Link

Association for Spina Bifida and Hydrocephalus/ASBAH 15p Jan/Feb 80

A parent replies to Reg Prentice: Leeds and Bradford: How the Mobility Allowance works in practice: Year of the Child: The ethics of antenatal diagnosis: The management of paralysed limbs: Holidays: MPs take the plunge: INDEX

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Association for Spina Bifida and Hydrocephalus/ASBAH

Correspondence to ASBAH at the National Office:
Tavistock House North,
Tavistock Square,
London WC1H 9HJ.
Registered Charity No. 249338
Tel: 01-388 1382/5

Patron:
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on Treasurer: Mr R M Nichols

ASBAH has an experienced staff ready to help with any problems relating to those with spina bifida and hydrocephalus.

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ids & Appliances Officer:
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Miss Jan Tomlinson

Information Officer:
Miss B Holland

LINK Editor:
Mrs S I Gearing

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Mr Tim Robinson, a University lecturer, and parent of a spina bifida child has written this personal response to Reg Prentice's Opinion article in the last LINK.

IN THE LAST issue of LINK, Mr Prentice, the Minister for the Disabled had some very flattering things to say about voluntary societies and the important role they have to play in society. It is nice to know that we are appreciated in Government circles but, as Mr Prentice must realise, it is not what the disabled and their families are most concerned about at the moment.

The cuts in public expenditure are beginning to hit services for the handicapped badly and even bigger cuts are promised for the future. There is no way in which voluntary organisations like ASBAH can possibly make up for these cuts. Many, like ASBAH, are already in financial difficulties themselves and, in any case, the amounts of money involved are far too great.

Elsewhere Mr Prentice has had something to say about the cuts. He told the RNIB that it would be insulting to the disabled to pretend that they could be contracted out of Britain's problems. They would have to pay their share in the price of economic recovery.

These cuts which Mr Prentice is insisting the disabled should bear are not just a bit of a nuisance (as is an extra 1p in the pound income tax to someone who is able-bodied). Thus one authority is already cutting back on the provision of telephones (often a vital lifeline) for the disabled. Another has told the family of a spina bifida teenager that they cannot have an urgently needed bath hoist. In other areas, young people will have to stay at home for most of the week because day centre and work centre facilities remain inadequate or get worse. These are not minor inconveniences. They drastically reduce the quality of life for people who already have more than enough to put up with.

Is Britain really so poor, and in such a mess, that we must make vulnerable groups like the elderly, the sick and the disabled share the cuts? Of course she isn't. We are still one of the richest societies the world has ever known despite our troubles. Nor are we extravagant in Government expenditure on health, education and social services. According to the most recent figures we spent 19% of our national resources (our Gross National Product) on this—less than France (22%), Germany (24%), Holland (26%), or Denmark (27%). Indeed, we are not even particularly heavily taxed compared with our Common Market partners. We actually pay a smaller proportion of our Gross National Product to the Government in taxes of all kinds than do the people of France, West Germany, Belgium, Denmark or Holland.

Some changes in the tax system may well be desirable and some cuts in public expenditure justified (e.g. the elimination of one tier from the administration of the health service) but we are not forced by economic necessity to cut services to groups like the handicapped. We can afford them and we could afford to improve them. If we do cut them it will be because the rest of us are selfish.

Mr Prentice ought to be fighting for a more humane and caring society, not encouraging a selfish one.

FRONT COVER: In fine voice—children of Trafford and Salford Association at the Saturday 'glee' Club.

LINK: Unfortunately due to postal increases it has been necessary to raise the cost of LINK annual subscriptions. The new rates are given below. A further increase will be necessary in the future due to extra printing costs, but LINK will endeavour to keep it as small as possible.

1. **Home £1.40**
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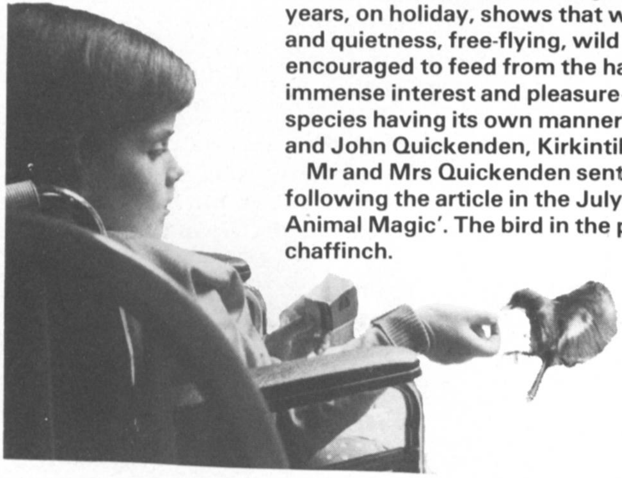

THIS photograph of our daughter, Julie, aged nine years, on holiday, shows that with patience, stillness and quietness, free-flying, wild birds can be encouraged to feed from the hand, and provide immense interest and pleasure—each bird and each species having its own manner of approach . . . Ann and John Quickenden, Kirkintilloch, Glasgow.

Mr and Mrs Quickenden sent this photograph following the article in the July/August LINK, 'It's Animal Magic'. The bird in the picture is a cock chaffinch.

S. Africa may form National Association

Parents in South Africa are taking the initiative. In the summer the first National Spina Bifida Congress was held at the University of Natal. It was organised by the Natal parents group and the guest speaker was Professor John Lorber.

The Natal association—the only one in South Africa—is hoping to help form a National Association.

Crawley enters computer age

A HOME Video Computer Game has been bought by Crawley group of Sussex Association. It is circulated among members, each family having it for a fortnight.

Frank Armour of Sussex Association comments: 'It seems to provide excellent entertainment, and some degree of education—for the wheelchair bound. It is more positive than television watching, and calls for participation'.

Some provide more educational value than others, but most test manual dexterity and quickness of eye.

It might be a useful purchase for a local association when given money to buy 'something for the children'. The game bought by Crawley group at cost price (including VAT), was just over £200.

Scaling the heights

YOUNGSTERS and helpers from Liverpool and District Association conquered a minor Everest of their own recently. Nine children in wheelchairs, plus 30 scouts and adults, braved the bad weather and struggled up Moel Famma, a mountain in North Wales. With great pride they stuck their flag on the summit, 1,820 feet up.

The weather for this outing could have been kinder and it took some courage on the part of those in wheelchairs to allow themselves to be pulled and pushed through rain and mist to the top of the mountain.

Paul wins art prize

CONGRATULATIONS to 10-year-old Paul Lister of Hull, who won a nationwide painting competition. He travelled to London in November to be presented with a special scooter by WRK products at the NAIDEX exhibition. The presentation was made by Roy Castle.

Walk raises £1,500

NOW that all the money has been collected from sponsors, Grantham Association is delighted with the results of a sponsored walk earlier in the year. Over £1,500 was raised from the 10-mile walk, and is being used to complete the purchase of a holiday chalet at Chapel St Leonards. One participant, Mr Michael Willows raised £100 on his own by running the 10 miles in a given time.

Draw produces coincidence

IT WAS a meeting of two interests for Brian Black when as President of Urmston Lions Club he presented a television set, as first prize in a Lions' Club draw, to Jean Slater of Trafford and Salford Association.

Brian has been a member of was Chairman of Trafford and Salford for a good many years. He is now their very active Vice-President.

Brian says that conflicts can arise through belonging to two organisations, especially when one approaches the other for help. He has to declare his interest when ASBAH approaches the Lions for help in any way.

Brian Black (right) and Jean Slater (left). Also in the picture are (centre back) Brian's wife Jean—Chairman of Trafford & Salford Association—and Mrs Edith Slater, Jean's mother, as well as members of the Lions.

Association favours personal touch

LEEDS and Bradford Association, with over 300 families, is one of the largest in the country. The monthly meetings are rarely well attended, but instead, members prefer to keep in touch more informally in coffee groups.

Each of the committee members has a group of families with whom he keeps in regular contact over coffee at each other's homes. These meetings are useful and popular and highlight where problem areas are in certain districts.

There is a similar, informal, relationship between the Association youngsters. Instead of the Saturday morning club sessions held in some parts of the country, they are encouraged to spend weekends at each other's houses.

Phab clubs, and an Association disco, held about four times each year, keep the older ones busy, and for the young ones there is a summer playscheme. It was started by the Association chairman, Mrs Jo Baxter and the ASBAH social worker, Mrs Ros Scott, three years ago, and last year the running of it was taken over by Barnardos.

Family affair

The regular monthly meeting is a family occasion. While parents enjoy a talk by a special speaker and a cup of tea together, the children are cared for and entertained by members of the St John Ambulance Brigade. However, as the meetings are not well attended there may be a move to a two monthly get-together instead.

The work involved in administering an Association of this size is considerable. The area covers the Metropolitan districts and strays into North Yorkshire. At present the secretarial work is tackled efficiently by one of the mothers, Mrs Pat Robinson who lives in Pudsey. Her work load, however, is already impressive. She has three sons to care for, aged 14, nine and two. One of them is severely disabled with spina bifida, and Mrs Robinson also cares for two children as a registered child minder.

The Association is now discussing the possibility of appointing a paid secretary on a part-time basis.

Three years ago Mrs Ros Scott was appointed as a social worker employed part-time in Leeds and Bradford, her salary being paid for by national ASBAH and the Local Association. Leeds Health Authority has two specialist liaison health visitors and ASBAH has a field officer, Mrs Margaret Pearson to cover Yorkshire/Humberside. The committee work closely with these four officers who are invited to committee meetings as co-opted members.

Over the years the committee has made 'welfare' its top priority in caring for the families. Benefits are paid automatically when the handicapped member is in hospital, as are death grants. A sub-committee considers other cases of financial need in complete confidence.

A toy library was established several years ago to supply large items of equipment which are not available through social services. These are lent to members free of charge for as long as needed. During a financial year welfare expenditure amounts to about £4,000.

The needs of this particular Association are diverse because of the wide age range of members.

There has been an increase recently in new spina bifida babies joining the Association—eight in 1978 and five in 1979.

Schooling and further education facilities appear to be generally good, and mean that the children can be educated fairly close at hand. They do not have to go away to boarding school.

Solving the needs of the older ones is not so easy. There is growing concern about the position of the young adults who will soon be leaving colleges of further education. The Association is aware of the problem and is planning a meeting to iron out

Continued on page 11

ABOUT ASBAH

ASBAH's financial difficulties were referred to in the Sept/Oct issue of LINK. Following the steering committee's report to the executive, a series of regional meetings are in progress to put the position to local associations and to get their views on ways and means of surviving the next year or two.

These meetings have, of course, enabled national officers to meet many members and the discussions have been very wide-ranging.

One thing that has emerged is that sometimes members apply for services which they have read about in LINK and when nothing seems to happen they give up. The national office exists to try to help when these difficulties arise—so *please let us know* if you do not get the reaction you expect from local authorities.

Working Party

As mentioned in the last LINK I am a member of the working party set up to prepare a draft constitution and first general meeting of an International Association for Hydrocephalus and Spina Bifida. This came about after a meeting in Stockholm in October. Other countries represented are Germany, Switzerland, Sweden and Spain. Among the papers presented at the meeting was one from Stig Melander of Sweden, the first part of which appears on pages 10 and 11.

We will keep you up to date with the progress of the new International Association.

Moyna Gilbertson

Shades of Summer

Memories of a happy summer: three mothers from the Wessex Association, won awards in the Bridport and Weymouth carnivals in 1979.

The ladies who made the Association's successful float were the chairman's wife, Mrs Sharon Brooks, vice-chairman, Mrs Elizabeth Poole, and secretary, Mrs Margaret Chelton.

An opportunity in computers

ALTHOUGH MICRO Technology is feared by many people, it has great possibilities for disabled people. The growth of the computer industry is in many ways ideal for those who are not mobile, and opportunities exist for a range of interesting computer programming jobs which can be done from home.

If disabled people are to enter this new industry it is important that they receive appropriate training.

To help meet this need the Queen Elizabeth Training College in Leatherhead, Surrey is starting a new course in February for the severely disabled—a 12 week residential computer programming course.

It will be funded by the Manpower Services Commission (through its Tops scheme) and will be run jointly with ICL Training for up to ten severely disabled students at a time. Candidates should be between 17 and 35 and although formal qualifications are unnecessary the ability to think logically and to concentrate are essential.

Details from Mr W. Dunn, MSC Training Services Division, 19/21 Fife Road, Kingston, Surrey. Tel: 01-549 7388.

Trust looks to sail training

THE JUBILEE Sailing Trust is a recently formed organisation which hopes to build and run a sail training ship accessible to handicapped as well as able-bodied people. The ship would undertake extended cruises off-shore and disabled members of the crew would take a full part in the running of the ship.

The Trust has assembled an advisory team, and is anxious to discover how much interest in the venture there is among disabled people.

If you are interested write to: Dr J. A. Hicklin, The Jubilee Sailing Trust, Beauvoir Lodge, Effingham Lane, Copthorpe, Sussex.

RANGERS HOUSE, Greenwich (which houses the Suffolk Collection)—an interesting place to visit, but not easy for anyone in a wheelchair—just look at those steps.

Obstacles in the way of art

'Needing a Push' is a report produced by the Greater London Arts Association, in collaboration with GLAD, and shows how the arts neglect the disabled.

Based on a study of venues used for the Greenwich Festival, the report highlights the many obstacles preventing disabled people from being able to attend these events. Because of these, disabled people—who form two-three per cent of the general population—made up only one-tenth of one per cent of people attending Festival events.

The best way for local association members to help change access facilities in their area, and change the attitudes of those in authority, is to join local committees of all kinds. Change from within is often the most effective.

'Needing a Push', price £1 from Greater London Arts Association, 25/31 Tavistock Place, London WC1H 9SF.

MR. G. COLLEY

ASBAH was very sorry to hear of the death, in October, of Mr Gerald Colley, the General Administrator of the Irish Association. Mr Michael H. Neville has been appointed as Director.

New housing coming available

•THE Shaftesbury Society Housing Association is currently considering applications for a new scheme in Aylesbury, Buckinghamshire, due to be completed this spring. The estate will consist of 50 flats, of which 19 have been designed for wheelchair users. These 'wheelchair flats' vary in size to accommodate households of between one and five people. The whole housing scheme will have a resident warden and communal facilities such as a laundry room and a common room.

Enquiries to: the Management Secretary, The Shaftesbury Society Housing Association, 112 Regency Street, London, SW1P 4AX. Tel: 01-834 7581.

•THE Habinteg Housing Association is considering applications for a new scheme in London, SE15. The estate will consist of 92 houses and flats of which 26 are designed for people in wheelchairs.

Eleven of the 'wheelchair flats' will have one bedroom, nine will have two bedrooms and six will have three bedrooms. The units will become available in stages throughout this year. In common with other Habinteg developments all the other dwellings are designed so that they can be visited by a person in a wheelchair.

Enquiries to: The Housing Officer, Habinteg Housing Association Ltd, 6 Duke's Mews, London, W1M 5RB. Tel: 01-935 6931.

Mr Croydon joins

ASBAH welcomes Mr Harry Croydon to the staff at national office. He joined ASBAH in January as the new head of field work—in charge of all the field staff. Mr Croydon was formerly principal area officer in Hampshire, and has a very varied professional experience. He has been in the RAF, the police force, a housemaster and child care officer.

Mobility Allowance helps children get out and about

WHATEVER else may go down in the history books about the 1970s, amongst the handicapped and their families, the decade will be remembered as the time when the government began to recognise some of the extra costs of disability and introduced a number of new benefits to help make ends meet.

Families with handicapped children have been included in these new developments. In 1971 the Attendance Allowance was introduced. Two years later the Family Fund was established to help families with very severely handicapped children and 1977 saw the payment of the Mobility Allowance to children aged five and over who have walking difficulties.

At the same time, a research team belonging to the Social Policy Research Unit at the University of York was carrying out surveys of the financial problems of families with handicapped children. One such study, recently completed, is of families with a child receiving the Mobility Allowance.

The study was commissioned by the Department of Health and Social Security, who wanted to know how much difference the allowance had made to people's lives and if the children were able to get out and about more than before. To give them this information, the Unit interviewed 500 families all over the country who had a child receiving the allowance. Nearly one third of the families in our sample had a child with spina bifida or hydrocephalus.

THE QUESTIONS

We had a number of questions to answer. How did families actually use the Mobility Allowance? Did the children get out and about more after receiving the allowance? Did they still feel restricted in going out?

Although the allowance must be used for the benefit of the handicapped child, there is, in fact, no legal obligation to spent it on transport. However, 450 of the families (90%) did spend it specifically on transport—usually to keep their car on the road. One mother said:

> *'It helped to pay the big bills we had to pay. £136 for one bill, then a £112 bill, then an exhaust, and now we need new tyres'.*

As well as finding out if the children got out and about more as a result of the Mobility Allowance, we wanted to know what kinds of journeys the allowance had enabled the children to make. To do this, we asked the families taking part in the survey to keep a daily record of all the journeys made by the child during a two-week period. We used these travel diaries to see which journeys would have been made anyway and which journeys were made *because* of the extra help from the Mobility Allowance.

We found that the allowance generally enabled the children to enjoy a wider social life, to go out with their families on day trips, to visit relatives or friends or to go to the cinema. These outings were more expensive too; on average, they cost three times as much as the journeys which would have been made anyway.

Our study showed that for many handicapped children the family car was vitally important in helping them to get out and about. But we were also able to measure the enormous drain on family resources which could be caused by having to keep a car on the road. The Motability scheme (which has now been extended to cover all children receiving the Mobility Allowance) has an important role to play here.

Families who opt to keep their Mobility Allowance rather than lease a car through Motability now receive £12 a week—more than double the amount when the allowance was first introduced. But these improvements can only benefit those children who actually receive the Mobility Allowance. We must remind ourselves—and the government—of those who are still excluded, particularly children under five, whose inability to walk may present their families with transport problems as severe as those of older children.

KEN COOKE, RESEARCH FELLOW
Social Policy Research Unit
University of York

'From School to What'—a Conference

THERE is great concern about the problems facing young people who are coming up to school-leaving age and, those who have recently left school. Of particular concern is the number of school-leavers who are unemployed and the opportunities available to them.

Young ASBAH, in conjunction with other voluntary organisations such as the Spastics Society, Phab and the Friendship Group of Charities, is arranging a conference entitled 'From School to What' aimed at the 15–18 year age group. It is hoped there will be 200 delegates, 100 disabled and 100 able bodied attending.

The conference is being held at Goldsmith College, London, from Friday 18–Sunday 20 April 1980. It is envisaged that the weekend programme will include discussions and speakers on work/unemployment, alternatives to work, i.e. youth projects, community services, youth opportunities programme, and leisure pursuits. Exhibitions, films and more social activities, will also play an important part in the weekend.

Ten young delegates from each of 20 major areas throughout the country are likely to attend. They will work together throughout the weekend discussing not only what is happening at a national level, but also what facilities and opportunities are available in the areas where they live. Following the conference it is hoped they will then, as a group, go back to their own areas to try to arrange projects, have meetings and generally be involved in what is happening in their regions.

These young people do not necessarily have to be involved in full time education. A mixed group would be preferred.

For more details or a form to nominate a young person please contact Jan Tomlinson, Young ASBAH officer at National office.

This article by Judith Stone, Director UK Association for IYC, first appeared in PHYSIOTHERAPY, the journal of the Chartered Society of Physiotherapy who kindly gave LINK permission to reproduce it. In the next issue LINK will report on the schemes started during International Year of the Child.

The importance of one voice

THE PROGRAMMES and projects created during the International Year of the Child will undoubtedly benefit children in years to come. Indeed, in some cases it will be several years before the full effects of IYC are felt. But although our National Children's Legal Centre, our Holiday Adventure Centre for Handicapped Children and other national and local schemes will remain as a memorial to the Year, something of equal value and importance is in dange[illegible] of being lost.

This year for the first time there has been one voice speaking for all children. We have 800 organisations affiliated to the UK Association for the International Year of the Child. They each speak for one group of children: handicapped children, gifted children, refugee children, children in developing countries. But IYC has spoken for them all.

We have highlighted the needs of immigrant children, not to show that they are different but to demonstrate that they have a right to the same standard of care and concern as British children within the UK. We have spoken out for the needs of children in care, not to show the differences between those children and children who are brought up within their own families but to stress that every child has the same need for love and understanding. Handicapped children were active members of our Young People's Parliament, not to show how special they are but to speak eloquently of

Continued on page 1[illegible]

INDEPENDENCE TRAINING COURSES 1980

Provisional dates

DATE	VENUE	AGE GROUP
*Wednesday, 26 March to Wednesday, 2 April	Newcastle Aids Centre	14-16 years
Saturday, 3 to Saturday 10 May	Jane Hodge Holiday Home, S. Wales	15+ years
Wednesday 2 to Wednesday 9 July	Church Town Farm, Cornwall	9-13 years
*Sunday 3 to Saturday 9 August	Birtenshaw Hall, Bolton	13-16 years
Saturday 13 to Saturday 20 September	Jane Hodge Holiday Home	

NOVEMBER COURSE DATES AND VENUES UNKNOWN AT THE PRESENT TIME

*The Newcastle and Birtenshaw Hall courses are being run jointly with other organisations. For further information on all courses contact Jan Tomlinson at National Office.

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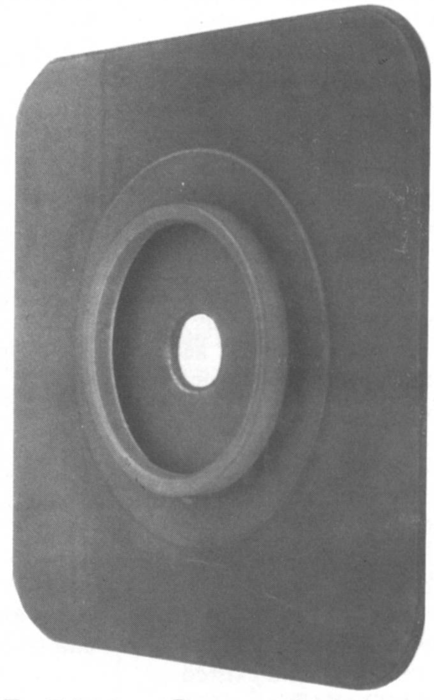

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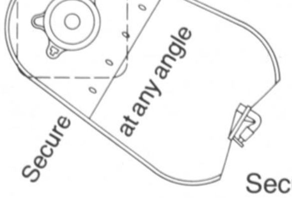

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A QUESTION OF

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HERE LINK presents the first of two articles dealing with some of the ethical problems connected with spina bifida.

This article deals with antenatal diagnosis and the possibilities which follow from it.

The second, which will be published in the next issue, will deal with the emotive question of operations on new born babies with spina bifida.

Both articles are based on a lecture given by Stig Melander, to the International Spina Bifida Conference in Stockholm in the Autumn of 1979. Stig Melander is an eminent gynaecologist/obstetrician with 25 years experience.

However, in his lecture, he was concerned to make it clear that he was not representing any official authority. Nor was he prepared to state that his views were right or wrong. But he did say he wanted to stimulate awareness of some problems and provoke thoughts and ideas.

THE ANTENATAL diagnosis of spina bifida may, at first glance, seem to be an advance. It presents the possibility of a screening programme leading to early diagnosis and the termination of abnormal pregnancies. But let us see if this view of the practical consequences of diagnosis can be accepted ethically on closer inspection.

It is obvious to me that the reason why antenatal diagnosis of spina bifida has become an ethical problem, at least here in Sweden, is that we have a spontaneous feeling that such a measure, and the subsequent abortion when spina bifida is diagnosed, is insulting, injuring, humiliating and a violation of the human dignity of those already born and living with the handicap.

I feel they must think: 'We are unwanted. We do not have the same worth as you—the non handicapped. If the possibility of antenatal diagnosis had existed when we were conceived, you would have eliminated us before we were born. We are tolerated only because the tool of discovering our handicap during our mothers' pregnancies did not exist.'

Accordingly, some of the main ethical points which arise are as follows:

1) Shall we permit antenatal diagnosis of spina bifida or shall we forbid it?
2) Shall we organise it as a screening programme?
3) Shall it be compulsory, and a civic duty, for all pregnant women to undergo such a test and, moreover, if spina bifida is diagnosed, shall it be a civic duty to have such a pregnancy terminated?

Now if we try to get an answer to these questions, I think we must develop our reasoning along the following lines. One undeclared, accepted moral principle is that we reject humiliation of individuals which would deprive them of their worth and personal integrity.

So, if to allow antenatal diagnosis of spina bifida means humiliation it also means a denial of human worth and we should not permit it. But it also follows that if antenatal diagnosis does not mean humiliation, it does not mean a denial of human worth, and it should be permitted.

Stig Melander said he had discussed this problem with an eminent colleague in Uppsala.

He wrote to me that antenatal diagnosis of spina bifida may not be regarded as an indignity to those now living and afflicted with the disability because they can argue it is such a suffering to live with spina bifida that they do not want others to suffer from the same affliction. Therefore they do not regard antenatal diagnosis and subsequent abortion as an indignity. If something very bad has happened to us, if we are emotionally normal people, we do not want the same to happen to others. We do not regard preventive measures as an indignity to those who have already been the victims of the disaster.

Implicit in this reasoning is that living with spina bifida is really a severe suffering. Only those with spina bifida and their parents and relatives can tell me if this is so and therefore if the argument holds that antenatal diagnosis is not an indignity. I hope it holds.

Now let us turn to other ethical problems concerned with antenatal diagnosis. It is my view that there is a deep feeling within us that we should be merciful. We consider it ethically right to be merciful.

It can be regarded as an act of mercy to use the possibility of antenatal diagnosis with the termination of the pregnancy if spina bifida is diagnosed. And it can be regarded as merciless not to use the possibility of antenatal diagnosis. An unborn individual without any opportunity to influence his situation; without any idea of his future, is doomed, by us, to a life of suffering if we do not utilise the possibility of antenatal diagnosis.

But it can be questioned if a woman, or a couple, who decide to have a pregnancy terminated are genuinely motivated by considerations of mercy. Are they honest? It may be a pretext of mercy, when it may simply be a matter of being rid of a problem.

And if society decides to organise antenatal diagnosis and allow subsequent termination with the official motivation that it is an act of mercy, one may also question the honesty of that declaration. The authorities might find it a handy way to be rid of a problem. And if the case is extended we can see elitism—a community where only perfect persons are tolerated. I am sure we

ETHICS

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would not like such a view.

So I am not sure that antenatal diagnosis may really result in mercy. Instead it can prepare the ground for contempt of handicapped individuals.

Let us now turn to the problems of the parents and relatives of those afflicted with spina bifida. Every child, and thus also a defective child, is born into a family unit. A handicapped infant becomes an added stress on each member of the family. And the parents will react in a manner consistent with their own personalities and their own experience of illness and disability. Some parents can bear the burden of taking care of such a child, others cannot.

The basis of parental response is also grounded in the prevailing social attitudes and assumptions about people who are handicapped. A handicapped child must be seen in its family and social context.

Now if we return to antenatal diagnosis it may be said that it can mean that parents gain additional time to prepare themselves emotionally, and in other respects, for the birth of a handicapped child. For note very well, the antenatal diagnosis of spina bifida does not necessarily imply that a pregnancy should be terminated.

Thus antenatal diagnosis may provide valuable information for parents. It is accepted that parents have a right to full information about their children—so why not the information that a child will be spina bifida.

So to my first question, posed above—shall we permit or forbid antenatal diagnosis of spina bifida—I will answer that we should permit it because it provides valuable information. But of course, the ethical issue is not the mere fact that we get information, but how we use and handle that information.

To my second question—shall we organise antenatal diagnosis as a screening programme—I will answer, No. Such a programme could imply a strong social pressure on the pregnant woman to undergo the test even if she did not wish to do so. Such pressure is not acceptable. We should tell prospective parents about the possibility of having spina bifida diagnosed before birth and if they want to have it done, we should help them to have the test. But the decision must come from the woman herself, or the couple.

It is also important to tell people about the possibility of antenatal diagnosis long before a couple decide to try to have a child. It is a serious decision and a still more serious problem to decide if the pregnancy should be terminated or not if spina bifida is diagnosed. We must avoid confronting people with a problem of which they have scarcely been aware. Perhaps society should have a duty to inform older school children about the possibility of antenatal diagnosis, and ask them to think over the problem carefully.

To the third question—should it be compulsory for a pregnant woman to undergo a test and let the pregnancy be terminated in cases of spina bifida—I will answer with a very definite NO. Such a compulsion would be an attack on, and a neglect of, individual integrity and this must be ethically wrong.

**Stig Melander's views on the ethics of operating or not operating on newborn spina bifida babies will be the subject of the second article, which will appear in the next LINK.*

Continued from page 5

some of the difficulties facing youngsters and parents.

Although day centre facilities are not adequate the social services departments in Leeds and Bradford have expressed their willingness to provide facilities as the individual needs become known.

Very few youngsters are in open employment. Some attend day centres or sheltered workshops, but most are unemployed.

But turning to a sunnier side—the Association is busy getting its new chalet at Mablethorpe ready for use in the summer. It was recently bought for just over £5,500, but adaptations and furnishings have still to be paid for and carried out. The Association also has a caravan in North Wales. Low cost holidays are just one of the benefits which members get from belonging to this Association.

Now for a good IDEA

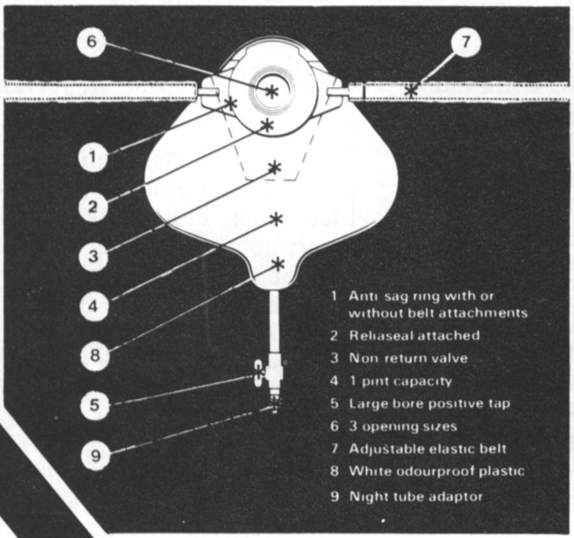
SOME disabled people in South Wales have set up a new association called IDEA (Independent Disablement Employment Association), to help unemployed disabled people who have some business 'know-how' to start up a business of their own.

The instigators of the scheme feel that 'the idea of disabled people going into business for themselves should be explored as an alternative to the existing employment situation for the disabled, in which, all too often, they are offered dull jobs at best, no jobs at worst'.

Project No. 1 is already under way with people working on 'Welsh Kitchen products'. Their ultimate aim is a £60,000 cannery in Cardiff which would provide work for 16 disabled people, including management.

Open again

The Disabled Living Foundation has been able to re-open its standing exhibition and training centre of aids for the disabled, due to an anonymous donation of £250,000.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3 Non return valve
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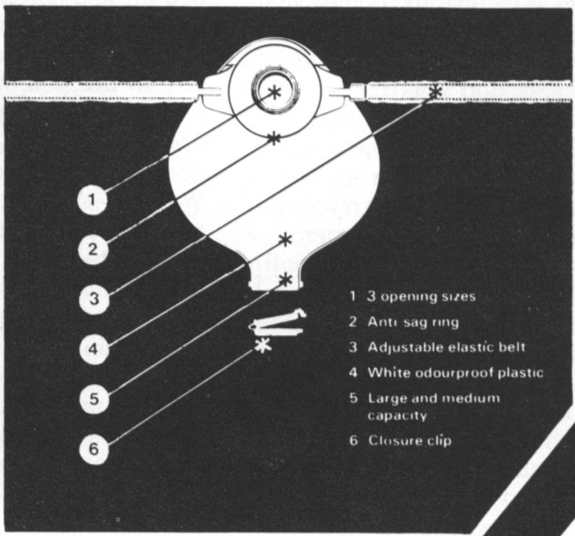
5 Large bore positive tap
6 3 opening sizes
7 Adjustable elastic belt
8 White odourproof plastic
9 Night tube adaptor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3 Adjustable elastic belt
4 White odourproof plastic
5 Large and medium capacity
6 Closure clip

The management of paralysed limbs in Spina Bifida

Why we try to keep surgery to a minimum

JOHN A. FIXSEN,
M.CHIR, FRCS
Consultant Orthopaedic Surgeon

ALL CHILDREN with open spina bifida will have some weakness or paralysis in the lower limbs. The amount of paralysis varies widely from minor weakness in some muscles, usually in the foot, to completely flail legs.

In the early 1960s, great optimism was expressed by the orthopaedic surgeons treating this condition. They hoped, by early operation, to correct the limb deformities and the muscle imbalance and that most of the children would be able to walk with or without aids.

Surgery at this time was based on that used in the past for patients with poliomyelitis. Unfortunately, this optimism has not been borne out in practice. The results of treatment in Sheffield published in 1971–72 showed that despite many operations, at least one third of the children were ending up wholly in wheelchairs. In fact, the more operations a child had, the more likely a wheelchair existence. This was clearly very depressing and very unsatisfactory.

Analysis of the failures showed that the principle of treating the leg problems of spina bifida, like those of poliomyelitis, was much too simple. The neurological problem in spina bifida is much more complex. Unlike polio, sensation is affected as well as muscle power. In polio, the muscles are either normal, weak or completely paralysed. In spina bifida, the muscles can be normal, or paralysed, weak and under voluntary control, or reflex and not under voluntary control. They can also be overactive or spastic as in cerebral palsy. Frequently, a mixture of all these muscle types is found in one leg and the situation between one leg and the other in the same child may be quite different.

On top of this, the spina bifida child can have problems of spatial orientation, vision, balance and, in some patients, considerable upper limb weakness and inco-ordination to cope with.

Finally, in poliomyelitis, once the illness is over the neurological situation becomes stabilised and does not alter, whereas in spina bifida a large number of children show deterioration of the neurological state of the lower limbs with growth, which at present we cannot prevent.

It is, not surprising that early surgery based on that used in poliomyelitis has not proved very successful.

How then should we manage the lower limbs of a spina bifida child? The modern attitude is best summed up in the title of the Casey Holter Memorial Lecture given by Mr Menelaus, Orthopaedic Surgeon from Melbourne in 1976, namely, 'A plea for realistic goals to be achieved by the minimum of surgery.'

Charted

The child should be seen soon after birth by the orthopaedic surgeon and the leg problems assessed. The pattern of muscle weakness is charted as a baseline but it is accepted that it is likely to alter with time. Deformities are treated by regular passive stretching and exercises which are taught to the parents by the physiotherapist. Sometimes splints are necessary but we try and avoid prolonged periods of splintage.

Surgery is avoided if possible until the child's general development can be assessed. Once the child is showing signs of wanting to stand, usually between the ages of one and two years although it may be later, then the leg deformities can be reassessed. If they need surgical correction and/or bracing with calipers (orthoses) this is undertaken.

It is commonly thought that because a hip is dislocated or a foot in a bad position, that the deformity itself is stopping the child standing. Conversely, that if the deformity is corrected, then the child will stand and walk. This assumption is quite natural as the deformity is obvious, but it is also quite wrong. If you have normal muscles and co-ordination, you can stand and walk remarkably well with a dislocated hip or a club foot. Children with a congenital dislocation of the hip rarely seek advice because they cannot walk but because they are walking with a limp. Similarly, children from countries where no orthopaedic treatment is available walk remarkably well on their club feet but cannot wear a normal shoe. The problem in spina bifida is a complex one of muscle control and weakness rather than simple deformity.

Weakness or paralysis can be supported by calipers but involuntary and spastic movements are much more difficult to manage. This gives rise to the paradoxical situation of having to get rid of active muscle function by surgery rather than performing muscle balancing operations which were so popular in the past but were doomed to failure as the muscles concerned continued to act in a reflex or hyperactive fashion in their new position.

It is very important to be realistic about a child's walking ability. Very few adult paraplegics will accept long leg calipers with pelvic and thoracic bands. Unless a

Continued over page

Continued from page 13

child can dispense with the pelvic and thoracic bands, he is unlikely to use calipers as a practical means of getting about as an adult.

If a child has serious spatial or upper limb problems, he or she may have to accept a wheelchair as the only practical method of locomotion. Many children who have managed well in calipers with crutches or a rollator may give these up in adolescence as too slow and clumsy when trying to lead an independent life.

The realistic aim in the management of the lower limbs is to avoid surgery if possible until the child's potential for standing and walking can be properly assessed: then correct those deformities which are preventing standing and caliper fitting by as few surgical procedures as possible.

Sufficient bracing should be provided to allow the child to assume an upright posture. If, after an adequate trial of calipers, aids and physiotherapy training, it is clear that a child is not going to manage, then training for an independent wheelchair life should be actively pursued. Deformities should not be corrected surgically simply because they are present but only if they are causing or are likely to cause in the future, functional or serious cosmetic problems.

FROM THE SOCIAL SERVICES

Mandy needs a home

MANDY is a 3-year-old West Indian hydrocephalic child. She is severely handicapped and cannot walk or talk at present and has poor eyesight.

She is a happy and contented child and responds well to individual attention. We are looking for a permanent home for Mandy—can you help?

If so contact me—Sheila French,
Social Services Area 5,
13 Brondesbury Rd., N.W.6. Tel.
(01) 328-1767

WITH . .

The Winged Fellowship Trust

AT ITS three specially built and equipped centres in Essex, Surrey and Nottingham, the Trust is able to give about 2,000 severely disabled people a fortnight's holiday each year.

Each centre is run by a small permanent staff, including qualified nurses, who are assisted by volunteers. All modern aids are provided at these centres, and the comforts offered are of hotel standard. The Trust also caters for those who are incontinent.

Cooking is of a high standard and simple diets can be arranged. Visits are made to places of interest and the sea. Nearer at hand there are trips to the shops or to the pub.

Many guests go home with increased confidence having tackled things they had never

. . . HOLIDAYS IN MIND!

thought possible.

Details from: Winged Fellowship Trust, 2nd Floor, 64/66 Oxford Street, London W1N 9FF.

Help with Insurance

MANY FAMILIES have experienced difficulty in obtaining insurance for their children when travelling abroad. Now, however, insurance cover may be taken out through the Norwich Union.

The company needs to be satisfied on the following points: the degree to which the disabled person is affected by spina bifida and hydrocephalus; whether treatment has been necessary in the last two years; whether changes in climate or diet are likely to have an ill effect.

Details from: Personal Accident Underwriter, Norwich Union Fire Insurance Society Ltd, PO Box No. 6, 16 Surrey Street, Norwich NR1 3NS. Please quote reference: PA/TRAV.

John Grooms opens hotel

JOHN GROOMS Association for the Disabled has opened the West Shore Hotel in Llandudno.

It is completely accessible to wheelchair users, has 16 bedrooms and can accommodate 30 guests. The hotel is centrally heated, has hot and cold water in most bedrooms and toilet en suite.

Guests can bring able-bodied relatives/friends to provide any help needed which will not be available from the hotel staff.

Specially reduced rates for wheelchair users and friends are being offered for March 1980, at £42 per week per person inclusive of VAT.

Details from the Holiday Secretary, John Grooms Association, 10 Gloucester Drive, Finsbury Park, London N4 2LP. Tel: 01-802 7272.

Calvert Trust Centre

FOR THE adventurous, who like a holiday with a purpose, the Calvert Trust Centre in the Lake District might have the answer. Set in two acres overlooking Bassenthwaite Lake and below the mountain range of Skiddaw, the Centre is open from mid January to mid November.

Facilities and tuition are available for angling, archery, birdwatching, canoeing, riding and sailing for disabled people over the age of 12 years. Accommodation is in twin bedded rooms.

Details from: The Warden, The Calvert Trust Adventure Centre, Little Crossthwaite, Under Skiddaw, Keswick, Cumbria.

A visit to Brittany?

HOW ABOUT a trip to the continent. Jugo Le Lacs, a village in Brittany, 25 miles from Dinard might fit the bill. Accommodation is in bungalows adapted for the disabled at a campsite beside the lake. The holidays are available for 12 or 14 days in May and June.

The cost includes all meals, transport to and from the airport or ferry, and daily excursions. Travel across the Channel is, of course, extra. Cost: £9.50 per day in May, and £10 in June.

Details from: Mr W. Millow, The Spinney, St Peters Valley, Jersey, Channel Islands.

Chalets and caravans

THE CHALETS and caravans owned by the different local associations in various seaside resorts round the country provide an ideal opportunity for inexpensive, family holidays with the freedom to plan your own day.

Some of these chalets and caravans are listed on p.19 of LINK, and national office has a full list.

Young Disabled on Holiday

CAROLE ARMOUR, of Sussex Association, spent a week at the Trefoil Holiday Centre in Edinburgh with a party organised by Young Disabled on Holiday. She writes:

"We travelled by train to Edinburgh and were met at the station by the warden who took us to the centre... The next day we visited the Castle and spent the afternoon making our way down the Royal Mile to Holyrood House, where we were told its history and about the extinct volcano which overlooks it.

Other visits were to Abbotsford House, home of Sir Walter Scott, Wemys Bay, where we took the car ferry to the Isle of Bute, and Dunfermline and Edinburgh Zoo. In the evenings we visited a cinema, had dinner in a hotel and enjoyed a disco and a barbeque..."

For details about the centre in Edinburgh contact: The Trefoil Holiday Centre, Gogarburn, Edinburgh, and for information about Young Disabled on Holiday and the activities planned for 1980, write to Mrs S. Hocking, 26 Chestnut Close, Alton, Hants.

Do's and Don'ts

IF IN doubt—ask—and who better to ask than staff at national office. We have details of all kinds of holidays, and are only too happy to give advice and maybe help with some of your arrangements to help you and your family have a good holiday.

● If you need help then *do* see that the holiday you have chosen provides adequate assistance or else take a friend with you. *Don't* rely on the goodwill of other people. Remember they are on holiday too.

● *Do* take sufficient supplies of everything you will need, including puncture outfit for the wheelchair, spare bags and pads and prescriptions if needed.

● If travelling by train, or plane, *do* see that the stations and airports you are departing from, and arriving at, know in advance. This should ensure that you are given any necessary assistance. Remember the journey is part of the holiday and a little forethought will see that it isn't spoiled.

Compiled by
BEVERLEY HOLLAND

Grandparents unite!

DURING the research for material about the problems extended families face with the arrival of a handicapped baby, I became very concerned by the special problems which grandparents have. The shock, and subsequent acceptance of the baby, and sadly also, the shock and non-acceptance of the baby; the loving attitude toward the new parents; and the rejection of the new parents. The ways of helping are manifold, but alas ways of helping are also ignored!

I have talked with many grandparents, and feel that underneath their sorrow is a desire to accept their handicapped grandchildren, although many times they themselves are unable to come to terms with their own personal distress. Our added years bring a desire for peace of which a family with a handicapped child knows little.

We are a high-risk family, according to Genetic Counsellors, and spina bifida and hydrocephalus keep appearing. When it does, the new parents need all the help they can get! Most important of all, they need all the love, and support possible. So it must be for every family.

I would like to hear from, and write to any who have problems accepting their handicapped children/grandchildren, and also to hear from those who have found the whole subject much easier to accept! So many people need the help of those in the latter 'brigade'. We have learnt the hard way about ways of helping and support, and quietly also about grief when these babies die.

Grandparents Unite would be a good slogan to start the year 1980! We must unite with our families in every way, to share the joys of progress and healthy days, as well as the days of sorrow, and distress. I found the acceptance of a handicapped grandchild very difficult, but the child was still my grandchild, handicapped or not.

If it is possible to help in any way the lot of any members of extended families, please write to me: Winifred Foster, 56 Douglas Towers, 2 Radwell Drive, Bradford, W. Yorkshire, BD5 0QR.

WINIFRED FOSTER

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continued from page 8

their right to have as full a part of normal social and working life as those who are able-bodied. Refugee children, sick children, gypsy children, delinquent children: our message has been that interests aspirations and needs are common to all children everywhere.

So when all those organisations begin a new year of working for children, as many of them have done for more than sixty years already, I hope that there will be one voice speaking for all children with a clear message and not a clamour of confused voices.

MPs about to take the plunge

THE PARLIAMENTARY Sponsored Swim, details of which were carried in the last issue of LINK, has been successfully accomplished. Altogether 72 Members of Parliament took part and it is hoped that the event will have raised more than £10,000.

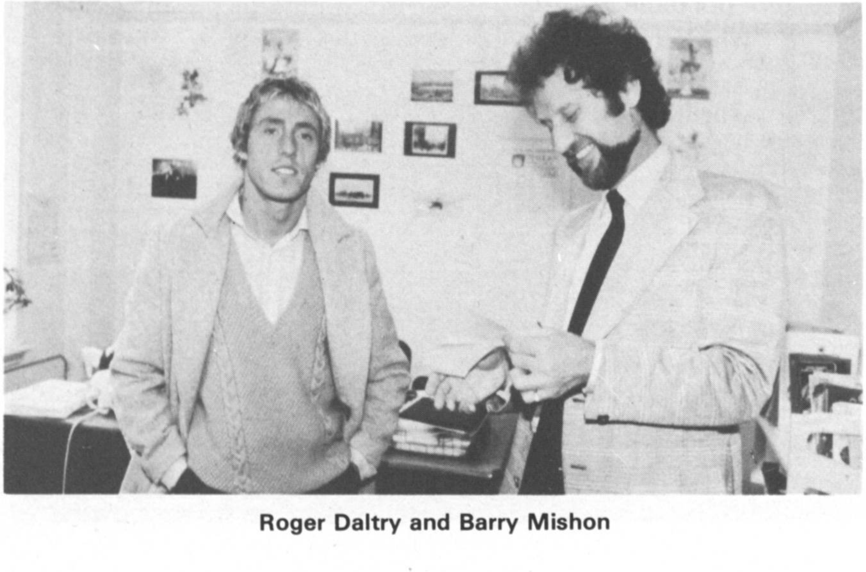
As the photograph shows we were most fortunate in that the Speaker of the House of Commons, Mr George Thomas (extreme right), agreed to start the swim for us and I am not sure whether it was his presence, or the cause for which the Members were raising money, which spurred them on to some fantastic efforts.

Mr John Prescott, the Member for Hull, swam each night covering a distance of more than nine miles. The winner of the event will be the MP to produce the most sponsorship.

November saw the visit of a rather special guest to ASBAH's offices in London. Mr Roger Daltry, lead singer of The Who, called in to present a cheque for £5,000, on behalf of the band, towards the Five Oaks appeal.

He and his fellow musicians have expressed a great interest in the home and are looking forward to hearing news of everything that happens there. It is also possible that they might drop in and meet everybody, if their tour arrangements take them in the direction of Yorkshire, which would be quite a treat for any young people staying there.

ASBAH was first brought to Roger Daltry's attention by special events organiser, Barry Mishon, and I think we are very lucky to find such generous and interested friends as The Who.



Roger Daltry and Barry Mishon

I am also very pleased to report that ASBAH's regular supporters have really responded magnificently to our appeal this Christmas and at the time of writing a record total of more than £12,000 had been received and donations were continuing to arrive with each post. At a time when all of us are finding the financial going rather hard I would like to extend our appreciation to all our generous supporters throughout the country.

INTO THE 1980's

All things considered, I have reason to hope that 1980 may be the year when ASBAH's income comes a little nearer to meeting demands and a contributing factor will be our involvement as a member of a consortium of eight charities in the purchase of Cashcade Lotteries from the Ladbroke organisation. Cashcade for Charity, as it is now called, commenced trading on 1 November and I would very much encourage readers of LINK to buy a 25p lottery ticket where they see them on sale, as not only does one have a chance of winning the major prize of £1,000, but every ticket purchased will include a donation towards ASBAH as well as our fellow consortium members: Anchor Housing for the Elderly in Need, The Leukaemia Research Fund, The Muscular Dystrophy Group of Great Britain, The National Association of Youth Clubs, The National Society for Mentally Handicapped Children, The Royal Commonwealth Society for the Blind and The Royal National Institute for the Deaf.

JUDY KAY

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CLASSIFIED 'ADS'

The advertising rate is:
£1.50 for up to 30 words. £2.50 for 30–45 words.
£3.50 for 45–60 words.

Please send remittance with your advert. You may like to pay for a whole year's advertising in one go.

Adverts for the next LINK (March/April) should be in by February 5. Send to the Editor Mrs Susan Gearing (or telephone her on Langton 3351).

HOLIDAY ACCOMMODATION

CAMBER SANDS: Well-equipped and adapted chalet (sleeps 6). Bookings taken by Mrs N. Kerswill, 28 Ilmington Rd, Kenton, Harrow, HA3 0NH. Tel: 01-907 8526 (2–7 pm).

GOLDEN SANDS, VORYD, RHYL, N. Wales: 8-berth caravan. Mains water, electricity, gas, shower, television. Every facility on site, right by sea. Details: Mr S. Foster, 84 Elmwood Drive, Blythe Bridge, Stoke-on-Trent. S.a.e.

EYSHAM, Nr Morecambe: Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 9 Belton Road, Whitchurch, Salop. Tel: Whitchurch 3691.

MABLETHORPE, Lincs: 2 well-equipped 6-berth chalets, self-contained, at Mablethorpe Chalet Park, Links Road. Details: Mr B. Guest, 57 Bloxwich Lane, Walsall. Tel: Bloxwich 31725.

MILLENDREATH, Nr Looe, Cornwall: Well-equipped holiday chalet (sleeps 6). Easy access. Details (s.a.e. please): Mr T. Gardiner, 72 Dale Valley Road, Oakdale, Poole, Dorset. Tel: Parkstone (0202) 744873.

PRESTATYN: 6-berth caravans. Accessible to amenities. Special reduced rates out of season. Details: Mrs J. Whiting, 33 Weston Avenue, New Moston, Manchester M10 0QP, and Mrs A. Lawton, 55 Wimpole Street, Shaws Road Estate, Oldham, Lancs.

WINTERTON-ON-SEA, Nr Gt Yarmouth: 6-berth chalet. Indoor swimming pool, shop, play areas. Details: Mr R. orris. Tel: High Wycombe 32184.

FOR SALE

Leisure Wear: White cotton **Tee Shirts** with green Family symbol and words 'Support Spina Bifida' £1.60 each size 22°–30°, £1.85 each small, medium, large. Also quality **Sweat Shirts** with reverse colours in all sizes including extra large adults. All at £4.50 each plus postage. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

FREE SERVICE

THE DISTRICT Advertising Company of EMI Elstree Studios, Shenley Road, Boreham Wood, Herts. WD6 1JG, offers a special service to Charities. They produce Telephone Address & Notebooks. These are a unique way of raising funds, also Fundraising Charts with Socks attached for Donations. These also help promote your cause and recruit new members, and are displayed in public houses, restaurants, on factory notice boards and other prominent places. Calendars, Diaries and Programmes for Fetes, Donkey Derby's, Bazaars, Charity Football Matches, etc., can also be obtained, all completely free of charge. For further information contact: Mr J. A. Alter at the above address or tel: 01-953 1600 Ext. 171.

ASBAH booklets etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	25p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	20p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	30p
The Care of an Ileal Conduit and Urinary Appliances, by E. Durham Smith, MD, MS, FRACS, FACS, and others	15p
Aids and Equipment	*60p
Sex and Spina Bifida by Bill Stewart	*£1 (75p to LIFT members)
The Handwriting of Spina Bifida Children by Joan Cambridge and Elizabeth M. Anderson	*£1
Information leaflets	100 for £1.30

All available from ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 12p per booklet.
*Postage—17p.

Scottish Spina Bifida Association Booklets

Growing up with Spina Bifida	30p
The Spina Bifida Baby	30p

both by O. R. Nettles, McSP, ONC.
Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

FUND RAISING AND PUBLICITY MATERIAL

Posters

Best Foot Forward 20 × 30 in.	**10p each**
Best Foot Forward 15 × 10 in.	**10 for 40p**
For local publicity 15 × 10 in.	**10 for 40p**
Car Stickers	**2p each**
Plastic Lapel Badges	**3p each**

All available from Appeals Dept.—postage extra.

Film 'Appeal for ASBAH' 10 mins 16 mm Colour/Sound	**..£4 Hire**

The Appeals Dept. carries a range of fund-raising items, i.e. pens, key rings, kits, games, etc. Send for list and order form.

Flag Day equipment can be obtained direct from: Angal, 48a Holmbush Road, London SW15 3LE (01-788 5464).

PUBLICATIONS

New Spina Bifida Journal: A new international journal, *Spina Bifida Therapy,* the only professional publication devoted completely to the treatment, care, and education of people with spina bifida is now available from Eterna Press, PO Box 1344 Oak Brook, Illinois 60521, USA. (£12 annually.) Original articles from the fields of medicine, physiotherapy, psychology, education, social work, and nursing appear with book reviews, news and thorough abstracting of current literature.

Management of the Neurogenic Bowel and Bladder: a new 189 page book by W. Chapman, MD, M. Hill, R. N. and D. B. Shurtleff, MD, of the University of Washington is the most current up-to-date guide on this subject. Illustrated and easy to read for both professional and parent, no one should be without it who has anything to do with spina bifida. £2. Eterna Press, PO Box 1344 Oak Brook, Illinois 60521, USA.

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162 Carr Bank,
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Derby. Tel: Derby 23734.

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West Midlands WV11 2HF

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Upminster RM14 1HS.

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Shurdington, Cheltenham.
Tel: Cheltenham 862517.

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80 Brinklow Crescent,
Woolwich, SE18.

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The Old Police Station,
Leepale Road, Guildford.

HAMPSHIRE SOUTH
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19 Lyndhurst Road,
Gosport, Hants, PO12 3QY.

HERTS & S. BEDS
Mrs P Thomas,
19 Florence Avenue,
Sundon Park, Luton.
Tel: Luton 55662

HUDDERSFIELD
Mr P Griffiths,
67 Dunford Road, Holmfirth,
Huddersfield.

HULL & DISTRICT
Mrs G D Brown,
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SCOTTISH ASSOCIATION
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190 Queensferry Road,
Edinburgh EH4 2BW.

NORTHERN IRELAND
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Flat 1B, Parkdale House,
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OTHER LOCAL ASSOCIATIONS

Blackpool & Fylde
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17 Queens Road,
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Beeston
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