximately two weeks later. The aim of the amnifiltration is to detect chromosome abnormalities such as Down's Syndrome.

An article in the Mail on Sunday, earlier this year, seemed to suggest that this technique could be used to detect spina bifida and anencephaly but this is not the case. However, some cases of spina bifida and anencephaly were detected, when using the amnifiltration technique, but this was due to the early ultrasound scanning which is performed as part of the procedure.

Accessible Youth Hostels

The YHA now offers accommodation for disabled people at two of its locations in central England. Ilam Hall in the Peaks and the hostel at Sheringham, on the Norfolk coast, have both been awarded the Accessible Symbol after inspection by the Holiday Care Service.

Costs are kept low - from £7 for bed and breakfast - and all ages are welcome. Further information on the YHA and facilities for disabled visitors from them on 0629 825850.

Exchange your home

HOMES (Housing Organisations Mobility and Exchange) is a Government funded organisation which works with councils and housing associations, offering a range of services to help people who want to move home.

If you would like to swap your tenancy for one elsewhere you can register with their 'Homeswap' service and they will put your details on their new computer system. Every month HOMES produces lists of people wishing to move into your area and you can see these lists at your council housing office, your details will be sent to the offices in the area you wish to move to. The details include whether or not the accommodation has been adapted for disabled tenants.

For more information contact HOMES at 26 Chapter Street, London SW1P 4ND, telephone 071 233 7077.

A Wholistic Approach

A three-day, multi-disciplinary conference for professionals is being organised by ASBAH in conjunction with North Derbyshire Health Authority.

Entitled "A Wholistic Approach", the conference will be concerned with Medical and Surgical Management (day 1); Statementing, Integration, Support and Psychological Implications (day 2) and Mobility, Community Therapy and Self-awareness (day 3). There will also be a choice of workshops, bookstalls and trade stands relevant to the subject of each day.

"The aim of the conference is to increase mutual understanding; share knowledge and raise the level of awareness of the multi-disciplinary problems experienced by professionals in the provision of care of children in hospital, in school, in the community and support for the family."

The cost, inclusive of full board, transport, dinner and entertainment on Wednesday and Thursday evenings is £230. If there are vacancies, consideration will be given to one or two day attendance at a cost of £50 per day plus the cost of accommodation and dinner, as appropriate.

The conference will be held from Wednesday 30 September to Friday 2 October at Willersley Castle, Cromford, Derbyshire. Delegates are welcome to bring partners, space permitting, as the venue and surrounding area offer many attractions.

Contact Michael Flynn, Conference Co-ordinator on 0335 42597 for details.

NEWS IN BRIEF

Irish Jig

ASBAH member Gerry Phelan hopes to set up a social and support group for Irish people with disabilities in North London. To raise funds for this venture he's organising a dance and buffet on 11 September at Haringey Irish Centre in Pretoria Road, Whitehart Lane, London N17.

If you would like to go to the dance or are interested in the new group, contact Gerry, at the centre, on Fridays between 1pm-4pm on 081 345 6893.

Welsh Wedding Bells

Our very best wishes go to Sandra and Ken Divall who were married in May. They are both members of ASBAH and have asked us to thank Mid-Wales Association for their "continued fantastic support".



Saddle sore for ASBAH

TWO long-distance, sponsored cycle rides will help to swell ASBAH's funds this year.

A 2,500-mile, round-England cycle ride has just been completed by Jim McGrady, who returned home to Skelmersdale, Lancs, in July - six weeks ahead of schedule. His log book was stamped at 220 police stations en route as proof of passage.

And Alistair Cameron, of Putney, South London, is planning a Land's End to John O'Groats bike ride beginning on 17 August.

St Helen's Celebrates

St Helen's Association celebrated its 21st birthday this year with a lavish party for members. Several founding members attended and tribute was paid to Nancy Maddocks who has been secretary since the beginning.

Nancy Maddocks (centre) with the Mayor & Mayoress and past & present members of St Helen's.



Photographic Evidence

Work has started on the joint housing project by Sheffield ASBAH and the Association for People with Cerebral Palsy - reported on in the June issue of LINK. And to prove it, here is the photo of the turf cutting ceremony - before the heavy machinery moves in.



Barcelona Bound

We wish good luck to all those athletes with spina bifida and/or hydrocephalus who are competing in the paralympics in Barcelona. We know there are representatives from swimming, weightlifting, tennis, wheelchair racing and many more sports - and we would be delighted to hear about your experiences - write to LINK or LIFT at ASBAH House, 42 Park Road, P'Boro PE1 2UQ.

Fond Farewell

Mike Mason bids farewell to Sheila Glaister, former Clwyd fieldworker, at North Wales ASBAH AGM earlier this year. Pam Heseltine will be taking over as fieldworker for this area, in August.



Coast to Coast for Fund-a-Fieldworker

Christine Ramshaw of Kilburn found the financial incentive of 'doing it for ASBAH' certainly helped when she needed that little extra boost to keep her going on Wainwright's Coast to Coast walk this summer. Miss Ramshaw walked approximately 192 miles from St Bees in Cumbria to Robin Hood's Bay in Yorkshire and raised £250 for our Fund a Fieldworker campaign.

IT'S YOUR VOICE - YOUR ASBAH

A 5-page feature on a vital discussion

- * This feature has been prepared to give some of the flavour of the discussions at our 'Your Voice within ASBAH' discussion day and to prompt thoughts on further action.
- * Letters for publication on any of the issues raised, or anything else relevant to the work of ASBAH, would be welcomed. Please write to: The Editor, Link/Lift magazines, ASBAH, 42 Park Road, Peterborough PE1 2UQ.
- * If any member would like to be involved in further discussions, or in the work of the proposed steering group, please contact Tony Britton at the above address.

ASBAH has relaunched its programme to ensure that the views of its members with disabilities continue to be represented at the highest levels within the Association.

A discussion day, entitled 'Your Voice within ASBAH', was held at the national centre in Peterborough earlier this summer - with volunteers being invited to return for the first meeting of a "central steering group" set for 21 October. The group will consider what role ASBAH's disabled members see for themselves in the Association.

Executive director Andrew Russell explained the need to shift direction. ASBAH's first groups had been set up by parents together with professionals and it was these groups which gave birth to the National Association, he said.

The children of these parents were now adult or growing up and wanted to voice their own opinions. It was now time for ASBAH to "come of age" by taking these views on board.

ASBAH chairman Patrick Daunt, in welcoming support for a steering group of disabled people to take forward ideas from the discussion day, said: "Doing something for yourself is absolutely fundamental to becoming powerful yourself."

The day had been an important first step which ASBAH will follow up by creating opportunities for our members with disabilities to meet, share ideas and develop more influence in ASBAH.

The discussion day, held on 27 May, was attended by 28 members with disabilities. Besides Mr Daunt, there were three other members of the Executive Committee present to listen and

report back to the executive.

Several participants who had been involved with the LIFT young people's working party in the mid-80s attended and were keen to see the resurrection of the LIFT structure, or something very much like it.

Zem Rodaway, from Hull, invited to give one of the keynote opening addresses, commented: "LIFT lacks direction at the moment. It seems to have faded, leaving only the magazine. Disabled members should be taking a more active part. We should take a more campaigning stance."

Moves to actively seek out people with spina bifida and/or hydrocephalus to join parents and professionals on ASBAH's decision-making committees have started to bear fruit.

The Cambridge-based actor, John Henry Hughes, who has spina bifida and is a leading disability rights activist in the actors' union Equity, joined our Services Committee this summer.

The only other person with a disability serving nationally at present is Phillip Brown, from Hull, who is a member of the Executive Committee.

POINTING US IN THE RIGHT DIRECTION

Welcoming visitors to ASBAH House, Mr Daunt said financial problems caused by the recession had resulted in many things being cut out of ASBAH's budget - including a full-scale LIFT Encounter to consider future representation by young members within the association.

But it had become evident to the Executive Committee in recent months that the views of our disabled members must be reflected at the highest levels, and this discussion day was a good way of relaunching this process.

Besides the chairman, there were three other members of the Executive present to listen to what was said - Brian Henley, John Lewis and Phillip Brown.

"We are here to listen to what you have to say to us. I am sure that also goes for the officers of ASBAH," said Mr Daunt.

Disabled people nowadays required more than a nice home, the best possible medical care and protection from the outside world. Today, their expectations were more challenging.

Our members demanded rights enjoyed by all young people to continuing access to **education** throughout life, to worthwhile **employment** which could be full or part-time, paid or voluntary, and to have the means available in the immediate **environment** to help people live life to the full. Mr Daunt called these facilities "The Three Es".

Individuals had their own way of combining the Three Es to make their own way in life. Although we all had to establish our own ways

in life, we don't have to do it all on our own but should welcome help and support from others. Mr Daunt saw ASBAH as a partnership of disabled people, their families and professionals which should be made to work as well as it possibly could.

Zem Rodaway, from Hull, who frequently writes for LIFT magazine, was invited to



Participants gather their thoughts for the report back session.

contribute an opening statement to help focus thoughts. She chose LIFT as her theme, saying the organisation had great potential even though it had faded in recent years into being just a quarterly magazine.

There used to be a LIFT committee, some areas had group meetings once a fortnight. There were even weekend conferences at Owens Park in Manchester when members could overcome problems by learning from each other - not just from able-bodied professionals perhaps lacking personal experience.

"LIFT seems to be lacking direction at the moment," she said.

Executive director Andrew Russell said that ASBAH had traditionally aimed its services at children and parents. Indeed, the first groups were set up by parents together with professionals and these gave birth to ASBAH.

Now we recognise that those with spina bifida and/or hydrocephalus were growing up. ASBAH had to recognise that their views were not always those of their parents and these separate opinions had to be taken on board.

ASBAH gathered information so that Government at all levels could be better informed about the needs of people with spina bifida and/or hydrocephalus and we supported research. Fieldworkers advised families and individuals over a whole range of issues, backed up by specialist disabled living advisers.

It is also part of ASBAH's role to educate professionals about the needs of people with the disabilities and to inform the public as part of "changing the outside world" to allow disabled people to operate successfully in it.

"ASBAH is quite a small organisation, we're not rich and we have to consider very carefully how we spend our money and how we target what we do. In the process, we must listen more regularly and more often to your voice," he said.

Mr Russell said decisions were made through committees which brought together people of all shades of opinion but with a common interest in disability. Most were made up of parents and there were few committee members with disabilities yet but we encourage more to join.

"I can't promise you that we can suddenly change things but we can move in a direction which gives proper weight to your views and wishes."

VISITS TO THE GROUPS

Tony Britton and Gill Winfield report from two of the group discussions

This group of 10 people - ranging from 18 to 48 - quickly elected East Sussex youth worker Kevin Towner as its leader. But it was Terry Denyer, who has just taken early retirement from his personnel job in local government, who fired the opening shots.

Mr Denyer, from Kent, said he went back to the 60s when national ASBAH had "a ghastly little place" in the City of London which was inaccessible. At Peterborough, that thankfully had changed.

Unfortunately, however, ASBAH's lack of public profile had not changed. There were also too few people with spina bifida and/or hydrocephalus actually involved in decision-making and that made him "very, very disappointed".

Hull resident Lee Edwards: "We have been formed for 25 years and still you never hear about ASBAH. There are people today who have children with spina bifida who know nothing about it."

Terry Denyer: "Certainly some people of my age and a number of people I know of have never had anything to do with the Association. The reason is clear: they coped before the Association came along and they're carrying on coping. I can't argue with that; my parents even felt like it."

Craig Allerton, an A-level student from St Helen's, said that although he had known of ASBAH for some years he had only started taking an active interest when he started receiving home visits from fieldworker Alan Langshaw. He was "lucky" to have gone to

mainstream school but this had reduced his contacts with people with disabilities and his knowledge.

Kevin Towner's hackles rose when the talk came round to the public imaging of disability. He was furious whenever able-bodied people turned people with disabilities into victims in order to generate funds - an approach he said which was epitomised in the Telethon programme.

Organisations of disabled people rejected this approach. Associations like ASBAH had never tried positive imaging, he said. "I can't agree that there are no ways of raising public support and money without using negative images of disability. I am sure I am right. I can prove I am right and there are plenty of campaigning groups behind me".

Several of the group had fond memories of LIFT conferences of old but were told firmly by disabled living adviser Leonie Holgate that it was no good expecting somebody else to organise them for you. It would be a good sign of the growing maturity of people with spina bifida and/or hydrocephalus if they took over the reins themselves.

The concept of the "central steering group", setting an agenda for future discussions and activities, emerged from Kevin Towner's group - with five people signalling that they wanted to be on it. This should lead on to a major conference and the steady tramp of people with spina bifida and/or hydrocephalus into positions of influence within ASBAH.

Zem Rodaway kicked off, in her group, suggesting that a group of members from various parts of the country should meet together, perhaps quarterly, to bring forward ideas from their locality and to let ASBAH know what they want. She also wanted to see more

representation on ASBAH committees.

Michelle Hawley (from Five Oaks) was keen to promote better understanding of disability amongst the general public and for new parents of spina bifida children. She said: "Helpful people can be patronising and take offence if you reject their help - we want to be able to make our own mistakes in learning independence".

Members of the group felt that a good way to 'educate' able-bodied people about disabilities would be to start with school children and several members said they would be very willing to go into schools to talk to pupils. But they also wanted to educate families with one disabled child - they felt that often the able bodied members of the family didn't understand the problems of the one with spina bifida. Members of the group again expressed a willingness to make themselves available to parents who had a young child with spina bifida to help these parents towards better understanding.

Although the original 'LIFT' organisation seemed to be defunct there was a desire to have something in its place, particularly in the form of weekends where members could get to know staff and each other and share their views. If there were to be any such weekends Zem suggested that the members should be more involved in both setting them up and running them.

Some members had tried mixed able-bodied/disabled social groups but found the able-bodied tended to be there as "do-gooders" and wanted to organise the groups.

Other subjects raised were access and labelling (members particularly objected to travelling

Continued on page 10

Continued from page 9

to school or social activities in a minibus with 'ambulance' on the side - this used to be a condition for obtaining tax allowance on the vehicle!).

One of the group volunteered to

get in touch with UDET to find out about the possibility of getting into schools to talk to pupils.

Zem wanted us to use the LIFT magazine to let members know that the LIFT group would be starting in a different way - possibly with a new name.

A taped version of LIFT was suggested for members who have visual difficulties or problems with reading.

A LIFT committee could meet at ASBAH house to communicate with the Association and keep in touch with what ASBAH is doing

FEEDBACK

At the end of two hours of discussion, the four groups reported back to a final meeting of all those attending.

Topics touched on by each group include:

Group 1

(Alan Langshaw reporting).

- He said the group felt ASBAH's counselling service was a necessary component and should not have been disbanded. This resulted in more work for other staff.

- We had to ensure our services were getting through to people who need them. One member said she felt isolated in her part of the country.

- Young people should be encouraged to take a greater share in the running of local associations. Running local LIFT groups would give aspiring members valuable experience of committee work.

- Mainstream school teachers need educating in the disabilities. Pupils from mainstream schools may also need help when they leave as they may not have had skills training in independent living which is provided by special schools.

- ASBAH should provide more information as to how it prioritises its spending.

- ASBAH needs to campaign more to get employers to acknowledge the rights of disabled people.

Group 2

(Zem Rodaway and Michelle Hawley reporting).

- Members wished to explore the idea of going into schools to talk to children directly about disability.

- ASBAH should consider starting a talking version of LIFT magazine on audio tape to help those with impaired vision.

- LIFT-type weekends would be a good idea, with disabled members having more say in running them.

- A committee could be set up by disabled members who wanted to pursue the ideas expressed today, perhaps meeting quarterly at Peterborough.

- Executive committee members could be listed in LIFT so members know who to contact if they want to make a point.

Group 3

(Points not covered in sketch of this group's discussions; Leonie Holgate reporting).

- She said the group stressed the importance of wider publicity with more disabled people involved in preparing it.

- All schools should be accessible to disabled pupils, not just designated mainstream schools.

- ASBAH should clearly define the role it was giving to disabled members in its decision-making structure.

Group 4

(Jean Isherwood reporting).

- LIFT weekends would be a good way of communicating and could provide beneficial self-help.

Identify the age-group which would qualify for membership. Should LIFT be regionalised? Disabled members to join in ASBAH policy and budget-making.

- Important to maintain pressure for civil, housing and benefits rights.

- Bursaries, scholarships and independent living funds were wanted.

- Professionals should be educated about the needs of people with spina bifida and/or hydrocephalus and theatre-in-education groups could help to communicate ideas effectively to children.

From Your Questionnaires

Those who took part were invited to complete a questionnaire after the event and return it to Peterborough. Comments received included:

● "Access, employment and education should be dealt with as equally important, and are in many ways linked to one another.

"We needed more time to do anything really worthwhile and maybe the most constructive thing happened when some of us volunteered to work together to take matters forward. I doubt if any of us got questions answered, and should not have expected to; it is not so much a question for me of wanting questions answered as it is a matter of how best we all can

ensure that the future generations of people with any disability do not suffer the same difficulties as previous generations.

"One real concern I have is the defensiveness of at least one member of staff of ASBAH. I hope he does realise that many of the things said come from frustration in not being allowed to have more say in the past in the work of ASBAH."

- What interested you most?
"Discussion about revitalising LIFT and about us - as people with spina bifida and/or hydrocephalus organising ourselves and taking responsibility for it - ie making it our organisation. Also getting LIFT magazine on to tape and having an input into the running of ASBAH."

"There was not enough time to discuss everything. I feel we only scratched the surface and didn't go away with many definite plans, although I realise this all takes time.

"I would like to be involved in an action group; I think it would be

helpful if such a group (if enough people are interested) could meet quite soon - say within two or three months - and if the meeting could be on a Saturday so as not to exclude anyone working full-time."

- "I enjoyed seeing the Director there and that some people were actually listening to what I said. I am concerned that the top management do not really listen to what the young people say."

- "Most of our group thought the LIFT group should be set up and that a LIFT committee should meet for a weekend, possibly once a year."

- "Right at the end of the day, there seemed to be a wish for some form of steering committee to put the wishes of people on the day into action. While I would very much like to be involved in this work, I don't think my local association would want to finance regular attendance at meetings at head office. Proper support and financing should be found.

"I know that there was an awful

lot of talk about the LIFT organisation, the way it was a few years ago, but I'm not convinced about following that model.

"Although there should be a specific 'club' within ASBAH for the younger end, say up to 16, I also feel there should more official input by anyone with spina bifida, whether through a separate section or not. In my view, the organisation can only remain credible with a shift in emphasis from control by parents and professionals to control actually by people with spina bifida and/or hydrocephalus."

- "I was not able to stress the importance of funding sufficiently forcefully. It seems impossible to make people understand that the money must be earned before being spent."

- "How will ASBAH consult and represent disabled people? I am interested in being on the 'central steering group'."

APLOGIES

Paul Fagan, an equal opportunities worker with the London borough of Brent, had hoped to attend. But he sent his apologies and left a list of questions which he wanted to put on the agenda for future discussions.

He wanted to know how many people were on ASBAH's payroll, full or part-time, and what percentage of those were disabled?

Mr Fagan said ASBAH should start targeting more disabled people to ensure the Association represented their views fully and should be more of a campaigning organisation.

One area to watch was the effects of local management of schools and opting-out of local authority control, on the intake of people with spina bifida and/or hydrocephalus into mainstream schools and the consequent level of resources which school governors would dedicate to pupils with special needs.

Would governors resist integration by "blacking" the selection of pupils of lower academic ability?

Another area was privatisation of local authority services and the likelihood that, without adequate contract compliance procedures, private contractors would not meet legal requirements on the employment of people with disabilities. Often, when the local authority shed its own staff following privatisation, they no longer retained enough skills in-house to claw back an errant service - even if they wanted to.

Peterborough couple **John and Mary Gilbert**, who also sent their apologies, said housing should be a top ASBAH priority and suggested that the Association explore link-ups with specialist housing associations to ensure a steady supply of fully accessible accommodation for people needing varying degrees of independence.

They were particularly interested in a story which appeared in 'Disability Now' about the Leeds Permanent Building Society which, with the Disabled Housing Trust, was offering an interest-free mortgage to disabled people wanting to buy a flat or bungalow in a development at Victoria Dock, Hull. People on income support would have the interest paid by the Social Security Department of up to £245 a week (the new residential care homes allowance), with a weekly service charge depending on the degree of care.

Mr Gilbert suggested that ASBAH should seek to persuade the Disabled Housing Trust to co-develop a similar scheme in Peterborough's proposed multi-million pound Southern Township.

A good start to a full life

By ASBAH Continence Advisers Mary White and Jane Williams

There was a time when people born with spina bifida and/or hydrocephalus did not die of old age. They died while still young, of renal failure, and the quality of their short lives was questionable when it became possible to preserve renal function, children were educated in special establishments which were frequently residential (Anderson, 1973). The children were well cared for in these establishments, changed every few hours and entertained, but their academic education was limited, and they had no responsibilities - everything was done for them and to them by care staff.

It was not envisaged that people with spina bifida would earn a living, and on leaving school they usually moved into a residential centre for adults. These people were denied the pleasures and traumas of family life, the right to make their own mistakes and the opportunity to receive an education which would prepare them for independent living in a caring community. Their quality of life was poor, although their longevity considerable.

Integration

Children born with spina bifida and/or hydrocephalus are now treated as 'normal' and educated with their able-bodied peers. Care centres on helping them to overcome the effects of their condition, so they can live as independently as possible. Healthcare and other professionals are endeavouring to foster a positive attitude in society towards people with disabilities, so that they are not discriminated against and can lead a full life. There is, consequently, much genuine concern in society about 'meeting

Managing continence in children with spina bifida and hydrocephalus

special needs' and 'integration' (Abeson, 1975), but the political issues raised frequently eclipse and overshadow the difficulties faced by children or their families, teachers and peers. In some cases, individual needs are not being met due to fear of 'labelling' and thus 'prejudging those concerned', and this means that some children are not being properly identified or assessed.

Education

Success in mainstream school for any child is dependent upon the child's resilience, and this is doubly the case for a child with disabilities. Continence and independence training are invariably non-existent in schools (White, 1990) and teachers are frequently unaware that a child with spina bifida is struggling with double incontinence and its social consequences. The added problem of hydrocephalus, with its effect on the learning process and the possibility of associated behavioural problems (White, 1990), is neither anticipated nor properly understood in the school system.

The amount of school time lost due to hospital appointments and time 'off sick' make it almost impossible for any but the brightest children with spina bifida to do much more than struggle through their school life. On leaving school they have not generally received sufficient relevant personal and social education to enable them to either

earn a living or live independently in a society which is increasingly geared towards self-sufficiency.

Many of these young people consequently suffer from low self-esteem and their sexual awareness is damaged by the intrusion of personal care (Hunt, 1981). Young people with spina bifida are likely to know little about their condition and understand even less. They have probably never had any counselling, so will have many unanswered questions. There is still much to be done to improve the quality of life of people living with spina bifida and hydrocephalus so that the prospect of long life becomes truly desirable.

Continence management

The physical and intellectual impairment associated with spina bifida and hydrocephalus is considerable (White, 1990), and affected children are likely to have mobility, educational, emotional and continence problems. The management of incontinence is a priority, and training should be undertaken at the usual age. Neural deficit is a barrier to full continence, but one that can be overcome, and a habit training approach should be adopted 'creating' the desire for bladder and bowel evacuation rather than 'responding' to it. Incontinence is unhealthy, socially unacceptable and expensive, and is a problem that can usually be successfully dealt with.

Babies born with spina bifida and/or hydrocephalus are likely to have a neuropathic bladder and bowel (Hunt, 1981). This may become apparent within a few days, but equally may not become obvious for some months or even

years. Parents will require careful counselling when their child's condition is diagnosed, and this should concentrate on the possibilities that exist for the child, rather than the negative aspects of living with the condition. They should not, for example, be told 'your child will be doubly incontinent' but rather that the presence of a neuropathic bladder and bowel means that full continence control will have to be achieved by early habit training.

Urodynamic studies and scans carried out early in the child's life and assessment of family dynamics and the social and domestic situation will give urologists, paediatricians and continence advisors all the information they require to decide upon the best method of continence management and training for the child concerned. The chosen method should ensure the future preservation of the child's renal tract, sparing the parents/carers from the emotional and physical trap set by more intrusive daily procedures such as manual evacuations and catheterisation (carried out by carers).

Incontinence in babies and toddlers is considered acceptable, some may even say endearing, but is totally unacceptable in young children, adolescents and adults, both to the individual concerned and to his or her family, peers and teachers. The long-term damage to self-esteem, sexuality and the ability to form relationships is inestimable, and must be avoided at all costs.

The damage to health can be measured in terms of the cost of hospital admissions, of treatment for urinary tract infections and of ordering, supplying and disposing of aids and appliances for years on end. The cost of treating the resulting behavioural, educational and psychological effect is measurable, but the fact that it is distributed between the different

disciplines makes it difficult to appreciate both the size and complexity of the problem.

Establishing a daily routine

As soon as investigations are completed, the continence advisor or a nurse with suitable experience should be introduced to the child. She or he can advise upon the importance of diet, and can devise a daily care plan that will fit in with the family's lifestyle; an awareness of the possible presence of emotional, financial or marital problems is also required, and this requires tact and sensitivity in eliciting. As the usual age for continence training approaches, the nurse or continence advisor can set the stage for habit training if appropriate.

Bowel A simple daily routine should be established to encourage self-evacuation, and exercises such as blowing up a balloon or coughing can be taught to facilitate this (Claydon and Agnarson, 1991). Giving the child a high-fibre diet and allowing him or her to spend 10 minutes every morning and evening on a potty with supported sides, back and safety bar may be enough to enable daily self-evacuation and to avoid the occurrence of the 'mega bowel' which is so much a feature of the neuropathic bladder and bowel. Self-evacuation is that which is achieved by the child without resort to intrusive intervention by carers, such as manual evacuation.

Bladder Urinary tract infections are symptomatic of inadequate bladder emptying. Carers need to be aware that dryness does not necessarily indicate that the bladder is empty. Children with neuropathic bladders with or without reflux generally respond well to catheterisation, and this can be introduced soon after birth if indicated. The size of bladder and competence of sphincter will dictate whether or not drugs are required. If there are concerns

about the use of oral oxybutynin, it can be used intravascularly (Jamieson, 1989). A simple clean procedure is sufficient and the catheter should be rinsed well before and after use and not sterilised.

Children with hydrocephalus can be taught a simple step-by-step route to self-catheterisation. The great variety of catheters available on the market enables the continence advisor to experiment and find the one which best suits the child. Results should be charted carefully to establish the maximum dry period, and this can be used to establish the child's 'safe dry period'. If, for example, the child is usually dry for three hours, the 'safe dry period' should last for 2.75 hours to avoid 'accidents'.

The use of nappies should be actively discouraged - they do little for the child's self esteem, particularly at school, and are not helpful in encouraging the child to become continent. Reusable pants with a reinforced crotch should be sufficient when the child's routine is well established. These can be easily purchased, and can be machine washed with the rest of the laundry. A daily intake of cranberry juice is known to have an antibiotic effect and would also be beneficial for bowel management. The commercially prepared juice has a low concentration of cranberries, but is still beneficial (Sobota, 1984; Blatherwick, 1923).

Charting results to assess the pattern of micturition is useful, and adjustments to the child's routine can then be made if necessary. The physiotherapists, occupational therapist and pre-school advisory teacher should now be involved to ensure inter-professional co-operation and a daily care plan are formulated that will allow for other demands on the child's time.

The child should be given a multi-professional assessment to ensure

that his or her physical, educational and emotional needs will be met at school. The assessment should result in a statement of special needs and the local education authority's recommendation for school placement, advisory and support requirements. If appropriate assessment is given during the pre-school years, the team should be already working well together and need only transfer their attention from home to school.

Reaching full potential

Children born with spina bifida and/or hydrocephalus can now benefit from medical and social urological management that will enable them to be educated alongside their able-bodied peers. They should be able to enjoy their education without carrying the social stigma and health threat of double incontinence. Relevant personal and social education and access to counselling when it is needed, will enable them to reach their full potential.

If healthcare professionals pool their expertise and resources and work together, the time will come when children born with spina bifida, hydrocephalus and other disabilities will be able to enjoy both good quality of life and a long lifespan. Their social, medical and educational management will then equip them for independent living.

This article originally appeared in Professional Nurse and is reprinted with kind permission of the publishers, Mosby-Year Book Europe.

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BOOK REVIEWS

Current Concepts in Spina Bifida & Hydrocephalus

Edited by Carys M Bannister and Brian Tew, published by Mac Keith Press 1991. Price £25.

This is a book written by those currently working in the field who have a commitment to their subject. Aimed at professionals this tome covers a range of relevant topics and though the medical chapters demand that the reader is informed about the subject, the rest of the book is readily accessible to the lay reader. The chapters are arranged to cover aspects of spina bifida from pre-natal through to adolescence.

Duncan Forrest (who has served on ASBAH's Executive and Medical committees) writes in the foreword: "For the effective management of both spina bifida and hydrocephalus there is a need for a multidisciplinary approach. It is the aim of this book to give guidance to all those who try to help children and adults with these conditions." The multidisciplinary aspect is evident in this book and this is a refreshing approach.

The book covers not only the physical difficulties but also the need to support the family of a disabled child, or the parents grieving for the loss of an unborn child. The difficulties, behavioural and sexual, that occur later in life are also covered but it would have been interesting to have more about marriage and parenthood as this is an important subject for many of our disabled members.

Unfortunately, there is no discussion of continence management which is, of course, an extremely important aspect. However, there is another book in this series entitled 'Neuropathic Bladder in Childhood', edited by Borzyskowski and Mundy. The two books need to be read together to give the reader a complete picture.

Costing £25 this may be rather expensive for individuals to purchase but it would be an invaluable addition to any medical

library and compulsive reading for anyone working in the field. An excellent book.

Talking About Miscarriage

Sarah Murphy. Published by Sheldon Press, The Society for Promoting Christian Knowledge, 1992. £4.99.

First impressions of this book are that it is rather 'congested' with a lot of information crammed into too small a space.

The medical approach used at the beginning of the book and the dense text give it a rather technical feel and this may not be the best first avenue into this delicate subject.

Chapters 3 and 4 deal with the possible emotional and psychological responses to a miscarriage and are far more readable. Sarah Murphy spends some time describing her own miscarriages: one early in pregnancy and the other much later, and how these affected her life. Although there are a few comments from other women "Talking about Miscarriage" does seem a rather one-sided conversation, from the author's point of view. Sheldon Press are Christian publishers and Sarah Murphy does make occasional references to biblical quotations which have helped her to give meaning to her experiences. Some readers may find these an unwelcome distraction, whilst others could find them uplifting.

There is a welcome discussion of how a miscarriage can affect an entire family and it is good to see that fathers are not forgotten.

Some of the author's encounters with medical staff were extremely negative and Chapter 7 "How the Medical Profession Can Help" is written with conviction.

On the whole, this book does contain much which is useful (including contact addresses and further reading) but this material does have to be extracted from a rather congested text.

LETTERS

Robert Zachary, ASBAH's Founder Chairman, brings us up to date with his travels

Dear Friends in ASBAH

Please forgive me for not keeping in touch with you all. I left Australia in July 1991 to go to Newfoundland, Canada, where Janetta and I were married on 1 August - we are the same age.

We had planned to come straight to Australia but that proved impossible, so we spent two weeks in Ottawa, then at the beginning of October we went down to Florida to escape the hard winter, returning in six months to Janetta's home in St Alban's, Newfoundland, Canada.

However, I discovered that my health insurance was very limited and, as I developed a chest infection, we returned to Australia where I am covered by Medicare. This is an ideal climate for us and we still have the opportunity of visiting family in Canada - probably in the summer of 93.

I have continued to receive LINK and am pleased with the progress of ASBAH.

With best wishes to all.

Yours,
Robert Zachary.

Five Oaks can help

We read the "Can We Help?" page in the last issue of LINK and would like to remind readers that ASBAH runs short courses at Five Oaks designed to look at ways to help an individual learn to manage their own intermittent catheterisation, as well as practise other personal care and daily living tasks, increase self-awareness and confidence.

We have many youngsters of this age (11-years-old) who have done extremely well on the five-day course at Five Oaks and it has made a lot of difference to their performance with personal care skills.

The written advice in LINK mentions noting the change in the child's continence management and therefore provides the opportunity for all to decide on the course of action that is needed. Perhaps Local Education Authorities would provide the funding for such a course, as has happened in the past.

Mary Barton MCSP

Disabled Living Adviser, Five Oaks

Attendance Allowance

I am writing regarding the article published in Link, April 1992, concerning Attendance Allowance and the age bar for under-two-year-olds. My daughter was born in 1971 when the Attendance Allowance was introduced and could not claim until she was two. Now, years later, we are informed that the age bar was illegal so I applied for back payment but was refused.

I am now awaiting the outcome of an appeal but I am not optimistic. I have also written to my local MP and will consider writing to the Ombudsman if my appeal is unsuccessful. I would be interested to know if anyone else has applied for back-payment and had a similar negative response. If I am prepared to pursue this matter, it would be better if I could have the support of other applicants.

Please would you print this letter as I feel disabled people such as my daughter are victims of a legal blunder and we as parents have to fight for their rights.

Mrs Jennifer Brewer

Editor's note: We would also like to hear from readers on this subject, please complete the questionnaire on page 18. If you would like to write to Mrs Brewer, send your letters to LINK and we will pass them on.

Discussing personal relationships

A course run by Mobility International offers young disabled people from the European Community the chance to discuss all aspects of personal relationships for people with disabilities. The expert group leaders from England, Holland and Spain are all people with disabilities (including our own disabled living adviser John Naudé) and the working language for the course is English.

This project, aimed at young disabled people, will be held in a completely accessible converted country manor house in Redhill, Surrey. There will be 24 hour personal assistance available and the social programme will include a trip to London or Brighton. The cost, including accommodation is £130 per person, travel awards are available. The course is from 10-15 October. For more details contact Annette Guerda Fischer, 228 Borough High Street, London SE1 1JX, tel: 071 403 5688.

Originally, this course was to have been held in Toulouse in France and was mentioned in 'Out & About' in the April issue of LINK.

Matching the buyer to the seller

If you are thinking of buying or selling a car, the service offered by Mobility Vehicle Search could prove useful. This company maintains a vehicle database of cars for sale, specialising in vehicles for disabled people, they also cover wheelchairs, battery cars, scooters etc. Their nationwide computerised database service matches the details of the seller's vehicle with the requirements of a prospective buyer.

Their service is exclusive to disabled people and is free to those wishing to buy a vehicle. For sellers there is a registration fee, which varies from £21.90 to £37.90 depending on the asking price for the vehicle, and this is a once only payment - your car details will then be retained on the computer for 30 days, this period can be extended free of charge if the vehicle has not been sold.

Buyers can phone 0992 654663 to hear details of vehicles on the computer which meet their requirements.

Sellers can obtain a registration form (or register over the telephone using credit card payment) from MVS at Freepost SB474, 74 Mandeville Road, Enfield, Middx EN3 6BR, telephone 0992 654663.

Keep Able open new centre

Keep Able, who specialise in products designed to make life easier for people with disabilities, have opened a new centre in the Midlands. This store has a 12,000 square feet showroom where customers can try out and choose products, with the advice of professional therapists on hand.

Products on sale include everything from power chairs to bath lifts and garden equipment. Keep Able have recently introduced two new models to their Shoprider range of four wheeled scooters and these, or other large items, can be supplied across the UK through their approved dealers. They also operate mail order for smaller items and a free catalogue is available from their head office - telephone 0933 679426.

The new store is situated at Units 3 & 4, Sterling Park, Pedmore Road, Brierly Hill, West Midlands DY5 1TB.

..... Canals and countryside

Two charities in Shropshire provide holidays for disabled people: one offers self-catering accommodation in the countryside, the other specialises in canalside or canal boat accommodation.

The PINES TRUST has self-catering available for groups or families in a specially adapted house in South Shropshire. The facilities include laundry, games room and a large lounge/dining room with TV/video. Open from March to December the cost is £6 per person per night. Camping is also available in the grounds of The Pines. More information from

Mrs Maureen Jones, The Pines, Colebatch, Bishop's Castle, Shropshire SY9 5JY, tel: 0588 638234.

The Trust's sister charity is the LYNEAL TRUST which can offer canalside holidays for disabled people and their families and friends. Facilities include a canalside cottage, two bungalows, laundry facilities and recreation room providing shore-based accommodation for up to 16 people. Alternatively, the Shropshire Lass is a specially designed and built 70 feet canal boat which accommodates up to

eight people. The boat has a hydraulic lift and ramps. Previous experience of canal boats is desirable if choosing this holiday and a minimum of three able-bodied persons are required for each boat trip. Prices range from £400 to £800 per week including full use of all shore based accommodation and the Shropshire Lass.

More details from: The Honorary Secretary, the Lyneal Trust, The Shirehall, Abbey Foregate, Shrewsbury SY2 6ND, telephone: 0743 252728

Sail away to paradise...

That's the suggestion of the Jubilee Sailing Trust who have a programme of voyages to the Canaries this winter. The sailing is done on board a traditional tall ship but it's not passengers they want but crew! The 'invitation' is open to anyone over 16 and under 70 who is able-bodied or physically disabled - the Lord Nelson was purpose built to promote greater integration between able-bodied and physically disabled people and incorporates special features to put them on equal terms when sailing. They do have some wheelchair user berths left but these are going fast, there are still quite a number of vacancies for disabled walkers.

This is not a cheap adventure with the cost of Canaries cruises starting at £395, plus your flight to the starting point in Puerto Rico, but we know it can be the exciting experience of a lifetime (an ASBAH member who went sailing with the Trust wrote about her experiences in LIFT magazine).

If you would like more information contact: The Jubilee Sailing Trust Ltd, Test Road, Eastern Docks, Southampton SO1 1GG, telephone: 0703 631395.



Self-drive hire for disabled drivers

Based in Enfield, Middlesex, Mobility Car Rental is a firm which specialises in hire cars for disabled drivers or disabled passengers. Their fleet of self-drive hire cars have adaptations such as hand controls, steering ball, left or right foot accelerator, elapse swivel seat, automatic transmission, power-assisted steering etc.



Rear access vehicles for wheelchair passengers - from Ford Transit minibuses which can carry up to four wheelchair passengers, to vehicles for one wheelchair passenger and a driver - are also available and can be hired as self-drive or with a driver.

The company also has one vehicle which is automatic with hand controls and steering ball and can carry wheelchair passengers as well.

Prices range from £31 to £50 per day, including insurance, RAC cover and unlimited mileage. More details from: Mobility Car Rental on 0992 87462.

including accommodation and food. Information from Chris Smith, MA, 15 Britannia Street, London WC1X 9JP. Tel: 071 837 1265.

17 November: 'Forward Together - Teachers with Disabilities' - a joint RADAR/NUT conference on the employment of disabled teachers. King's Fund Centre, London. Contact Rachel Scott, Conference Officer, RADAR 25 Mortimer Street, London W1N 8AB, tel: 071 637 5400 for details.

DIARY DATES

18-23 September: Leadership Training Course for young people with physical disabilities. This is a project run by Mobility International and will be held in Denmark. Topics of discussion will be: assertiveness, communication skills, organising international projects. The main working language will be English. Accommodation is fully accessible. Cost: £110 per person inclusive, travel awards and personal assistants' bursaries available. Contact Annette Guerda Fischer, 228 Borough High Street, London SE1 1JX, tel: 071 403 5688.

14 October: 'Learning from Experience' - a one day conference organised by the Home Farm Trust to review the lessons learnt and the implications for future services, and to examine key factors affecting progress. Venue:

Church House Conference Centre, Westminster, London SW1. Aimed at carers and professionals involved in provision of services for people with learning disabilities. Fee: £70 plus VAT. More information from the Conference Administrator, The Home Farm Trust, Merchants House, Wapping Road, Bristol BS1 4RW, tel: 0272 273746.

17 October: ASBAH AGM, National Children's Bureau, 8 Wakley Street, London EC1V 7QE. 10.30 for 11am.

23 - 25 October: Disabled People: Pregnancy and Early Parenthood - a two-day residential conference at Hereward College, Coventry. From Friday evening to Sunday afternoon. Organised by the Maternity Alliance to promote exchange of information between parents and professionals. £40 for parents, £165 professionals,

Unless otherwise stated the information given in 'Out & About' has been supplied by the organisations concerned and the services have not been tried or tested by ASBAH. Please ensure that your particular needs can be met before booking.

Attendance Allowance for the Under 2s - Disability Living Allowance Care Component

In an article on Attendance Allowance for the under 2s in the April 1991 issue of LINK we gave details of how to appeal against the DSS - Benefits Agency decision not to award backdated Attendance Allowance.

As many of our readers will be aware the DSS are now considering further action. In order to put further pressure on them to award ex-gratia payments, to those who were unlucky and did not receive backdated allowance, we need to know how many people have been unsuccessful. Please fill in this questionnaire and return to ASBAH by 30 September 1992.

- 1 Did you apply for backdated allowance? Yes/No*
- 2 Were you successful? Yes/No*
- 3 If yes to the last question, how many months backdated allowance did you receive?
- 4 You have decided not to continue to pursue your claim Yes/No*
- 5 You have decided to appeal the decision. Yes/No*

**Please delete the answer which does not apply.*

If you have decided to appeal the decision please continue below. If you have decided *not* to appeal please tell us why on a separate sheet of paper.

- a) When did you appeal the decision? (date)
- b) Have you received a response yet?
- c) If you received a response, please give details (ie has your appeal been listed, if so when etc)

- d) Please give us a brief description below of the person you are claiming for ie age, condition etc

Thank you for completing this questionnaire, please also give your name and address below in case we need to contact you in the future.

Name of claimant _____

Appointee/parent carer _____

Address _____

All information given in this questionnaire will be treated in confidence.

Please return completed questionnaires to:

Mary Malcolm, Assistant Fieldwork Manager, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

ADVERTISING

FOR THE USE OF LOCAL ASSOCIATIONS

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

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

Small adverts for the next issue of Link (October/November) should be submitted by Friday, 4 September. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

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