Link

Association for Spina Bifida and Hydrocephalus/ASBAH 15p May/June 81

IYDP—Asians in Bradford: Another Marathon: Experts on the Education Bill: The Budget: Children's Fears and Worries: Spina Bifida worldwide: *ASBAH's Spring Conference—a four-page report:* Aids: Reviews: How 1981 is adding up

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The external dimensions of the pouches are:–
172mm x 102mm
($6\frac{3}{4}$" x 4") approx.
Flange 82mm dia.
($3\frac{1}{4}$") dia. approx.

paediatric

Salts Baby Pouches can be supplied in three distinct styles ILEO, COLO, and URO. All three types are odourproof and also share a new adhesive which is particularly suitable for application to the most delicate skin. This is so because the plaster allows the skin to breathe beneath the flange. The flanges are provided with a starter hole to facilitate accurate cutting to fit almost any stoma. Full instructions are provided in every packet.

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are complete appliances and can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.
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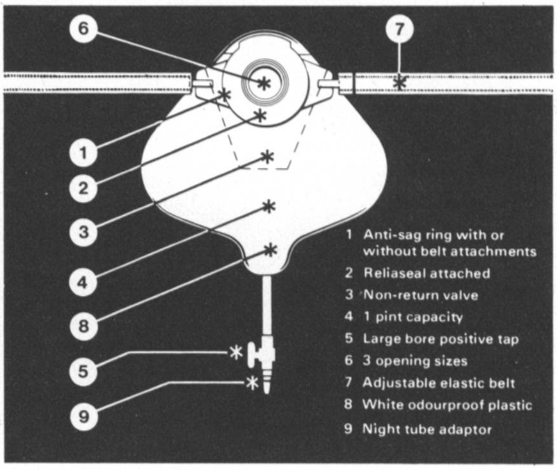
3 opening sizes available: 1", $1\frac{1}{4}$" and $1\frac{1}{2}$".

*** Now available in Small capacity size**



LIGHT WHITE ILEOSTOMY POUCHES

can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.
LW is disposable, has bag covers, belts, closures, stabilising rings, is supplied in two capacity sizes, large and medium, odourproof, can be worn for a week without anyone knowing, and it looks as good as an appliance can look.
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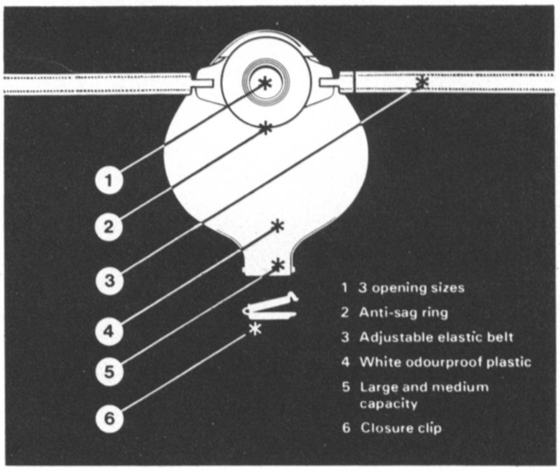
3 opening sizes available: 1", $1\frac{1}{4}$" and $1\frac{1}{2}$".

*** Now available in Small capacity size**



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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:
HRH The Duchess of Gloucester

Chairman: Mr D M Bryant

Hon Treasurer: Mr R M Nichols

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

Chief Executive Officer:
Miss M P Gilbertson, MCSP

Finance Officer:
Mr F G Armour, FCA

Director of Appeals:
Miss Judy Kay, MIPR

Head of Field Work:
Mr H Croydon

Education, Training & Employment Officer: Mrs B Newman

Disabled Living Adviser:
Miss J Vernon, BSc

Senior Administrative Officer:
Miss P Silverthorne

Information Officer:
Miss B Holland

Link Editor:
Mrs S I Gearing

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YOU DON'T need me to remind you that this is the International Year of Disabled People. After receiving a duplicated circular from ASBAH regarding the usual Spring conference, I was amazed to see that this was to be the Association's main contribution to the IYDP. For the first time ever I feel stirred to put my own feelings on being disabled onto paper: my spontaneous reaction after twenty years of being so labelled.

I have continually tolerated the patronizing attitudes of "normals"—the way the general public regard me and other handicapped people. Society is slowly changing its attitude but there is still a long way to go.

I think it is very sad when a young disabled person, upon reaching adolescence and usually well adjusted to their handicap and the limitation it imposes, finds that on setting out to make their contribution to the community (or should I say to try) they have to encounter a sea of problems, which, in all probability, may swamp their efforts to attain a normal life. This striving to establish a normal life within the community is the first hurdle for the adolescent to overcome.

Improved medical advances, particularly genetic counselling, plus pre-natal screening, could mean fewer handicapped children being born. However, improved neo-natal care could also mean that children born severely handicapped are more likely to survive.

This emphasises the necessity for social awareness and acceptance of the disabled child by society and the need to encourage those involved in the welfare and development of that handicapped child, to teach the child to lead as normal a life as possible. Society must therefore be educated to accept these children and not condemn them to second class citizenship because they are born non-perfect, and to realise that more and more will survive into adulthood. Being less able does not mean being useless!

May we say to society, and not just because it is the year of the disabled, avoid handicapping us further, when we are trying to live in a world constructed for the ablebodied: with forethought and adaptation this objective could be more readily achieved. Disabled people can offer a great deal to the community as a whole, and should be able to take their rightful place in society without prejudices. Often the attitudes are negative ones telling the disabled person what they can do or cannot do.

Why is it that so many able bodied people discuss, and in some cases, decide what is best for the disabled? Why are there not more disabled people sitting on committees? Surely the disabled know best what problems face wheelchair users, being so confined themselves—yet how many times do you see an ablebodied person sitting in a wheelchair experiencing such problems. The disabled person lives these problems not just for the odd day, as a gimmick, but for the majority of us the rest of our lives.

Helen Garthwaite

FRONT COVER: Dave O'Toole at the helm of the square rigged ship 'T.S. Royalist' on a cross channel pilot scheme for the Jubilee Sailing Trust. Dave, who has spina bifida, was a member of a mixed crew of able and disabled youngsters. As a result of the Trust's pilot schemes, a 135ft square rigged sail-training ship, The Jubilee Barque, has been designed especially for an able and disabled crew. Work is due to start on her this year.

Time for a Marathon

ANOTHER Marathon takes place in London at the end of the month, and this time it's in aid of ASBAH. On May 31 at 9 a.m. about 5,000 competitors are expected to gather at Clapham Common North Side for the start of the marathon to Ham Common (West side).

The organisers would be pleased to see as many members and their families as possible at the finish, between about 11–11.30 a.m.

The very first wedding!

NOTTINGHAM and District Association proudly sent LINK this happy picture (below) of Annette Oldham and Malcolm Smith on their wedding day. Annette, aged 17, was the first of the Association's young members to be married.

She is in a wheelchair—although able to walk a few steps—and after leaving Thieves Wood School she went on to West Bridgford College of Further Education.

Annette now works as a receptionist at County Hall. She and Malcolm have a flat of their own, the kitchen of which was adapted for them by Nottingham City Council.

Malcolm who is able-bodied is proving a wonderful husband and nurse, according to Annette's sister.

The couple was the first to receive a £25 wedding grant from Nottingham local association and Annette has used it to help equip her kitchen.

Kevin Astridge, 16, riding around his parents' farm at Clemsfold, Sussex, on a Honda ATC 110 bike thanks to the ingenuity of staff at a local car dealers, Harold Lines. They converted the three-wheeler, all-terrain bike from a footgear change to hand change. Kevin, who has spina bifida, and is a pupil at Chailey Heritage School, thinks the bike is 'great'.
Photo: West Sussex County Times.

RADAR opens New Library

LINK readers who may be engaged in research or writing about disability will be interested to know that RADAR (The Royal Association for Disability and Rehabilitation) now has a reference library. It is open during office hours and contains over 1,000 books on the medical and social side of disability. If you have any enquiries or wish to visit the library please contact the librarian, Jenny White. Tel: 01-637 5400.

Welsh chairman

The Chairman of IYDP in Wales is non other than Alistair Wood, the first Chairman of the North Wales Association for Spina Bifida and Hydrocephalus.

Mr Wood who has a daughter with spina bifida, is currently a trustee of the Association in North Wales.

A big hug for Christopher Davies from Harry Secombe when, as President of the Lord's Taverners, he visited Christopher's School in Swansea—Broadway House special school—and presented a new £11,000 mini-bus. Christopher who is 10 and has hydrocephalus lives at Mumbles, Swansea.

An offer from 'Rent a Riot'

LINK couldn't resist publishing this enthusiastic letter from 'Rent a Riot':

We are known as *Rent a Riot* and have adopted ASBAH as our charity. We are a group of adults who do 'stints' to raise money for the Wigan and Leigh group. Over the past two years we have raised a vast amount of money and have bought hand-propelled trikes, wheelchairs and helped sponsor Dr Roger Bayston in his work with shunts.

We do fancy dress pub crawls, carnival parades, sponsored bike rides, pram pushes, Country and Western evenings, Caeli nights, jumble sales . . . This year, as it is IYDP, we want to hold a street party for the children of the association. We love the work we do and give all our spare time to this cause.

None of this would be possible without the help of the landlord at the Legh Arms, Golborne, Lancs, Ben Griffin who encourages us to go on, and lets us have the run of the place when we are making preparations for a 'do'. He's the unsung hero of our group.

We hope this letter might encourage others to start a *Rent a Riot*. You would be amazed at the fun you can have. When you present a trike etc. to a child who really appreciates the trouble it took to raise the cash, it's a beautiful feeling.

Rent a Riot
Golborne, Lancs.

In at the start

LINK has been asked to mention two of the people who had large parts to play in the successful campaign to buy an image intensifier for Queen Mary's, Carshalton, and who were not mentioned in previous reports.

Tommy Burr was the man who decided to try and launch the campaign. A special committee was formed, with Miss Murkin as Secretary and she worked extremely hard to involve local celebrities, other organisations and the Variety Club.

Karen has her very own Royal day

Karen Foley, 14, of Sussex Association meets HRH Princess Anne and receives a cup for first prize in her age group in a competition for the design of a plate.
The competition was open to members of Riding for the Disabled of which Princess Anne is President.
Photo: Coventry Evening Telegraph.

Sarah Greeves, 10, of Easton-in-Gordano, near Bristol, with the highest award that can be given to a brownie—the Star of Merit. The award was made to Sarah for her courage in facing and overcoming the problems of having a physical disability. Sarah—a member of Crockerne Brownies—has spina bifida and was nominated by Mrs Jean Keeley, a member of the committee for Handicapped Guides and Brownies.
Photo: South Avon Mercury

Britain—please take note

"A Mr Vern Sprock developed a ski ranch in the Rockies which is only open in the winter—when the snow lies some 12 feet deep—and can only be reached by chair lift. He could not get a licence to run the ski ranch because he had failed to instal lavatories adapted for wheelchairs users, as required by state law."

With thanks to Scottish Spina Bifida Association, who first published this in their Lanarkshire branch newsletter.

Special seminar

AN international seminar on the prevention of disablement is being sponsored by the government as part of its contribution to IYDP, and it will be held at Leeds Castle, near Maidstone in Kent from November 8-12. A team of distinguished experts will meet together to consider how to tackle the causes of disablement, which now affects about 450 million people in the world.

Disabled miss out on benefits

ONLY FIVE out of 39 households of disabled housebound people were getting all the benefits to which they were entitled, according to a survey carried out recently by the National Association of Citizens Advice Bureaux.

The Report was carried out in Chapeltown, Leeds and covered 39 randomly selected households of disabled housebound people. It was calculated that the group as a whole was missing out on nearly £9,000 a year in unclaimed benefits.

The largest category (30%) of unclaimed benefit was attendance allowance, and about 15% of the sample were not claiming supplementary benefit.

With the help of CAB workers, 22 people completed claims for extra weekly benefits, obtaining an average increase in weekly income of £6.31 per person.

Motability turns to electric wheelchairs

MOTABILITY has recently begun to provide electric wheelchairs. Under agreements, which Motability has made with Batricar, Meyra Rehab and Vessa, it can now offer, on hire purchase over two years, a selection of electric wheelchairs at a discount.

For further information contact Jill Vernon at ASBAH National Office, or write for leaflets about the vehicles available to: Motability, The Adelphi, John Adam St., London WC2N 6AZ.

Programme moves

'DOES He Take Sugar?', BBC Radio 4 programme of special interest to people with disabilities has moved back to Saturday afternoons (4.30 p.m.), as from April 25.

YMCA Centres

THE YMCA has five centres in Britain providing facilities for disabled people to enjoy a holiday. Beverley Holland at National Office can give you the addresses.

London Naidex

LONDON Naidex '81 (National Aids for the Disabled Exhibition) takes place at the Cunard International Hotel, May 28-30. Running concurrently with the exhibition will be the annual conference of the College of Occupational Therapists whose theme, this year, will be 'The Disabled and the Community'.

NAIDEX later this year will be at the National Exhibition Centre at Kenilworth, October 21-24.

Welsh offer 'Treasure Trove'

THE WELSH Association of Youth Clubs is running a special one-week residential holiday course for physically handicapped and able-bodied young people, aged 16-25 from August 8-15 at the Army Apprentice College, Chepstow, Gwent.

The course, entitled 'Treasure Trove' will offer a wide range of social activities and quite a lot of free time. It will cost £30 per person, and it is not necessary to be a youth club member to participate.

Details from: Mr Roger Jones, Welsh Association of Youth Clubs, 18 Coed Y Brain Court, Llanbradach, Caerphilly, Mid Glamorgan CF8 3JT. Tel: 0222 862630.

Instructors get chance to learn

CADBURY will be sponsoring swimming teachers on special courses to help them to learn to teach handicapped people to swim. This is part of its 'Learn to Swim with Cadbury's Dairy Milk' scheme.

It is hoped that after these courses, qualified instructors will use their expertise to promote swimming for disabled people within their own communities, for example, by establishing new clubs.

Windsor Park's Special Offer

WINDSOR Safari Park is interested in offering ASBAH its own special day on Saturday July 25, when concessionary rates of 80 pence per person would apply, and where if the response merited it, additional attractions could be provided.

These prices include entrance to the dolphin/killer whale show. If you are interested in the idea of a special day contact Beverley Holland at National Office as soon as possible.

Harlow Car for gardening ideas

THE NORTHERN Horticultural Society is putting on a special Exhibition of Gardening Tools and Books for the Disabled, June 15-28, at their gardens and trial grounds at Harlow Car, Harrogate, North Yorkshire.

Harlow Car Gardens cover 60 acres and are a paradise for garden lovers. Much of the area is accessible by wheelchair. Admission 80p to non-members. For more details ring the Society on 0423 65418.

A 'Souper' idea

H. J. HEINZ have equipped a Range Rover trailer unit to serve free soup to the public at specially selected outdoor events, including charity functions.

Where the 'Soupervan' appears in co-operation with a charity a collecting box is available on board for donations. Details from: Hilary Stevens, B-M Marketing Communications, 25 North Row, London W1R 2BY. Tel: 01-499 0414.

Correction

IN OUR last LINK, in the article on statistics of babies born with congenital malformations, it was stated that Manchester and Salford together were the same size as London. This should have read 'the same size as Liverpool'.

Experts give their view of the Bill

THE HOUSE of Commons Special Standing Committee on the Education Bill 1981, which is considering the Bill clause by clause, has heard evidence from witnesses from the professional and voluntary sectors.

Mary Warnock who gave her name to the report on education for the disabled, expressed concern that if the Government did not provide extra finance to local education authorities (LEAs), integration would not be properly implemented. She said this could be detrimental to the children involved.

Witnesses involved in special education recommend that LEAs should have a duty to seek to identify children under 2 years who were in need, and said that teacher training was fundamental to the success of integration. Money had to be found for in-service training, and special education should be included in initial teacher training.

It was stressed that education did not end at 16 especially for pupils who had missed schooling because of medical reasons. LEAs should provide education up to 19 years, and an education element should be included in adult training and day centres.

The witnesses said that the right of parents to see reports on children was essential, and all strongly endorsed the role of a named person (someone like an involved professional) to give continuing advice and support to parents.

Teaching representatives felt that adequate support services were important in promoting an accepting attitude amongst teachers. Special schools could become resource centres, servicing ordinary schools for pupils with special education needs.

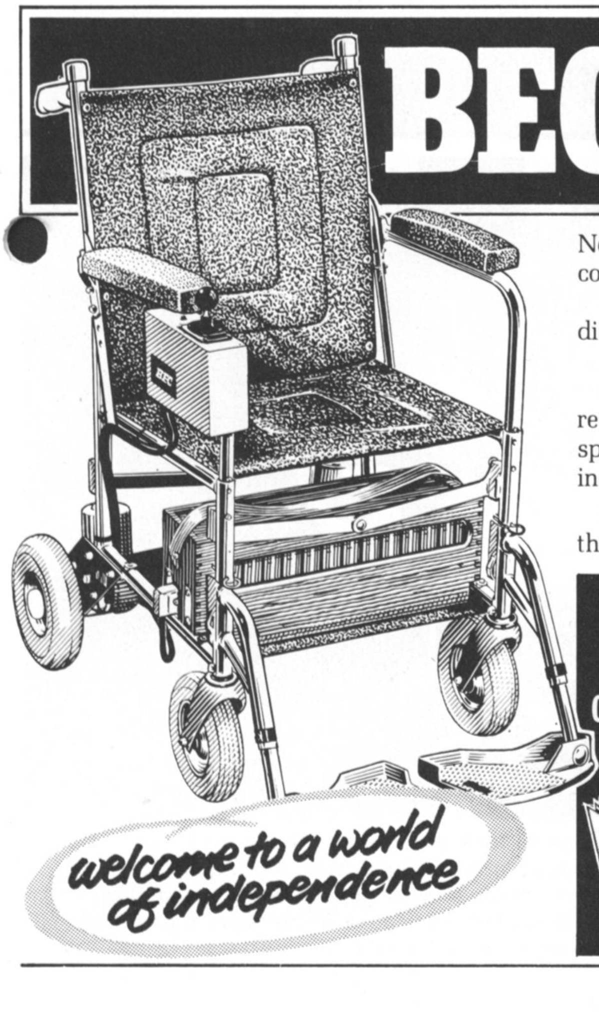
Could you give a Home to Mandy?

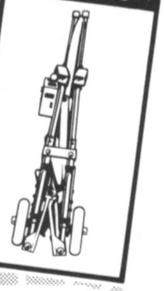
MANDY is a four-year-old West Indian girl, with a cheerful smile and a great deal of determination. She was born physically and mentally handicapped and needs skilled care. She loves doing things like painting and playing with toys, and she giggles a lot. Best of all she likes to be cuddled.

We are looking for a permanent home for Mandy. If you think you can help, please contact Michael Goldberg, London Borough of Brent, Area 5 Social Services, 13 Brondesbury Road, London NW6. Telephone 01-328 1767.

THANK YOU to those who wrote offering to help following the piece in the Jan/Feb LINK about David who needed a long-term foster home. All of you have received a direct reply. David has been introduced to a family and it is anticipated that he may be going to them during the summer. We wish them all well.

Harry Croydon





Attempt to make Act work goes on

THE AMAZING response to the short-term project on the enforcement of Section 2 of the Chronically Sick and Disabled Persons Act 1970 has persuaded RADAR and the other charities involved (including ASBAH) to continue the appointment of a special project worker for another twelve months.

Over the past few months Mrs Ursula Keeble and other members of RADAR's staff have investigated several hundred letters from disabled people from all over the United Kingdom who contacted them following publicity in the press and on radio and television. In addition to many complaints about non-provision of services under the Chronically Sick Act there were numerous letters concerning housing and the great difficulty many people were having living on inadequate social security benefits.

TAKEN NOTE

Although at the time of going to press no individual cases against local authorities have been taken either to the Secretary of State for Social Services, or to court, numerous local authorities appear to have taken note of the legal advice received by RADAR, and have rescinded decisions not even to assess need for various services, for example the provision of telephones or assistance with a holiday, on the grounds that no money is available. On many occasions the intervention of Mrs Keeble has also rapidly resulted in the provision of the services required.

Thanks to Mrs Ursula Keeble's hard work many more disabled people are now receiving the benefits to which they are entitled and, with the successful continuation of the Project, the future looks a little more optimistic.

ASBAH INFORMATION SERVICE

The parts of the budget which help

THE CHANCELLOR of the Exchequer, in his Budget Statement on March 10 announced a number of measures which will be of help to disabled people. On March 11 Mr Patrick Jenkin, Secretary of State for Social Services, announced further measures. These are:

1. New and extended VAT reliefs on a number of aids for the disabled, including VAT relief on adaptations to cars for the disabled.
2. Widening of scope of reliefs from Capital Taxation for trusts for the disabled.
3. Mobility allowances to be increased from £14.50 to £16.50 per week.
4. The 5% abatement of the uprating of invalidity allowance made in November 1980 is to be restored from November 1981.
5. Attendance Allowance higher rate will increase to £23.63 (from £21.65) and lower rate to £15.75 (from £14.45).
6. Increases in supplementary benefit.

These upratings will take place in the week beginning November 23, 1981.

Attendance Allowance

ATTENDANCE Allowance is a tax-free, non-contributory, non-means tested allowance for severely disabled people who need either frequent attention in connection with their bodily functions or continual supervision in order to avoid substantial danger to themselves or others.

It is paid to severely disabled children aged 2 and over. There are two rates of allowance: a lower one, which at present is £14.45 per week, and a higher one of £21.65 for people who need both day and night attention. (See above for increases due in November).

If you have been refused the allowance, it is worth re-applying as over 60% of all reviews are successful. In order to help you with your appeal, a check-list is available from ASBAH. Please contact Beverley Holland for details.

Irene Smith has every reason to look so pleased. She is holding the Duke of Edinburgh Gold Award which she received from the Mayor of Barnet. It is an Award which always entails a great deal of work and dedication. But it was especially difficult for Irene because of her severe physical handicaps. Congratulations to a "golden girl".

Photo: Maria Bartha

Fears and worries of children with spina bifida and hydrocephalus

by Steven Dorner
Principal Psychologist
Wessex Unit for Children & Parents
Milton Ford, Portsmouth

MOST CHILDREN at some time in their lives show clear signs of being frightened or worried. Sometimes there is an obvious cause, but sometimes it is far from clear what is worrying a child. Children also vary greatly in the extent to which they seem fearful or anxious. Thus one child may only occasionally show such feelings, while another may express fear and anxiety so frequently as to be labelled anxious, worrying or fearful. It should be emphasised that fears and anxiety are unavoidable and necessary emotions in everyday life, and can be useful in helping a child to adapt to difficult events and to avoid foolhardy behaviour. However, there are clearly major problems for a child who has frequent, severe and persistent worries.

How much do the children worry?

It has been known for sometime that children with handicapping physical conditions are more vulnerable to emotional problems in general than able-bodied children and that in medical conditions, such as spina bifida which involves the central nervous system, the vulnerability of children is greatest. Even so, it should be emphasised that the *majority* of such children do *not* suffer from emotional problems; there is a big difference between worrying and having an emotional problem.

The research that has been done into whether children with spina bifida and hydrocephalus are prone to worrying suggests fairly conclusively that they are. In my own work with families, it was common for parents to report that their child was inclined to worry, particularly the older children with spina bifida, though only a small number of patients reported *severe* problems. This observation is confirmed by other research.

It is of some interest that children who have hydrocephalus *without* spina bifida also appear to be much more likely to be "worriers" than able-bodied children, or children with, say, cerebral palsy. Obviously, this is understandable where there are problems with the treatment of hydrocephalus necessitating revision of shunts etc, but even where the hydrocephalus has been successfully treated, there is evidence that hydrocephalus children tend to worry, be fearful, etc.

One other observation that may be of interest is that research points fairly consistently to the conclusion that spina bifida girls with hydrocephalus are more likely to have worries and fears then boys. Finally, more severely handicapped children may be the ones that worry most.

Why are they liable to worry?

Research into the worries and fears of children generally shows that their nature changes with age. Babies and young children tend to show signs of fear etc, in relation to *actual* events that occur. Fear of strangers, marked reaction to separation, distress in the absence of mother are particularly common over the age range of 6 months to 4 years.

Later on during early school years, in fears of imaginary things (ghosts, witches, the dark etc), or of possible events in the future are of importance. Still later, (middle childhood), there is an increase in fears of illness and worries about dying. At this time, too, and later, children become particularly concerned about lacking friends and may worry about their performance at school.

If one relates this brief description to children with spina bifida and hydrocephalus, it seems obvious that these children's *actual* experience might well make them more vulnerable to fears and worries. Hospitalisation for treatment of spina bifida, usually involving separation and inevitably involving strange situations, is particularly common at the age when children are known to be most affected by such experience.

It is therefore hardly surprising that children who have been through actual stressful experiences find it difficult to deal with imaginary fears, particularly when some of them, eg. fears of illness, are not imaginary at all! Indeed, it is a tribute to children with spina bifida and hydrocephalus and their famili that so many of them cope with their *real* worries and *real* fears without them becoming so severe as to constitute an emotional problem.

In the same way, there is a reality basis to spina bifida children's worries about friendship and school performance. Many of them do have general learning difficulties or problems with specific subjects, (especially maths and handwriting) about which they may be naturally concerned. Attending special schools *does* often make it difficult to develop friendships in the immediate locality, as does the feeling of being different.

To summarise, therefore, I would argue that one of the reasons, probably the main reason, why children with spina bifida and hydrocephalus are inclined to be worriers is the very obvious one, that they have been through experiences which *anyone* would find worrying. The same is true for parents and I must admit to feeling very uncomfortable when some professionals criticise parents for being worriers. We should rather admire how well they have coped.

It still remains a possibility, however, that hydrocephalus itself increases children's tendency to worry or to be fearful. Although there is no exactly comparable group of children, there is some evidence that children with similar handicapping conditions are less likely to be worriers (though more likely than children with hydrocephalus and spina bifida to have *other* problems, eg. aggression or other anti-social difficulties).

What do spina bifida children worry about?

Worries that are reported can range from worries "about anything and everything" to very specific isolated fears.

School: It is common for children with spina bifida who worry to report difficulty in keeping up with schoolwork generally and certain subjects in particular. Fairly early on, they may be conscious of problems with maths and this may develop into a specific worry; this is also true for spelling and reading. Such anxieties may lead to a general worry about going to school and this feeling can become stronger if a child has to miss school and part of the syllabus because of hospitalisation or illness.

On the whole, children with spina bifida do not seem to worry about friendships *at* school apart from occasional distress when they, (girls especially) happen to fall out with close friends, a problem that is no different with any children. On the whole, too, they seem to feel that teachers are friendly and sympathetic.

Residential schooling does sometimes add to children's worries. Apart from some homesickness, it is not uncommon for children to feel anxious about what is happening at home, whether or not there are actual problems.

Personal worries: Some of the most commonly expressed worries are to do with spina bifida children's lack of self-confidence. These feelings may develop at school, as I have mentioned, but they may also affect how a child feels about strange or new situations, such as meeting new people, going to new places, going out, going to clubs or on school trips or even buying things at a local shop. In an important piece of research Elizabeth Anderson, a Psychologist, found that nearly a half of teenagers with spina bifida had fears of this kind, considerably more than able-bodied youngsters.

Friendships, too, may be a cause of worry *outside* school. Particularly as they get older, children with spina bifida tend to feel increasingly isolated from others of their age group and at an age when they want to be with, and be like anyone else, a worryingly high proportion come to worry about their lack of friendships. I personally have come to feel that this is one of the major difficulties for older children and teenagers with spina bifida and hydrocephalus.

The family: We know from research and clinical experience that many parents worry, with reason, a good deal about their spina bifida child. Often this leads to the very positive result that they ensure that their child receives the best possible care, tiring and frustrating as this may sometimes be. There is no doubt that parents usually try to protect their child from the full force of these worries but in my experience children with spina bifida do sometimes come to worry that they are a burden to their parents, especially their mothers.

Even when the cause of worry is nothing to do with them, eg. job worries or other illness in the family, some children with spina bifida will feel that they are somehow to blame. They may even feel responsible for arguments between parents or for more serious problems that exist in the parents' marriage, even though this may be far from the truth.

Girls in particular may worry about their mother generally, so that a small complaint from a mother about feeling tired or unwell may be blown up in the child's mind to something much more serious. Often it becomes difficult for a child to say what worries they have about their mother in case they are thought silly or in an effort not to make their mother feel worse.

Medical condition: One of my own worries is about the number of children with spina bifida who appear to know very little about their condition. In some research I carried out a few years ago, only about one spina bifida teenager in three had any adequate understanding of their condition, while others knew nothing more than its name.

While one can understand that there may be some aspects of spina bifida about which a child might come to worry unnecessarily, in my experience, children with spina bifida who are inclined to be worriers, often develop quite unrealistic fears and worries about spina bifida on the basis of their ignorance about the condition. Most of us are readily able to think of situations where known facts turn out to be far less worrying than fantasies about what might be wrong and this is probably true for handicapped children.

Obviously, knowledge about spina bifida does not totally remove worries, but it may well help children and their parents to distinguish between situations where there is a *need* to worry (eg. about particular symptoms) and situations where there is not.

Although it is difficult to generalise, it is probable that younger children's worries about spina bifida are most strongly attached to what is going to happen, ie. hospitalisation, unpleasant physical procedures, changes of school, or routine. Older children worry about this but also take on some of their parents concern about their physical problems especially when there are recurrent urinary infections or symptoms suggestive of raised intra-cranial pressure.

The future: From early adolescence, sometimes before, worries about leaving school may be quite strong. Foremost, there are worries about job prospects or future training but there are frequently many other anxieties. These range from worries about the future medical care to worries about the future in terms of getting married and having children and social relationships in general.

Many teenagers also share their parents' preoccupation with the question "What will happen

Continued on page 21

BRADFORD is the hometown of quite a number of English families who have a spina bifida child. They are nearly all members of ASBAH, and meet together regularly, helping themselves and each other by this mutual contact. Bradford is also the home of Asian families—many not known to ASBAH—who have a child with spina bifida and, or, hydrocephalus.

Our Bradford ASBAH Social Worker, Mrs Ros Scott has been very helpful in trying to get the cooperation of the Asian families known to her; asking if they would be willing to talk to me about their experiences, and feelings with regard to their spina bifida children. Mrs Scott knows of only a few families, and two of these were prepared to help. So it is from these contacts, and long discussions with teachers that the information here was collected.

Spina bifida is a great leveller. The bodies of the children, be they black, brown, white or yellow, bear the same tell-tale scars. The same type of shunts go into tiny heads, whether those heads are covered by black, blonde, or brown hair. The misery, and pain of the bad times, and the joy of the good times is not determined by the colour of the skin, and no amount of sharing really eases the awful times.

MRS WINIFRED FOSTER

Jabeen "swings along" at a holiday play

ASIANS IN BRA

JESSICA is two and a half years old. She is the fourth child of a family who came from Kenya eight years ago. On the bright October morning when I visited their home in Bradford I was truly welcomed!

Jessica's father, and uncle came to greet me, and then retired into the back room, leaving Jessica and her mother to talk to me. Jessica looked so 'normal', and walked so well unaided that I asked if she was the spina bifida child?

Her mother's smile was radiant as she said 'Yes!' Hastening to lift up the pretty white dress, she showed me the scars on the back.

The shunt had been in place for over a year, but in the first year they had much trouble with shunts which blocked, and these had to be replaced seven times! The family are Gujaratis, and the grandmother, a beautiful middle-aged woman was moving slowly in, and out of the small garden collecting flower heads which were grown specially to use as decoration for the Temple dance which would take place that evening.

Jessica's mother wore a richly coloured, orange, and gold sari. She talked very intently about how she felt when Jessica was born, and of the concern, and help of the family in general. She had nothing but praise for the services of the medical teams, and how grateful she was for the visits of Mrs Scott! (ASBAH's field worker).

There was no need, she felt, for contact with other spina bifida families. Could this be, I wondered, because of the full family life under her own roof. With a loving, helpful grandmother on hand all the time, she did have help. The chores were shared, and she was able to do a part-time job which helped greatly her command of the English language. Jessica's brothers and sisters are all of school age, so she has undivided attention for much of the time.

Arrangements are underway for a nursery place, and hopefully normal schooling. The Health Visitor is very much appreciated, and has been most helpful.

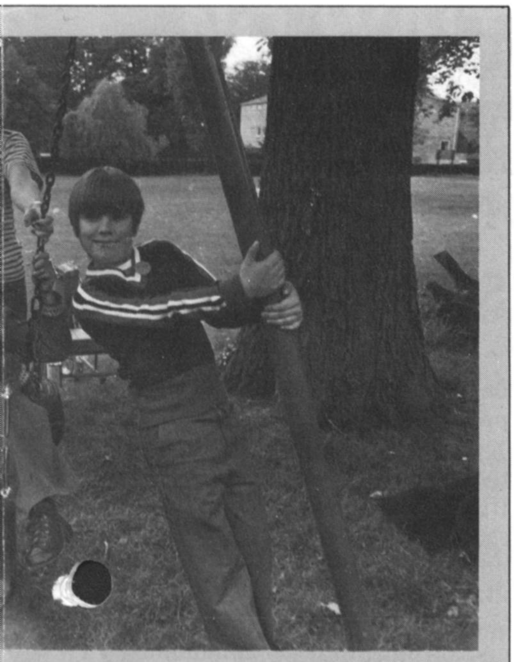
Jessica is incontinent, and this problem troubles the family very much. She also had bad bouts of vomiting if she gets upset, or too tearful. When I tentatively asked about—'more babies', Jessica's mother quietly stressed: "Oh No No—No more babies". Then smiled broadly as if to say 'You understand how I feel'.

Jessica was very interested in playing with the biscuits which were offered, along with a beautiful cream cake, and a glass of coffee served on a glass saucer. I was interested in Jessica's biscuit playing, and also her fascination with the contents of my handbag. Her mother tried to stop both these activities, but I have since learnt that Asian children are not brought up on a diet of toys, as their English 'cousins' are! The biscuit playing was just normal brick building as we understand it.

During the pregnancy there had been no suggestion of spina bifida. But within minutes of the birth the mother was told.

She says that she really does not fully understand what it means. Here of course the language barrier rears its troublesome head again. I found myself echoing the requests for information leaflets* which will help the professionals who moves amongst these families, and help the families themselves to understand what it is all about.

RASHID is a tiny Indian boy at a



scheme. Photo: Telegraph and Argus

ADFORD

special school. He, and his family have many problems. His teacher is a dedicated, observant professional, and it was she who detected the 'bulge' behind Rashid's ear, and the 'thick vein in the neck'.

Not only was he a 'problem child', he had hydrocephalus too. But there was no mention of this on his records, which leads me to wonder how many children are tucked away in Asian families, who have been treated, and fitted with these marvellous life saving devices, and yet whose parents have little, or no idea, what these devices really do.

Rashid is lucky that his teacher, having a spina bifida/hydrocephalus son of her own, knew just what she had found, and will be aware that when Rashid is miserable, and off colour, just how serious, or otherwise his condition may be.

JABEEN is eight years old, was born in Bradford the child of parents originally from Kashmir. She is one of the 'wheelchair brigade' and attends the special school where she seems to be happy, and shares her knowledge of English with her brothers and sisters.

Her mother has little command of the language, though she is able to understand the spoken word reasonably well. Jabeen's father is a local newsagent, and he mixes well with the varied assortments of creed and colour.

The X-Rays which Jabeen's mother had before the birth showed no abnormalities, so they were deeply shocked when the baby arrived with spina bifida. The family speak very highly of the medical care Jabeen has received, and their membership of ASBAH has given them great help in coping with their own particular problems.

Jabeen's father tells of the awful plight of the babies born in Pakistan, and India with spina bifida. They are unable to get, or cannot afford treatment, and if they do manage to get help it is often too late for the baby to benefit.

This family realise how fortunate they have been to be in England during this time with Jabeen. But they do not feel any real need to mix with other families who have a spina bifida child.

This year Jabeen went to Five Oaks for one week, and this was the first time she had been away from the family. Her father speaks disappointedly about that week, saying that Jabeen did not seem to enjoy being away from the family, and she was off colour too! The language difficulty is overcome on hospital visits by taking one of the other children along to translate.

Once again there is a marked absence of toys in the house. When Jabeen was much younger she played with jewelry, and household objects. Rings, bangles, books, marbles, knitting wool, and needles. She responded well to jangling coins, and squeeky toys. They are members of the Toy Library, and have found this 'therapy' beneficial too.

The skin colour of the parents of spina bifida children makes no difference to their reaction when faced with the alarming truths. Black and brown parents feel just as troubled, and guilty as white parents. One family put its child in a cot, far removed from the rest of the household, and said, "No walk, no good". Luckily they were persuaded that this need not necessarily be so, and that particular child was some good even though it could not walk!

Another family left their child lying on a cushion on the floor screaming his days away. Curled in an embryonic position he lay there, until the professionals moved in. When investigations were well underway it was discovered that the child was hungry. Fed, the screaming stopped, and with daily help, and support for the mother the child is gaining strength.

According to an article in our local newspaper recently—in Bradford in 1979 nearly 22 Asian babies out of every 1,000 died within a week of birth or were stillborn. Hopefully work now being done will increase ante-natal care among Asian, and West Indian mothers.

We know that the children, handicapped or not, growing up in Bradford learn English quickly, and more easily than their parents. It has been observed many times that the children never notice the difference in colour of their friends, it is only adults who bring this difference into 'play'.

We must hope that the Jessicas, Jabeens and Rashids of our Asian community grow up to understand their own problems, and are helped, in the knowledge that the Johns, Margarets, Elaines, and Simons of the English community are not exempt from spina bifida. Together they could go far, helping and supporting each other. Many things will be different, but this they will have as a common bond.

The writer of this article, Winifred Foster, is the grandmother of a little boy with spina bifida and hydrocephalus. Her book "Little Joe" is reviewed on page 21.

**ASBAH is producing an information sheet about spina bifida and hydrocephalus for Asian families in this country. It will be translated into the main Asian languages, and be available later this year.*

Spina bifida exists around the world, but is more common in the British Isles

K. M. Laurence
Professor of Paediatric Research and Consultant in Medical Genetics, University Hospital of Wales, Cardiff.

SPINA BIFIDA is the single commonest serious malformation present at birth in the British Isles and is found in about 2½ of every 1,000 newborn babies. However, the incidence varies considerably in different parts of these islands, with Ireland, Scotland, the North West and South Wales most severely affected with up to 5 per 1,000 births. The Midlands, the North East and the South have an intermediate incidence and London and the Home Counties and East Anglia the lowest with less than 1½ out of every 1,000 births.

On the continent of Europe and especially in the Mediterranean countries, there are far fewer babies born with spina bifida and the incidence generally is less than 1 per 1,000 births. The same is true for Australia, North America, Africa and most parts of Asia, though in India and parts of North Africa and the Middle East there are areas where rather more affected babies are born.

In general, spina bifida is an abnormality characteristic of the population of the British Isles and people who have emigrated from here, but one rarely found amongst negroes or the Far Eastern people. This is well illustrated by the incidence of these abnormalities in Boston, in the United States, where those of Irish descent have the highest incidence, the Protestant whites have a lower incidence, the Jews a lower incidence still and with few cases found amongst the negroes. Similarly, in Singapore those of European and Indian descent seem to have most cases whereas spina bifida is rarely found in the Chinese.

In Britain there is a clear difference in the incidence with social class. Relatively few cases are found amongst the children of professional and managerial workers and most are born to wives of the manual and especially the unskilled manual workers.

It seems to affect mostly the first children of young mothers and the later children in large families and elderly mothers. There is a slightly greater risk to babies conceived in winter and early spring. However, all these factors have lately become less pronounced and the incidence of spina bifida in the British Isles has dropped considerably during the last decade, even when the terminated pregnancies following amniocentesis are added to those which are born.

This drop in the incidence seems to have been most pronounced in the most affected areas such as Ireland, Scotland, and South Wales. In South Wales the number has dropped from just over 4 per 1,000 births between 1956 and 1966 to just over 2 per 1,000 births between 1976 and 1979. Hopefully this fall, which has also been reported from other parts of the world, will be permanent.

The difference in incidence in various races and the data which has been collected over the years from family studies and genetic clinics suggest that there is a strong hereditary element in the causation of spina bifida. Most of the other information supports the notion that environmental factors trigger off the abnormality in early pregnancy in those developing babies which are genetically predisposed.

Recent work suggests that one of the more important environmental trigger factors in the British Isles seems to be poor maternal nutrition. The drop in the incidence would be in keeping with the improving standards of living and of nutrition, the community, and presumably the mothers in Britain, have been experiencing in recent years. Radiation exposure, drugs, infections, smoking and alcohol in early pregnancy do not seem to be significant factors, except insofar that they may interfere with the diet.

With further attention to maternal nutrition before a pregnancy is begun, with special dietary counselling for known high risk women, together with supplementation of the maternal diet with some of the deficient dietary elements which also would have to be started before the beginning of pregnancy, it should be possible to reduce very substantially the number of babies born with spina bifida in Britain. Backed up by alphafetoprotein screening and amniocentesis at 15-19 weeks, we may also completely eliminate this problem in the future.

DIG aims to build support

THE Disablement Income Group (DIG) is launching, this year, a new National Subscription membership. The aim is to build up the backing for the campaign for DIG's objective, a National Disability Income. For further information contact DIG Special Projects. Tel: 0243 829857.

DIG has recently produced a useful booklet entitled *On Your Way* by Lorma Roberts. It is aimed at handicapped young people leaving school and gives information about grants for further education, benefits, pensions and allowances and the agencies available to help find work. The booklet is intended as a signpost towards independent living. It is priced at 25p and is obtainable from DIG at Attlee House, 28 Commercial Street, London E1 6LR.


SPEEDWELL
SUPAKART

ASBAH's Spring Conference

ASBAH's Spring Conference this year on the theme 'ASBAH into the '80's' attracted more people than ever before, including a wide range of professionals.

Over 200 people, including members from all over the country and ASBAH's staff, met together at Goldsmith's College London.

ASBAH's Chairman, Mr D.M. Bryant chaired the Conference, and he made particular mention of the number of young disabled members present—many of them members of LIFT (the young ASBAH group),—and of the way in which they took such an active part in the proceedings.

As the Conference was ASBAH's main contribution to IYDP—but by no means its only contribution—it was pleasing that Mr Kit Aston, Chairman of the IYDP Committee of Voluntary Organisations was the opening speaker. Once again ASBAH was pleased to welcome Lady Jean Mackenzie as Hostess for the weekend.

THE INTERNATIONAL Year of Disabled People is a further step in the long process of improving attitudes towards disability said Mr Kit Aston, Chairman of the IYDP Committee of Voluntary Organisations.

In his introductory talk to the Conference he said that improved attitudes led to better facilities. He hoped the Year would be the start of the 'decade of the disabled'.

He said he would not feel satisfied unless a significant improvement could be made in the lot of the millions of disabled people in the developing countries where 'disability means death', and he also hoped that the Year would help in the vital task of preventing disability.

The Year should not only boost the work of established organisations, but also fire individuals with enthusiasm to make their voices heard. As an example he said that local groups and individual disabled people should fight for their rights under the Chronically Sick and Disabled Persons Act.

It was a great step forward, but was being blocked because the Government claimed there weren't sufficient funds to implement it. Councils did, however, have a statutory duty to meet the needs of the disabled in their area and if individuals went to their councillors and told them what their needs were and demanded their rights then the Councils would have to act.

Local groups could do much by going to see their MP's and putting them 'in the picture'.

Mr Aston said he hoped that ASBAH and similar organisations would gain renewed support and vigour during IYDP so that they could carry on the work into the 'decade of the disabled'.

Now a simple test for valves

THERE IS now evidence to show that valves to treat hydrocephalus are not always properly tested and not always working properly when they are inserted into the heads of hydrocephalic patients.

This evidence was brought to the attention of the Conference by Dr Roger Bayston, ASBAH's Research Fellow for three years and now furthering his work at The Institute of Child Health.

"A lot of surgeons have been sending me valves to look at and some are definitely faulty. Some hardly work at all, so much so that in tests the pressure never tailed off, and I leave it up to you to assume what might happen if such a valve had not been tested", said Dr Bayston.

He said further work was needed to see whether tests were an accurate reflection of how the valves would work when actually inserted in the head.

When problems occurred after valves had been fitted, he said, it was often the case that the exact causes of the failures were never accurately discovered. They might have been due to valve malfunction.

In answer to questions, he said that some surgeons were cooperating and sending valves for testing, but some didn't believe in it. There was now a test which he hoped surgeons would use which they could carry out for themselves in the theatre. It was a simple matter and only took 1½ minutes.

Dr Bayston said he was continuing the work he had been carrying out as an ASBAH Research Fellow into the problems of valve infection (colonisation). He had been successful in treating, with antibiotics, the substance used for making the valves, but he was now taking the work further to see how the treated valves worked in practice. Antibiotics behaved very differently in different situations.

He spoke of the problems of treating infection of valves already in the head without having to resort to surgery. Giving antibiotics in the normal way hadn't worked well because they had failed to get into the brain through the 'blood-brain barrier'. The only way had been to insert a reservoir into the brain, or by injection into the head, both of which were unpleasant procedures and meant keeping the patient in hospital for long periods.

But different drugs had now been found which could be taken by mouth and which did get through the 'blood-brain barrier' and into the brain and the shunt.

He said the work was in its early stages, but he was hopeful that if successful it could decrease the number of operations necessary to deal with shunt infections.

"We are studying it to see if we can give these drugs by mouth—after a few initial injections—and to find the right dosage," he said. The patient would be able to be at home or at school during the treatment instead of staying in hospital.

Dr Bayston said that in an ad hoc study he had carried out at Sheffield there had been a 50% success rate.

"I want to tidy it up and get the success rate up to 80%," he said.

ASBAH's team of 18 field workers is there to offer encouragement and support to families at all times, said Mr Harry Croydon, the Head of Field Work. A list of the field workers and the areas they cover will be published in the next issue of LINK. Their addresses are available from national office.
Please do get in touch if you feel they could be of help.

Vitamin boost may be important

EXTRA VITAMIN supplements taken before a child is conceived could help to prevent the birth of children with neural tube defects, but much more research is needed before a more definite statement can be made. There is cause for cautious optimism, said Professor R.W. Smithells, Professor of Paediatrics at the University of Leeds, talking to ASBAH's Conference.

He told the conference that it was certain that the taking of these vitamins was 'absolutely safe'.

Prof. Smithells and his colleagues, working together over the past ten years have come up with the possibility that a deficiency of certain vitamins particularly absorbic acid and folic acid, might be a contributory factor in causing the malformation of the neural tube of a fetus at a very early stage of pregnancy leading to the birth of a baby with anencephaly or spina bifida.

The results of the first study were published last year. A group of high risk mothers (who already had given birth to spina bifida babies) were asked to take the vitamin supplements before they conceived. Another group of high risk mothers were studied who chose not to take extra vitamins. Out of 250 babies born to supplemented mothers only 1 had a neural tube defect, whereas of 300 babies born to non-supplemented mothers 13 had neural tube defects.

"This work has inevitably had a lot more publicity than it should perhaps have had at this stage", said Professor Smithells. The case for vitamin supplementation was not yet completely proven.

Other groups were setting up paralled studies, he said, and if any high risk mothers wanted to have another child and were interested in vitamin supplementation it would be a help if they could contact him so that they could be included in someone's study.

Professor Smithells said he would be prepared to write to the woman's doctor and tell him the supplementation to prescribe. The vitamins were not available over the chemists' counter.

He said that general medical opinion was that there was no single cause of spina bifida but that it was the consequence of the interaction of many different factors.

The second study of mothers was proceeding and the results so far, looked promising.

Professor Smithells also spoke of the move away from more traditional forms of antenatal care to preconception clinics, where a couple who felt they would like to have a family could go and talk to a doctor about diets, extra vitamins, immunisation against german measles and about general health.

Hydrocephalics and "hidden problems"

HYDROCEPHALIC youngsters have a number of 'hidden problems' which it is important that their parents recognise and understand, said Mrs Leonie Holgate at the Conference.

Without proper understanding these young people could easily feel they were failures, and consequently make no effort to progress at all.

She was describing her work as Project Co-ordinator for an ASBAH project at Banstead Place assessment centre in Surrey, into the effects of hydrocephalus on vocational and non-vocational training.

One of the main problems, she said, was lack of spatial understanding, "which is something most of us have naturally and it is, therefore, hard for us to understand." In young people with hydrocephalus what their eyes see is not correctly interpreted by the brain. This made simple manipulative tasks very difficult, such as using scissors properly, or sewing on a button. They could not work out properly what happened to the needle on the other side of the material.

Sequencing was another problem, she said. Students with hydrocephalus at Banstead found if difficult to remember sequences of movement or thoughts. "They are able to understand isolated facts, but are not able to link one fact with another and come up with a logical conclusion".

They also experienced immaturity of hand and arm movements, which in many cases were more like those of a four year old. But it should be borne in mind, she said, that they might not remain at this level and they could slowly mature.

Mrs Holgate said it was necessary to find a constructive way of encouraging these young people because it was all too easy for them to get dispirited and worried about their frequent failures. She felt group operations could help—doing fairly simple procedures initially as a group, and gradually changing tasks within the group, thus slowly building up skills and helping the members of the group to experience a sense of achievement, rather than repeated failures.

She pointed out that young people with hydrocephalus did continue to mature and should be assessed from time to time and the jobs they could be given increased and expanded accordingly.

A CHEQUE to help ASBAH's work was presented at the conference by Stannah Lifts, makers of stair lifts and home lifts. Mr Duncan Forrest who received the cheque on behalf of ASBAH thanked the company for its help in this way.

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Mrs Holgate said it was necessary to find a constructive way of encouraging these young people because it was all too easy for them to get dispirited and worried about their frequent failures. She felt group operations could help—doing fairly simple procedures initially as a group, and gradually changing tasks within the group, thus slowly building up skills and helping the members of the group to experience a sense of achievement, rather than repeated failures.

She pointed out that young people with hydrocephalus did continue to mature and should be assessed from time to time and the jobs they could be given increased and expanded accordingly.

A CHEQUE to help ASBAH's work was presented at the conference by Stannah Lifts, makers of stair lifts and home lifts. Mr Duncan Forrest who received the cheque on behalf of ASBAH thanked the company for its help in this way.

Some barriers to training

SPINA BIFIDA and hydrocephalic students at Derwen training college for the physically handicapped appear to make less progress in vocational training than other students. One of the reasons might be that more time is needed to enable them to adjust to 'maturing' away from a protective home and to learn to be independent in their personal care.

This is just one of the initial findings of a project, sponsored by ASBAH, which Mrs Hazel Benner is carrying out at Derwen College, and of which she spoke at the Conference.

Mrs Benner said that many of the students found it difficult to sustain interest in a particular training programme; some had a high incidence of moodiness and depression and lacked motivation. Many of them failed to progress as well in training as the initial assessment during the first term had suggested.

She said that students with spina bifida and hydrocephalus tended to talk fluently and have wide vocabularies. As a result instructors could easily assume that they understood instructions, when, in fact, their comprehension of the language might be quite poor, and they might be reluctant to admit it—being content to 'muddle through'.

Students could gain many benefits from being at Derwen other than just training for a particular job. Mixing with others, taking responsibility for their own personal care, regular attendance were valuable and could increase their eventual occupation prospects.

Both Mrs Benner's and Mrs Holgate's projects are continuing and full reports will be published after they are completed.

Factors in trying to assess risk

DR M. PEMBREY, MRCP—Senior Lecturer in Paediatric Genetics at the Institute of Child Health, said that when he was asked to assess the likelihood of a particular couple having a child with a neural tube defect he had to weigh up a great many factors. These included environmental factors, family background, personal medical histories, and ethnic backgrounds. In this way he was able to give some idea of where the couple figured on 'the liability curve', and their chances of having an affected child.

As a general statistic normal couples in this country had a 1 in 250 risk of having an affected child. If they already had one spina bifida or anencephalic child this risk went up to 1 in 25.

In answer to a question he hazarded a guess that if two people with spina bifida married the chances of their having an affected child was about 1 in 8 or 1 in 10.

Dr Pembrey said that it was difficult to be precise because, in many cases, an accurate family history was not known. For example in the past many children born dead or who died within a very short time were simply said to have been 'still born', often because the midwife did not want to distress the mother any further by mentioning encephalocele spina bifida, or anencephaly.

He said that we, in this country, had the highest incidence of spina bifida and it was particularly high among the celtic race, even among those who no longer lived in Britain. He cited as an example the Irish living in America who still had a higher incidence rate than the rest of the population. As another example of the inherent liability of particular races, he said that negroes had a low incidence rate, and this was true of negroes who had been settled in this country for some while.

Encouraging independence

ASBAH's independence training programme, which has grown rapidly over the past two or three years, was the subject of the talk by Barbara Newman and Jill Vernon of National Office.

The week-long courses in independence and daily living skills are continuing and there are now also shorter four-day courses for small groups (about 4 children) aged 8–13 years.

Parents had told ASBAH that the courses had provided useful breaks, and given them a chance to think seriously about the fact that their child was growing into an adult.

Barbara said it was important for parents not to 'switch off' from independence because they felt that their own son or daughter would always need supervision or care. Even the most severely disabled person could learn to do simple tasks and should be encouraged to practise these.

Independence was about knowing and understanding one's own needs, so that one could tell others how and when to help. It was also about being part of the process when decisions were being made about the future.

Parents had to adjust to their child becoming more independent and to try not to feel rejected. For instance, some students, on courses, had been reluctant to tell their mothers that they could change a urinary appliance without help, because they thought their mother would be upset.

Barbara said that young people needed to be treated not only as members of a family group by the professionals, but also as individuals. And parents should try to understand if their son or daughter wished to talk in private to the professional. It was quite natural that we sometimes found it easier to talk to someone who was not emotionally involved.

ASBAH, too, both locally and nationally had to give opportunities to young members to express opinions and to gain information. The establishment of the LIFT group and newsletter was the beginning of this. Many young people were able to contact the staff at national office directly through LIFT for help on a wide range of problems.

"Many young adults have proved that with help and support—often only needed initially—they are able to live independently in their own homes, and some of them are represented here today. When they left school they probably never believed it would be possible."

IT WAS announced at the Conference that ASBAH will be setting up workshops and seminars for parents in different areas in the near future. The Chief Executive Officer, Miss Moyna Gilbertson said these would give parents an opportunity of understanding better, the changing problems presented by spina bifida and hydrocephalus. Parents often found it difficult to relate properly to their children, and to help them sufficiently, as they grew towards adulthood. By discussion with professionals and with other parents such problems might be resolved. More details of the workshops will be announced in due course.

The work of Five Oaks

SLIDES OF the care and activities at ASBAH's Home, Five Oaks at Ilkley, Yorkshire, were shown by Gillian Harrison, Head of the Home, and Mary Barton the Activities Organiser in charge of the new Activities Unit.

There are long-stay children at Five Oaks—as well as children who attend for short stays, and those on mini independence courses.

The staff at Five Oaks were able to provide special care for two severely disabled youngsters, said Miss Harrison.

Five Oaks was a home—a welcoming place where children of all ages and young adults were able to develop and gain independence in happy, relaxed surroundings.

ASBAH was delighted to welcome Mrs Marion Viglione from America to the Conference. She came over especially for the weekend from the Delaware Valley where she is a member of the spina bifida association.

Homes—importance of personal choice

ACCOMMODATION is a complex, personal matter, and it is important that the disabled person is always fully involved in any decisions that are made about where he or she should live, or adaptations to be made.

Mr H.D. Macfarlane—'Mac' to so many people—spoke on the subject of accommodation and referred to a new leaflet 'Home Improvement Grants'* which gives up-to-date details of grants.

He said it was not uncommon for a local authority to try to move a family to another house where adaptations could be carried out more cheaply than in their existing home. This move was often resented by families with roots in a particular road, he said, but it must be said that there were houses which could not be adapted reasonably and by co-operating with the Housing Manager it was not impossible for the family to be rehoused within a reasonable distance of the former home.

Mr Macfarlane spoke of the exciting housing initiatives around the country, and of new developments being undertaken by housing associations with units for the elderly and disabled. He was pleased that a number of different attendance schemes, and daily help schemes, were being developed to help severely disabled people to live alone.

Mr Macfarlane felt there might always be a need for communities of disabled people—so long as there were people who preferred this way of life.

"After all, stockbrokers tend to live in enclaves, or ghettoes!" he said. "I do not want to see all institutional homes closed" said Mr Macfarlane.

He felt there could be great happiness and opportunity for personal development in such homes, and they should form part of the range of total provision.

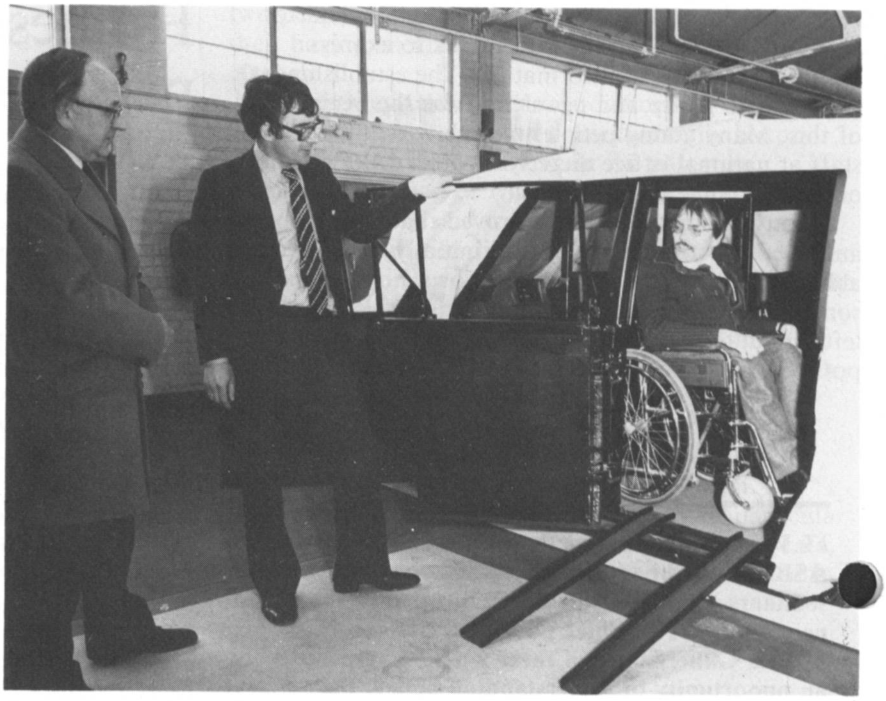
Finally, he wondered if ASBAH might consider getting involved in small local schemes to meet the housing needs of young adults with spina bifida and hydrocephalus.

**Home Improvement Grants is available from Local Authority Housing Departments and most main libraries. . .*

ON SATURDAY afternoon a number of workshops were held in which everyone had the opportunity to discuss matters of particular concern. The discussions were reported back to the Conference.

Mr Bryant showed his skill as a Chairman in a succinct summing up of the two day Conference. He said he hoped that those who had been at the Conference would go away refreshed, invigorated and fired with enthusiasm to 'spread the word'. He said he felt that everyone had gained a lot from the balanced programme, and the opportunity to meet such a wide range of people.

Coming soon —a taxi worth hailing



Bert Massie of RADAR—in the wheelchair—tries out the new style cab, with Sir Peter Baldwin, Permanent Secretary, the Department of Transport (left), and Mr Grant Lockhart, Managing Director of the manufacturers, Carbodies. Photo: Coventry Evening Telegraph.

AFTER complaints that their London-style taxi cab was useless for carrying wheelchairs, the Coventry firm of Carbodies set to and have produced a new-style cab which is ideal for wheelchair passengers.

The new model will be launched in 1983 and features a wide swinging passenger door plus ramps to allow wheelchairs access, with the driver's partition further forward so there is room for a wheelchair in the back.

Managing Director Grant Lockhart said, "We have had the idea of a taxi for the disabled in mind for some time but this year as the Year of the Disabled really decided us to go ahead."

Trays that will stay put

THE VARIFIX Tray, designed and manufactured in this country, is a useful tray which can be attached to round or flat surfaces—wheelchairs, bed rails, desks, benches, etc.

It has hundreds of different positions, can be adjusted angularly and moved horizontally and vertically and folds away when not required. It can be removed in seconds.

Price: £15 plus VAT. For details contact : Pittas Engineering Designs Ltd., 1 Wroxham Gardens, London N11 2AY. Tel: 01-889 1529.

THE CARRYSAFE Tray is a stainless steel tray with a folding handle. It is suitable for someone who walks unsteadily and needs one hand free.

It is available in two sizes, and the folding handle locks positively in the storing or serving positions.

Price: Small—£11.95; large—£16.95. Inclusive of VAT, post & packing. For details contact: Warmex Ltd., School Lane, Swavesey, Cambridge, CB4 5RL. Tel: 0954 30467.

The Varifix Tray

Disposable gloves

ARBROOK Dispos 'a' Gloves, These EMA film gloves are disposable, and are for use as a barrier during manual evacuation of the bowel.

They are packaged in 30's and are available in sizes small, medium and large. Ask your doctor for a prescription. They are on the Drug Tariff list of 'protectives'.

Electric spinner brings opportunity

THE Dingle Hill 'Spinner' is powered by a small electric motor enabling anyone with more or less normal manual dexterity to spin and derive the same satisfaction as when using a normal spinning wheel.

Dingle Hill Products who manufacture traditional spinning wheels felt that there might be people, unable to pedal a foot operated wheel, but nevertheless, keen to take up spinning as an occupation or hobby.

The 'Spinner' has been tested and highly approved by two well-known spinning instructors. Fleeces are available from the Wool Marketing Board at a price which makes hand spinning economical.

The price: £49. (a traditional foot operated wheel is £84) Details: Dingle Hill Products, Mid Cowden, Comrie, Perthshire PH6 2HU.

REVIEWS . . .

Little Joe
Price 50p plus postage from ASBAH national office.

As part of its contribution to IYDP, ASBAH has brought out a new-style booklet *Little Joe*. It is the personal story of a grandmother, Mrs Winifred Foster who lives in Bradford, and whose grandson *Little Joe* has spina bifida.

In her very readable and moving style Mrs Foster shows the effect his arrival had on the family, the stresses, the hopes and the fears, and the ways in which these changed their lives and their outlook.

ASBAH feels that it is a valuable addition to its booklist and should prove of real support to other families and their relations and friends.

All Write Now is available from RADAR, Publications Dept., 25 Mortimer St., London W1N 8AB Price 50p plus 20p post and packing.

All Write Now is an excellent non-technical book for anyone who wishes to write about disability for his local journal or newspaper. The idea is a sound one, as most local papers might well be interested in running a regular column, weekly or maybe monthly, concerned with disability, particularly if it is written by someone who themselves is disabled in some way.

The book has been enthusiastically written by Pat Saunders, a tetraplegic, and the first ever weekly feature writer on disability. The idea of the book was put forward by the IYDP Information Committee of which Beverley Holland is a member, and was financed by the London Law Trust.

All Write Now gives you all the information you are likely to need, but might tend to make the task seem more difficult than it needs to be. If you want to write for your local press, read this book, but also make sure you thoroughly read the local paper itself over several issues.

Study the way in which an article is constructed and then take the bull by the horns and go and see the Editor and discuss with him what you have in mind. Offer to write one article for him and see what the response is.

Benefits for Handicapped People of Working Age **is an information sheet, now available from the Greater London Association for the Disabled (GLAD), 1 Thorpe Close, London W10 5XL. Tel: 01-960 5799.**

Fears and worries . . . *Continued from page 11*

when my parents are no longer there to look after us''? There may also be even more basic anxieties about life expectancy. When I met some school leavers with spina bifida as part of my research, a number of them had not met any adults with their condition; this led them to worry that patients with spina bifida did not survive beyond late adolescence!

How can parents help?

Worry is a part of life and, as I have said, it can have a positive and protective function. When a child develops intense and frequent anxieties, it is important that parents should do their best to support each other in not letting the feeling that they have failed in someway, overwhelm them, particularly since I have suggested that children with spina bifida and hydrocephalus and hydrocephalus alone do appear to be more vulnerable. It is also vital that the presence of worries should not be denied since children need to be sure that they can confide in their parents even if their fears are irrational. Irrational fears are no less powerful than rational ones!

A further way in which parents can help is by doing their best to ensure that their child has as much *relevant information* as possible about the situation that is causing them to worry. Fears about hospitalisation or illness can be considerably reduced if this is done. Parents may have to do some homework themselves if this is to be achieved as well as trying to ensure that their child is given appropriate opportunity to hear direct from the specialist what the actual situation is.

Parents can also help by *preparing* children as carefully as possible for situations that they think may cause their child to worry. Worry is usually increased if children have situations ''sprung upon them'' and good preparation fosters trust and respect for parents as people who know. In a previous article I wrote for LINK I stressed the value of dolls play or puppets, as a way of preparing very young children or children with very limited learning ability for hospitalisation, operations etc.

Children can also be helped with specific fears by the use of a *gradual approach* to the real situation. Children who are frightened of going to a new school, for example, may be helped by doing the journey to the school several times before they start there and, if possible, going around the buildings or meeting teachers several times before hand. As each gradual step is taken and overcome without panic, it is important to give energetic praise or where appropriate, a tangible reward or treat!

Finally, of course, there are people such as myself, whose job it is to help children with their worries. Most parents, using their common sense and understanding are able to help the children in the way that I have described, but there are times when parents feel they have reached the limit of what they can do on their own, and in these cases, a trained professional may be able to help. All local authorities have Child Guidance Clinics to whom referral may be requested, or such help may be arranged at the specialist hospitals which the child attends.

1981—And how it's beginning to add up

THE EARLY months of 1981 have produced some frenzied activity within ASBAH's appeals department, all of which has been most encouraging, both in terms of income and awareness.

Hopefully most readers of LINK will have seen the commercial television appeal which went out on March 15 presented by Michael Aspel. Nearly £15,000 has already been received, which is a gratifying return from this network and we have also been informed of many events which generous people have undertaken to organise on our behalf.

Plans are well in hand for the Crown Jewel Ball at the Dorchester and despite the gloom generated by the Budget more than half the tickets for the Ball have already been bespoken. One can only assume that people have planned to drown their sorrows in grand style?

The new Special Events Organiser, Miss Maggie Corbett, has got off to a great start by organising the Spring Collection, a "diminishing" coffee morning which works in much the same way as a chain letter and is spreading the word and the fundraising net throughout the country.

Donations are already coming in and it is hoped that the end result in terms of income will be in excess of £30,000, which goes to prove that mighty oaks do indeed grow from little acorns!

Miss Corbett is also well on the way towards making quite an impression upon the gentlemen who are working on our offshore oil rigs, but as this is still an exclusive story within the oil trade press, details will have to be revealed in the next issue of LINK.

Space Angels, Sarah-Jane Thirlby-Smith and Joanne James, who helped to promote the first ever British Space Invasion Championship in Nottingham in March. The video machine in the picture, plus a cheque for £250, was the magnificent first prize.

The Championship was organised by our Appeals Organiser in the Midlands, Mrs Jane Evans in conjunction with Radio Trent, and the event raised £2,500 for ASBAH.

As if this were not enough to be getting on with, Maggie has also enlisted the support of Angling Times who are running a sponsored fishing competition nationwide to benefit the Association. As angling is the most widely practised sport in this country, I think we can safely say that public awareness of ASBAH will be increasing dramatically as a result of her efforts alone.

Mr Ian Morrison is making substantial inroads within places of education and the sponsored initiatives scheme, which LINK reported on in an earlier issue, is very popular with regional educational departments, who have promised to spread the word for us within nearly 15,000 schools. Several universities are also running rags on our behalf.

In the Midland area Mrs Jane Evans has inspired the local media to great things and I believe that the Susan and Friends Appeal, which is being run by BRMB radio in Birmingham, has superseded the weather as a topic of conversation.

One million envelopes have been distributed to households and the organising committee are confidently anticipating donations in the region of £100,000.

Radio Trent have also fallen victim to Jane's persuasive ways and have promoted in conjunction with Game World, the first UK Space Invaders Championships. These took place at Rock City on March 22 (see photo).

Madeleine Legg has gained the support of a radio celebrity to assist her fundraising—Mr Ed Stewart has most kindly recorded a taped appeal which will assist Madeleine enormously in enlisting the help of commercial companies in her area, hopefully inspiring them in the direction of payroll deductions.

She is also engaged in organising another highly successful theatre night and repeating the most memorable event held at Blazers in Windsor, last year.

I will be taking to the skies, aided I hasten to add by modern aero-engineering, during the second week in June, weather permitting.

This is in connection with the Tiger Club of Redhill's Dawn to Dusk Competition. With Mr Charlie Shea Simonds I will be attempting to, during the daylight hours of one day, take off and land from one farm airstrip in each county of England and Wales.

We are most fortunate in that the Flying Farmers Federation are backing us fully in this venture and first reports indicate that the Young Farmers Federation will also be rallying to the cause. We have been lucky in being lent a Mighty Maule aircraft by Mr Michael Collins of Capital Aviation Sales in Cheltenham, and we hope that the eventual financial outcome of the contest will justify our optimism in this high flying event (ouch!).

JUDY KAY
Director of Appeals

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.

Adverts for the next LINK (July/August) should be in by June 6. 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).

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

HEYSHAM, 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, Shropshire. Tel: Whitchurch 3691.

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MABLETHORPE, Lincs: Well equipped holiday chalet. Sleeps 6. Colour TV. Details: (sae please), Mrs G. Foster, 47 Almond Avenue, Lincoln.

WITHERNSEA: Well-equipped 6-berth chalet at Golden Sands Chalet Park. Shop, licensed club, play areas, amusements on site. Details (sae please): Mrs P. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax. Tel: 0422 56402.

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Tenby, 6-berth caravan. Fully equipped. Bathroom, WC, TV. Convenient for wheelchairs.
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FOR SALE

Leisure Wear: White cotton **Tee Shirts** with green family symbol and words 'Support Spina Bifida'. Sizes 22″–30″: £2 each. Adult sizes, small, medium, large: £2.75 each. **Sweat Shirts** in reverse colours. Adult sizes, small medium, large, XL: £6.50 each, postage included. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

ASBAH booklets etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	35p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	35p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	50p
The Care of an Ileal Conduit and Urinary Apliances, by E. Durham Smith, MD, MS, FRACS, FACS, and others	15p
Aids and Equipment	60p
Sex and Spina Bifida by Bill Stewart ...	awaiting reprints
The Handwriting of Spina Bifida Children by Joan Cambridge and Elizabeth M. Anderson ...	£1
The Nursery Years by Simon Haskell & Margaret Paull	35p
Little Joe (A Grandmother's story) by W. Foster ...	50p
Information leaflets	100 for £4.00

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 15p per booklet.

Scottish Spina Bifida Association Booklets

Growing up with Spina Bifida	35p
The Spina Bifida Baby	35p

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).

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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).

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1075 Warwick Road,
Acocks Green,
Birmingham B27 6QT.
Tel: 021-707 2930

NORTH EAST (Northumberland)
Mrs E Grant,
27 Redwell Road, Prudhoe,
Northumberland.

NORTHAMPTONSHIRE
Mrs J. Cockings,
57 Little Street,
Rushden, Northants.

NOTTINGHAM & DISTRICT
Mrs S E Plant,
305 Foxhill Road, Carlton,
Nottingham.

OXFORDSHIRE
Mrs A Elbrow,
10 Bowyer Road, Abingdon,
Tel: Abingdon 25712

PONTEFRACT CASTLEFORD & DISTRICT
Mrs N Robinson,
4 Sandal Rise, Thorpe Audlin,
Pontefract WF8 3EX

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

ROTHERHAM & DONCASTER
Mr & Mrs D Barringer
10 Fullerton Crescent, Thrybergh,
Rotherham, S. Yorks.

ST HELENS & DISTRICT
Mrs N Maddocks,
324 Warrington Road, Rainhill,
Prescot,
Merseyside L35 9JA.

SALISBURY & DISTRICT
Mrs J Renshaw,
1 Philip Court,
Coronation Road,
Salisbury SP2 9DA

SHEFFIELD
Mr T Robinson,
3 Cecil Avenue, Dronfield,
Derbys, S18 6GW.
Tel: Dronfield 415523.

SHROPSHIRE
Mrs A Ashfield,
35 Trenleigh Gardens, Trench,
Telford, Salop, TF2 6RN.
Tel: Telford 612542.

SOUTHAMPTON & DISTRICT
Mrs C Taylor,
22 Brickmakers Road,
Colden Common, Winchester,
SO21 1TT.

STAFFORDSHIRE
Mrs J Davies,
8 Oakhill Avenue,
Stoke-on-Trent, ST4 5JN.

STAINES, HOUNSLOW & DISTRICT
Mrs M McGuigan,
7 Winchester Road,
Hanworth, Middx.
Tel: 01-894 9230.

STOCKPORT
Mrs S Silver,
1 Brookside Avenue,
Offerton, Stockport.

SUNDERLAND
Mr W D Easton,
4 Irene Avenue,
Grangetown, Sunderland.

SURREY
Mrs B Blackmore,
80 Sunnymede Avenue,
West Ewell, Surrey.
Tel: 01-393 0971.

SUSSEX
Mrs M White,
Averys, Rusper, Horsham,
Tel: Rusper 217.

SWINDON
Mrs S J J Trembling,
3 Church Place, Swindon.

TRAFFORD & SALFORD
Miss J Slater,
20 Lester Street, Stretford,
Manchester M32 8BF.
Tel: 061-865 1298.

WARRINGTON & DISTRICT
Mr S J Charlton,
36 Park Avenue,
Latchford, Warrington.

WESSEX
Mr P Chelton,
93 Wessex Oval, Wareham, Dorset.

WHITCHURCH & DISTRICT
Mrs D R Calder,
Sedgeford, Whitchurch, Shropshire.

WIGAN, LEIGH & DISTRICT
Mr R G Eccles,
19 Edale Drive,
Standish, Wigan,
Greater Manchester.
Tel: 0257 421136

WIRRAL
Mrs S Keeler,
7 Church Road,
Upton, Wirral L49 6JY.
Tel: 051-677 1104.

WORCESTERSHIRE
Mrs Ann Cotter,
1 Willow Drive,
Droitwich, Worcester WR9 7QE.
Tel: Droitwich 4193.

YORKSHIRE NORTH
Miss F M Seward,
45 The Paddock, York YO2 6AW.

WALES

LLANELLI
Mrs Y Pudner,
83 Denham Avenue,
Llanelli, Dyfed.

MID WALES
Mrs J Carter,
1 Meadow Road,
Craven Arms, Salop.

NORTH WALES
Mr J Jones,
2 Llandaff Drive, Prestatyn,
Clwyd.

SOUTH WALES
Mrs D Cox,
28 Cromwell Road,
Bulwark, Chepstow NP6 5AD.

SCOTTISH ASSOCIATION

Mrs G McIntyre,
General Secretary,
190 Queensferry Road,
Edinburgh EH4 2BW.

NORTHERN IRELAND

Mr J Egar,
Flat 1B, Parkdale House,
Seymore Hill, Dunmarry,
Co Antrim BT17 9DA.

Ballymena
Mrs F McNeill,
123 Broughshane Street,
Ballymena, Co. Antrim.

Belfast
Mr F D Hunter,
55 Wanstead Road,
Dundonald, Belfast.

Coleraine & District
Mrs L E McClure,
27 Tober Rd,
Ballymoney, Co. Antrim.

Lurgan & Portadown
Mr B J P Byrne,
Hollyvale,
Hollymount Road,
Laurencetown,
Craigavon, Co. Armagh.

Mid-Ulster
Mrs V McKenzie,
11 Woodland Drive,
Cookstown,
Co. Tyrone.

Newry & Mourne
Mrs P Rushe
161 Barcroft, Park,
Newry, Co Down.

Omagh
Mrs A Cochrane,
Bonnybrooke,
Pubble, Temple,
Co. Fermanagh.

OTHER LOCAL ASSOCIATIONS

Blackpool & Fylde
Mrs D Sharples,
17 Queens Road,
St Annes-on-Sea,
Lancs. Tel: St Annes 723547.

Beeston
Mrs S S Goodfellow,
5 Cyril Avenue, Beeston.

Cannock & Walsall
Mr C Bird,
2 Lime Grove, Rushall,
Walsall WS4 1JS.

Chesterfield
Mrs K M Tomlinson,
23 Hathern Close,
Brimington Common,
Chesterfield.

Consett & District
Mrs M Holmes,
39 Derwent Cote,
Hamsterly Colliery,
Newcastle-upon-Tyne.

Gainsborough & District
Mrs Eva Hines,
42 Melrose Road,
Gainsborough, Lincs.
Tel: Gainsborough 3906.

Isle of Wight
Mr D J S Sprake,
Springfield, Town Lane,
Chale Green, Ventnor.

Lancaster, Morecambe & District
Miss G Sutcliffe,
10 Sylvan Place,
Heysham, Lancs.
Tel: Heysham 51456.

Rochdale
Mrs Ann Lawton,
55 Wimpole Street,
Shaw Road Estate, Oldham.

Somerset
Miss June Roberts,
1 Ilford Court,
Wiltshire Close,
Taunton.

Spenborough
Mrs M Cartwright,
9 Delmont Close,
White Lee Road,
Batley, West Yorks.

Teesside
Mr J Gray,
Marchesi Centre, Tollesby Ro
Middlesbrough, Teesside.