

Link

July/August 1974 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)





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Link No. 33

**Association for Spina Bifida
& Hydrocephalus (ASBAH)**

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Miss F. A. Birkett
Link Editor:
Mrs. Susan Gearing**

**Front Cover: Claudia
Stevenson of Southampton
Local Association looks very
pleased with her new "friend"—a
blow-up Ford man. He and 100
other "men" were given to
children of this Local Association
at a social evening by Bristol
Street Motors.**

Photo: R. W. Holmes.

Editorial

The season of fetes is upon us, and few people would care to count the number of events large and small held by Local Associations, and those put on by other societies in aid of ASBAH.

Because fetes and similar events are so commonplace, it is easy to overlook their significance. Not only do they bring a welcome increase in funds, but they also provide an atmosphere for informal meeting between spina bifida families and supporters. Much good publicity and many new friends are made at these annual summer occasions.

It is worth saying in this column how much ASBAH appreciates the tremendous amount of work put in by the fete organisers and their helpers—whether it be a small back garden affair, or a grand stately home event.

Meeting the needs of all members

The Association aims to be a family, and like a family must be aware of the needs of all its members and of changing emphases within the family group.

The Local Associations came into being to give support to parents, but they are not "parents' associations". This is particularly important to bear in mind as the number of spina bifida and hydrocephalic teenagers grows. Teenagers are starting to feel the need, and find the way to get together occasionally (see Jackie Page's account of the teenage weekend p. 14). These younger and growing members need to feel that they have their own place within the Association,

It is equally important to encourage people of goodwill to join Local Associations, bringing with them new attitudes and a variety of skills. They can enrich the quality of the Associations and make a valuable contribution towards running them.

Membership of the Association should be a help and not a burden to the individuals concerned. It exists to serve its members. Each member has different needs. Some get a great deal from the regular meetings, others do not find them so valuable, or find it impracticable to attend. Other members may need to be contacted in their own homes by personal visit or over the phone, and there are other members, equally important, who wish to maintain contact through newsletters, Link and other publications.

Variety is the spice of life and this applies to the activities of Local Associations. A flexible family structure is surely the aim.

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News from the groups

£500 for theatre

Derby: The Derby and District Association is giving £500 to buy a lift car for the new Derby Playhouse which is being built. The Playhouse will cater for handicapped people—there will be a lift, special toilet facilities and an area for wheelchairs in the auditorium. This will cost about £7,500 and the Playhouse Manager thanked the Derby Association for its help.

New film on offer

Dudley and Wolverhampton: A new film showing spina bifida children in action on Sports Day has been made for this Association by a local supporter, Mr. Guinness. It is an 18-minute colour film with sound commentary (Super 8 mm) and parents were very pleased when they were shown it at a recent meeting. The sports day was held at H. M. Hobson's sports ground. A copy is being made for the Association, and anyone interested in seeing it should contact the Hon. Secretary of Dudley and Wolverhampton, Mr. B. Attwood (see back cover).

Change of name

Leeds and Bradford: This Association has changed its name to the Leeds and Bradford Districts ASBAH. In April the normal monthly meeting took the form of an outing to the Achievement Exhibition at the Royal Baths, Harrogate, where the Association organised and ran its own excellent stand showing all aspects of its work.



Cheers!

London South: This Local Association has found some very good friends at the City Arms pub in Portsmouth Road, Long Ditton, Surrey. Last Autumn, the publicans, Ann and Dave Hiscox decided they would like to do something to help spina bifida children, and so they introduced a "swear box" into the pub. Every time a customer swore he was made to put something in the box. The language must have been pretty bad because the money soon mounted up! Then the Hiscoxes decided to raise some extra money by holding a weekly raffle of vegetables, fruit and other goods. Altogether since November the City Arms has raised the magnificent sum of over £322.

Birthday steps

Darryl Bulman of Hull gave himself and his parents the best birthday present of all—the achievement of learning to walk.

Just before his recent third birthday he surprised everybody by starting to walk with the aid of elbow crutches. Mrs. Bulman was so pleased that she wrote to tell 'Link' about it.

She was full of praise for the creche run by the British Red Cross which Darryl attends.

"It's a wonderful service and one to be proud of. We are also members of the Hull and District ASBAH and I am so grateful for all the help they give too."

The photo (left) shows Darryl with Mrs. Brenda Smith one of the voluntary workers at the creche.

Busy bus

Sheffield: It's proving a busy Summer for Sheffield Association's minibus. It has taken the older children and teenagers for a trip to Jodrell Bank Radio Telescope, and later in May it took members to the Mediaeval Pageant at Ashby Castle, Ashby-de-la-Zouche, which was in aid of ASBAH. There have been other special excursions and most week-ends the minibus has taken families to the seaside for their holidays.

Claudia's award

Congratulations to ten-year-old Claudia Bevan of Welford, Northants, who was recently awarded the Brownie Star of Merit in recognition of her

courage and strength in coping with spina bifida. Claudia belongs to the 1st Welford Brownies.



News from the groups



Photo: Essex County Newspapers

"Lend-a-toy"

Mrs. Diane Britton (left) with her 3-year-old daughter Sarah who has spina bifida, at the toy library which Mrs. Britton has started in Colchester.

The library is run for all handicapped children in the town and now opens on the last Thursday of each month at the Salvation Army Hall. Children have a choice of over 100 toys which they can borrow for up to three months.

Mrs. Britton decided upon a toy library because of the high cost of buying suitable toys for handicapped youngsters. The money for the library equipment was raised through a variety of different fund-raising events.

The value of conferences

The Greater London Liaison Committee has again held a very successful conference in London attended by 120 people professionally interested in the care of those with spina bifida.

Following London's earlier lead, Manchester's Liaison Committee held a Conference at Trafford in February entitled "The Aim is Independence".

This kind of gathering does much to make the conditions of those with spina bifida and hydrocephalus more widely known, and brings together those people concerned with different aspects of care.

Other areas might like to consider the value of this kind of approach.

Read all about it

Trafford: The Year Book which Trafford Association produced for the first time in 1973 has been repeated again this year in time for the AGM which was held in June. "This book, published free of charge, has been a wonderful way of publicising our Association and its aims. We can certainly recommend this to other Associations and will gladly send a copy and details to any Secretaries who are interested," says Mrs. Jean Black.

Adrian at the wheel

Warwickshire: Adrian Taber, aged 7, of Kings Norton, is the proud owner of his own battery-driven car, registration AJT1, thanks to the efforts of four teenage apprentices at the

British Leyland Apprentice Training School, Longbridge. They converted an old pedal car for Adrian. It has hand controls, and several special refinements which Adrian is thrilled with—an ignition switch, lights, throttle, and a switch to throw the car into reverse. He can operate the car at a fast walking pace.

£770 Coffee Morning

Sussex: A successful Coffee Morning was held in May at Arundel Castle with the kind permission of their President, Her Grace the Duchess of Norfolk. In two hours £770 was received from the sale of cakes, plants, bathroom items and at other stalls. Mayors from different parts of Sussex were there.

Blood tests give hope for antenatal diagnosis of spina bifida

by J. Lorber, M.D., F.R.C.P.

Important developments have occurred since I last wrote in "Link" about the antenatal diagnosis of spina bifida. Since then many more pregnancies have been studied with amniocentesis, and several more spina bifida cases have been diagnosed in time for termination of the pregnancy.

Even more important is the fact that it is now possible to detect the same substance, called alphafetoprotein, in the blood of pregnant mothers. This substance is present usually in excess if the mother carries a spina bifida or an

anencephalic baby. It is much easier to get blood samples than amniotic fluid. Once the reliability of this test has been confirmed, and when suitable techniques have been developed for mass testing of blood samples, then all pregnant women could have this check, and their fears of the birth of spina bifida babies will be greatly reduced.

This research is being carried out by Dr. Brock of Edinburgh with the help of a grant from ASBAH and is still continuing. There are several centres now which can carry out these tests.

How one Local Association gained the full backing of their Borough . . .

It all began with correspondence with the Medical Officer of Health explaining how we (Greenwich ASBAH) would like to work with the Health Visitors, and could we hold a meeting so that we could let them know about us. Also in the correspondence we suggested setting up a Spina Bifida Club where families could meet regularly to discuss practical problems.

At the meeting a doctor, who works at our local special school, spoke on the medical aspects of spina bifida. We showed the film, "What is Spina Bifida", and I said a little on the aims of the Association: one of our aims being to start the Club, particularly for mums of very small babies, as we felt that these mums had very little chance of meeting others with similar problems, and they possibly felt quite isolated. Once the children reach school age, then the school caters for this need.

And then it all seemed to happen. The Local Authority

Working together in Greenwich

Mrs. Judith Gillham, former chairman Greenwich Association.

was marvellous. Premises were provided: a Maternity and Child Health Centre with two good-sized rooms, one where the mothers could meet and talk, and the other where the children could be looked after. There was already a good selection of toys and equipment there, which was available for our use. It is called the Mothers' Discussion Group, and they meet every Thursday morning. The Local Authority provide transport for those families living within the London Borough of Greenwich.

Beyond all our expectations a Health Visitor was provided to run the Mothers' Discussion Group, so that they had someone they could turn to for help with any practical problems. All the other Health Visitors know about the Group and are encouraged to refer families through the Health Visitor running it.

This Health Visitor is available to attend Mr. Nash's clinic at Sydenham Hospital so that she is absolutely up to date with the treatment and management of these children, and again the other Health Visitors are encouraged to refer to her for any practical help their families might need.

I think we have been extremely fortunate in our area in the help we have received, and in fact the Group has always been officially run by the Local Authority: ASBAH purely originated the idea. I would certainly recommend that other Associations try a similar approach. Good luck!

Summary of the lecture to ASBAH's Spring conference in York given by Mr. Malcolm Doney, ACIS, DMA, Director of Inskip St. Giles Housing Association.

A home of their own

"Suitable housing is a basic human need. For the physically handicapped it has a special importance, and yet it is constantly used as a political ping-pong ball. . . . Every government within living memory has been going to tackle our serious housing problems. The trouble is that each successive government has a different approach. . . . The net result has been a general decay of existing housing stock and the provision of the wrong type of new housing, much of it in the wrong place and mostly designed for physically fit average families with 2.4 children. At local authority level the story is similar."

Mr. Doney said that although in the last decade there had been some improvement, particularly as far as the elderly were concerned, very few local authorities or housing associations have as yet made any real attempt to find a housing solution for the disabled population. . . .

Mr. Doney explained that we have the legislation necessary to provide proper housing for the handicapped but now we must

Inskip St. Giles is a voluntary housing association providing flats and houses for handicapped people of all ages, single and married, and for the elderly. Its work is spreading quite rapidly throughout the country, and an article in *The Times* described it as "A really visionary organisation, anxious to de-institutionalise the disabled and to encourage young people especially to lead normal independent lives".



show that there is a real need for such housing, and encourage local authorities and housing associations to provide it.

" . . . we must also be aware of the history of housing handicapped persons and of past, present and possible future social attitudes and prejudices of the population at large, and of the handicapped persons themselves."

He referred to the practice, accepted as normal until now, of isolating the severely disabled from the community, "preferably" in the country behind high walls, and not allowing the "inmates" to think or act for themselves.

"I believe that the majority of the population, if they ever considered the problem at all would see little wrong in continuing this practice."

Denise in her own service flat at Poole, Dorset. It is one of 25 specially designed flats for people with disabilities built by the Inskip St. Giles Housing Association.

" . . . My Association is dedicated to keeping as many disabled and elderly people as possible in the community in a home of their own, with their own front door key, who would otherwise face the prospect of living out their lives in an institution or hospital ward. We have already brought out into the world young people, some very severely handicapped indeed, who had lost all hope of achieving any degree of independence, and we have prevented others from ever

Turn to page 13



Aids and equipment

Sitting comfortably

Rosemary E. Barnitt,
Occupational Therapist,
Queen Elizabeth Hospital
for Children in London

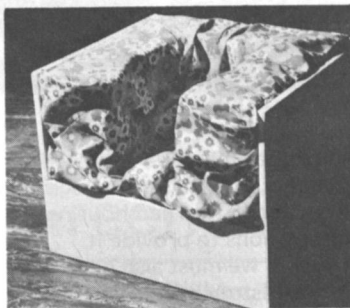
Foam chairs were developed at Queen Elizabeth's for the small spina bifida when he first attempts floor sitting, and for the older spina bifida who cannot be catered for in normal manufactured chairs.

The foam must be of high density so that it can be cut with precision, does not "give" too much when a heavy child sits in it; and so that the corners and edges do not rub away.

The foam should be fire retardant both for the safety of the child and to meet regulations in a National Health Hospital. Most foam used in the home is highly inflammable.

The foam should be covered first with a waterproof fabric such as "Sandra" plastic and then with material which is non-slip and comfortable next to the skin. Foam should *not* be used next to the skin as it causes the child to sweat and is most uncomfortable.

However, the advantages are numerous. The chair can be cut to fit the child, and can be enlarged as the child grows. Most hospitals can have a block of foam available for cutting. A small chair can be cut in ten minutes and taken home for covering and immediate use. They are cheap and can be washed and reused.



The foam is available from: *Progress Mercantile Ltd., 246, Brixton Hill, London SW2.* They will send details of "flame retardant" medium high density foam. The largest cube which is manageable is a 30-in. cube. From this fifteen to twenty floor-sitting chairs of the smallest size can be made. This would be first sitting size for approximately a seven-month-old child. A very sharp knife should be used to cut the foam, although special foam cutting implements are available.

The floor-sitting chair is 15 in. by 12 in. by (6-8 in.). This

last measurement depends on the depth from the floor to one inch below the child's armpit when he is in a sitting position. The child is then sat on this block and a keyhole the size of the child's bottom is marked. This shape is then cut out conservatively as it is very easy to enlarge the hole but most annoying to have to glue the bits back!

When the shape has been covered and the child is sitting in it, the chair should first be used with the back against a firm surface, such as the wall or cot. This means that if the child pushes, the chair does not move and give the impression that it is unsafe.

A small table should *always* be supplied with a chair so that toys can be played with while the child is sitting. A cardboard box can be cut down and covered with Fablon. The chair can be placed in a wooden box frame to make it sturdier.

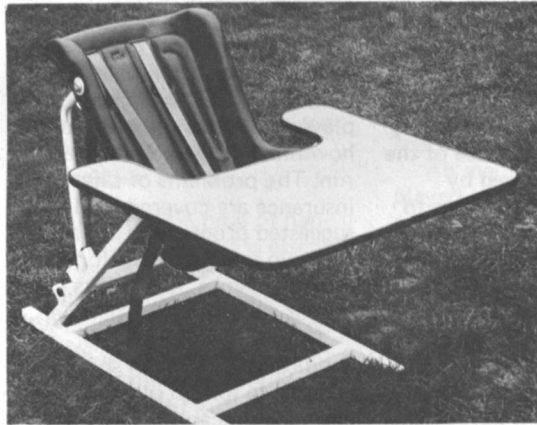
The larger chairs are cut to stand off the ground but are on the same principle as the floor chairs. However, these are more likely to require a wooden box frame. This can be put on castors.

Finally, several parents have told me that their children have learnt to wriggle out of the floor-sitting chairs. This may be because a table and toys were not supplied. Or, it may be because the stage has been reached when the child WANTS to MOVE—an encouraging sign of progress.



Aids and equipment

Bin Chairs: This chair is based on a plastic dustbin and is extremely comfortable. It is upholstered with foam padding all round the back, sides and seat. It has brightly covered removable and washable covers. The dimensions of the seat are: length of back 15 in., width of seat 15 in., depth of seat 18 in., and the seat is 11 in. from the floor. It is therefore suitable for the older child who has sitting problems. It is available from Rowen Community Ltd., Seven Sisters, Neath, Glamorgan, at a cost of £18. A Do-It-Yourself kit costs £15 and is easily assembled if you have half an hour to spare and a practical streak.



Mr. Hayes of the Leicester Association has designed and produced this beautifully made chair and table. It has been tested on many children and found suitable for those children who cannot sit unsupported and have grown too big for the Baby Relax Chair. It has three different positions from the reclining to sitting upright. The dimensions of the seat are: height of back 20 in., width of seat 11 in., depth of seat 9 in. The cost is £36 and delivery should be quite quick. For further information and orders please contact Mr. Hayes, 65A Main Street, Kirby Muxloe, Leicestershire LE9 9AN.

The Trans-Sit Seat has proved a very useful piece of equipment when travelling, whether it be by plane, ship, train or coach. It makes transference from a wheelchair to any form of transport much easier for all concerned. I have had reports that it saved a lot of problems last Summer at the beach—those of you who have tried pushing wheelchairs on sand or pebbles know it isn't easy. It has also been used at swimming pools for those who cannot transfer themselves from their wheelchairs to the pool. It folds into a neat small parcel, is washable



and has shoulder straps which can be fitted to make long

distance carrying easier.

There are two sizes:

	Height	Width	Depth
Large	18½ in.	15 in.	15 in.
Small	15½ in.	13 in.	13 in.

It costs £6.50 for the large and £5 for the small. Further details and orders should be forwarded to Ellis, Son & Paramore Limited, Spring Street, Sheffield S3 8PB.

Please mention "Link" when writing to firms. Prices are only approximate.

Felicity Birkett.
Appliance Officer.

BOOKS



"The Disabled Schoolchild"

by Elizabeth N. Anderson

This book is an investigation into the integration of physically handicapped children in ordinary primary schools. Elizabeth Anderson has produced a wealth of statistical information in an exploration of the physical, emotional, social and educational problems of disabled children. The results are interesting but cannot offer significant evidence to support entirely the pressures of parents and voluntary bodies for the handicapped to be educated in ordinary schools.

The study does show that integration cannot be expected to follow automatically from placement in an ordinary school and that the severity of the physical nature of the handicap bears little relation to educational progress, social adjustment or popularity.

Parents who prefer ordinary school placement for their handicapped children will do well to heed some of the problems likely to be encountered, such as very little remedial help

available, especially with arithmetic; poor provision for physiotherapy and speech therapy; an unwillingness to accept the incontinent child; and in many schools an outstanding need for modifications and adaptations to help with mobility and toileting problems. The staff in ordinary schools also have a need for advice and information in order to provide the right kind of help. Increased integration is only desirable if a number of basic facilities can be provided for handicapped pupils in ordinary schools. Such provision greatly varies from one area to another.

The findings are encouraging with regard to acceptance of the physically handicapped by ordinary teachers who seem to be sympathetic providing sufficient extra help and advice is given.

One hopes that this book will stimulate more flexibility in planning special education.

Methuen paperback. £2.40

Reviewed by Barbara Sturges
Head of Physically Handicapped
Unit of St. Michael's C. of E.
Secondary School, Warley,
Worcs.

"Aids for the Handicapped"

This is an excellent handbook produced for parents by the Spastics society. It is a guide to the supply and use of equipment for the handicapped, and although it deals with the problems of the spastic, much of the information is relevant to other handicaps.

It is not just a list of equipment and where to get it. It gives advice and information on a host of other problems.

The book aims to inform the adult handicapped as well as parents of their rights to aids for better living, and is excellent value.

Price 50p, plus 5p postage, from the Spastics Society, 12 Park Crescent, London W1N 4EQ.

Felicity Birkett

"Holiday playschemes"

This booklet has been produced by the National Playing Fields Association and the National Council of Social Service, who have drawn on the expertise of playleaders, parents and students with experience of holiday playschemes.

It is excellent value at 25p, and is brimful of practical help and ideas on how to start a playscheme.

There is also valuable information on how to finance a playscheme and estimates of how much it is likely to cost to run. The problems of safety and insurance are covered, and a suggested programme for a week is drawn up with ideas for outdoor games, local visits, indoor activities and materials.

It is recommended that handicapped children should be allowed to join in playschemes provided precautions are taken for their safety. A number of schemes are run for handicapped children up and down the country and the National Playing Fields Association would be happy to give further information about them.

Price 25p, plus 3p postage, from National Council of Social Service, 26 Bedford Square, London WC1B 3HU.

Please see page 15 for news of the latest ASBAH publication—
"The Nursery Years".



Freedom of movement

Swimming is an activity which most children love and spina bifida children will get just as much pleasure, if not more, from the water as their brothers and sisters.

Getting about on dry land is not easily achieved for many spina bifidas and what a joy it is for them to be able to move freely in the water without their calipers and crutches. Once they have learnt to control their bodies in the water and are confident they can play and swim with physically normal children and be at no disadvantage whatever—they can even race together and win.

To ensure this type of happiness in the water, it is essential that your child is introduced to the water in the best possible way. Someone must always go into the water with your child—don't push him in a rubber ring or armbands and just pop him in

the pool while you sit on the edge. This is not only frightening for a child but can also be dangerous. Go in with your child and support him in the water by holding him around the waist; if your child has hydrocephalus and a valve never hold him by the head.

Armbands may be used once a child is familiar with the water and wants to be independent of your arms. A large expanse of water is frightening to a small child so try to make sure that there are plenty of other people in the pool or else break up the space with floating toys..

All manner of games can be played to teach your child head control, correct breathing, and to put his head under the water while keeping his eyes open. The movement of the head is very important as it influences the movement of the rest of the body, e.g. if you tip your head forwards your legs will come up

*The joys
of
swimming*

behind you, if you bend it back your legs will swing up in front.

Incontinence should be no bar to swimming if handled carefully. Those children who express their bladders should do so immediately prior to swimming. If bowel incontinence is a problem one of the best methods is to put on trainer pants or a nappy and a well fitting pair of plastic pants under the child's swimming costume. Children who have a urinary diversion should make sure that the bag is well sealed and empty before going into the water.

The stretch nylon swimsuits are the best as they give pressure on the bag holding it against the skin; little girls should have the ones with frills round the waist as they are an effective disguise for the bag; boys can wear a second pair of cotton or towelling shorts on top.

A few words of warning—never let your child go in the water if he is in any way off colour or has a urinary infection; never let him get cold or sit around in a wet swimsuit and keep a look out for sharp or hard objects on which he could unknowingly damage his legs. Enjoy this therapeutic and recreational activity with your child and have a swimming summer.





Appeals and publicity



Old friends . . .

Left: Mr. Zachary, receiving from the Chairman of the British Homing World the splendid cheque for £3,600, representing the proceeds from the Doncaster Show last January. We are so grateful to all the Committee members and to the donors of the very valuable prize birds which were auctioned in aid of our funds—they came from all over the United Kingdom and from Europe.

Proceeds of the 1975 Doncaster Show will again be in aid of ASBAH. It's good to have good old friends!

RESEARCH FELLOWSHIP

Thanks to the generosity of many of our Local Associations, charitable trusts, companies and of a large number of concerned people, we now have achieved our target of £60,000.

It is not possible to thank everyone individually but our particular thanks are due to the Loyal Order of Moose. A magnificent contribution of over £10,000 was presented to Mr. Jim White, Appeals Committee Chairman, at the Order's recent Convention in Weston-super-Mare. Thanks are also due to the Order for the interest it shows in the work of our Local Associations.

The Medical Committee is actively seeking the first holder of the Fellowship by national and international advertising and we hope to be able to let you know in the near future what the subject of this research will be.

Meanwhile it is encouraging to have sponsored the work into antenatal diagnosis in Edinburgh which is yielding such good results. Other projects are in progress and new applications for grants are being considered, so money for research is still a priority.

The value of co-operation

The way to a man's heart is often the best way to a man's pocket too, as we found at the May Fair at Chelsea Town Hall on May 8th. We ran a buffet and bar, which raised nearly £400 for our general funds.

It was particularly gratifying to have so much ready support from members of our London

Associations who baked wonderful puddings and pies and then came along as customers.

We at the National Office are very pleased if we can co-operate with Local Associations—I am sure by working together we get to know each other better and by a united effort we can all make progress more quickly.

Reports

by

Kate White,

Appeals

Secretary



Appeals and publicity

... New friends

We have good new friends too. The crew of HMS Bacchante, on hearing that their Petty Officer's new baby was spina bifida, resolved to adopt ASBAH and at a ceremony to welcome them back from their West Indies cruise, Jane Baker and Tony Stevenson of South Hampshire ASBAH received on our behalf a commemorative plaque and a photograph of the ship—one of the Leander class frigates. The picture shows one of the crew giving a present to Tony Stevenson.

The splendid sum of £1,034 had been raised by the crew of 250 during the cruise and this money will be used to "name" a bed in the short-term care home now being planned.



Cont. from page 7

experiencing the limitation of institutional life. We aim to continue this work.

"We are now designing housing estates and flat developments where small numbers of physically handicapped persons are integrated with ordinary general family accommodation, and in consultation with the local authority . . . ensuring that the necessary welfare support is provided.

Mr. Doney said that Inskip St. Giles' projected building programme for the next ten years was £50-80 million. He explained that although it was non-profit making, a charity relying to a very great extent on voluntary donations, it had, like all housing associations, access to other money. It was able to borrow most, and sometimes all

the capital cost of each housing project, either from the government's Housing Corporation or a local authority. These were 40-60-year loans and were repaid out of rents, government subsidies, local authority grants and donated money.

"The rents are fixed by the rent officer and most disabled people are at least entitled to a rent allowance from the local authority. Those not in employment and entitled to supplementary benefit receive the whole of their rent from rent allowances and social security benefits."

Mr. Doney believed that housing was a first priority, because as more handicapped people were integrated into the community, their other social and welfare needs would be dealt with more readily. Integra-

tion was the only effective way to break down fears and prejudices among the general public.

"Not all those with disability have the physical ability or desire to be in their own home, but . . . for all those who can and wish to do so the opportunity must be provided," he said.

* * * * *

For further details of this Housing Association write to Mr. Malcolm Doney, Director, Inskip St. Giles Housing Assn. Ltd., Joliffe House, West Street, Poole, Dorset.

* * * * *

Mr. Doney is anxious to hear of any pieces of land likely to be suitable for development by his housing association.

Getting to know you

by Miss Jackie Page (aged 17)

A group of young people, handicapped by spina bifida got together for a weekend recently at Felbury House Youth Centre, near Dorking, Surrey. The weekend was organised by the Association's Greater London Liaison Committee and its Secretary, Miss Gretta Bennett.

The main purpose of the weekend was to get to know each other. There were 12 disabled people altogether, their ages ranging from 15 to 25 years. There was a nurse, Mrs. Hilary Gatfield, to look after our medical requirements, and Mr. John Collier who runs Felbury House, organised the catering with help from teenagers from a neighbouring village.

The discussions proved very helpful to us thanks to the leadership of Miss Bernie Spain of the Greater London Liaison Committee and Mr. Stephen Dorner, a psychologist from Gt. Ormond Street Hospital, and there were some interesting talks, too. One of the speakers, Mr. D. M. Forrest from Westminster Children's Hospital, talked in detail about our disability. Dr. Cedric Carter talked

about a survey which has been carried out with spina bifida adults who were formerly patients at Gt. Ormond Street Hospital, many of whom now have healthy children. One of the women in this study, who is in a wheelchair, came by on Sunday afternoon with her husband and little boy.

On Sunday morning Miss Margaret Morgan who works in a unit for family counselling for the Spastics Society, showed us a film about a handicapped couple who have learned to help each other to lead as normal lives as possible together.

On the social side, the teenagers from the youth club came and met us and we went out for walks with them, and they gave us a very good disco.

As a result of discussions over the weekend, it was proposed that we write a letter to Mr. Alf Morris, the Minister for the Disabled, with our suggestions for changes that could be made to enable the disabled to lead fuller lives.

It is hoped that there will be further meetings.



THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN

Patent applied for in
UK, Commonwealth Countries, USA, Canada

This Trolley was designed by Mr. Ken Charrett of Southampton for his daughter who was born with Spina Bifida. It was soon found that here was a chair that would enable a child paralysed from the waist down, to become mobile.

The Trolley, weighing only 14lb, is strongly constructed, completely manoeuvrable and easily propelled by the child. Due to the low centre of gravity and rear castor action it is virtually impossible to be overturned.

The Trolley is finished with foam upholstered durable vinyl and comes in a wide range of attractive colours, this is to give the child the impression it has a toy. The child soon learns to use the Trolley, which adds much happiness to the child's life.

Standard model for children one to five years old costs £8.25 plus carriage.

Large model for children five to ten years old costs £11.50 plus carriage.

These prices include VAT which has now to be paid on these aids in the UK. Overseas prices on application.

Produced by **Southampton and District Spina Bifida and Hydrocephalus Association**

We should like to acknowledge the help of Tatchbury Mount Hospital, and voluntary work of the members of Southampton and District Spina Bifida and Hydrocephalus Association to make this Trolley.

All enquiries to: Mrs. K. Charrett,
46 Tillbrook Road, Regents Park, Southampton.

Telephone enquiries: Totton 3365
(Mr. Mortimer)

ASBAH publications and publicity

<i>Your Child with Spina Bifida</i> by Dr. J. Lorber, MD, FRCP	15p*
<i>Your Child with Hydrocephalus</i> by Dr. J. Lorber, MD, FRCP	15p*
<i>Equipment & Aids to Mobility</i> by O. R. Nettles, MCSP, ONC. A folder of four booklets	complete set 25p*
<i>Clothing for the Spina Bifida Child</i> by Barbara Webster, SRN, RSCN	15p*
<i>The Nursery Years</i> , by Simon Haskell, M.A., Ph.D., and Margaret Paull, Dep. Ed., Ph.	15p*
General information leaflets	100 for £1
Leaflet for young people	100 for £1

Scottish Spina Bifida Association booklets

<i>The Spina Bifida Baby</i> by O. R. Nettles, MCSP, ONC	10p
<i>Growing Up with Spina Bifida</i> by O. R. Nettles, MCSP, ONC	20p

All available from: ASBAH, Devonshire Street House, 30 Devonshire Street, London W1N 2EB. (*Special rates available to Local Associations.) Bulk orders of Scottish Association booklets to: The Scottish Spina Bifida Assn., 7 South East Circus Place, Edinburgh EH3 6TJ (at special rates).

The Nursery Years

by Simon Haskell, M.A., Ph.D. and Margaret Paull, Dip.Ed.Ph.

This book, recognising that the early years of a child's life are vital years, is a guide to some of the ways in which parents can help their children to develop physically, emotionally and mentally. It takes a general look at the ways in which ordinary everyday experiences can be adapted to stimulate a handicapped child. Sometimes, it is only after a child starts school that it is discovered that many learning problems have their roots in less obvious handicaps such as poor hand control, or language difficulties, which might have been, at least, partly overcome during earlier years. It has many practical suggestions, for parents, and also useful addresses for books and learning material.

Price 15p.

Posters. Double Crown, 5p each, "Future Bright", 10 for 20p.
Flag Day emblems. 1,000 for 50p.
Cards for notice boards. 10 for 10p.
Car stickers. 5p each. Postage extra.
Fund-raising items. Price list/details on request.

Local Association offers

Badges. Silver and green enamel with pin fastening. Replica of the Spina Bifida emblem. Bulk orders are welcomed particularly. Price: 22p per badge. Postage extra. (For a single badge please enclose s.a.e.) Apply to: Mr. K. McKenzie, Badges Secretary, Salisbury & District ASBAH, 111 East Gomeldon Road, Gomeldon, Salisbury SB4 6LZ.

Badges for children. Good quality 1½in diam. SB symbol and the words, "Spina Bifida Children" in black on green background. Price: 25 badges for 75p; 50 for £1.40; 100 for £2.65, including postage. Cheques and postal orders crossed and payable to "SASBAH". Send with order to: Mrs. I. Olditch, High Lea, Turners Green Lane, Wadhurst, Sx.

Ties. Heavy weave washable terylene with SB symbol on dark blue or dark green. Sold by N. Hants, S. Berks and W. Surrey ASBAH. Price £1.10p plus postage, while stocks last. Reductions for bulk orders. Cash with order to Mr. B. High, 10 Woodruff Ave., Burpham, Guildford, Surrey. Please state colour.

Inter-association holiday opportunities

Camber Sands, nr. Rye, Sussex. New, well-equipped chalet, in pleasant situation near the sea available for families with spina bifida members. Sleeps six. Please apply to Mr. S. Evans, 1 Coniston Gardens, Wembley, Middx. 01-904 7840.

Cleethorpes. Three-bedroom bungalow to accommodate 6-8 persons at Humberston Fitties, nr. Cleethorpes, Lincs. Further information from Mrs. W. Steele, 59 Louth Road, Holton-le-Clay, Grimsby.

Great Yarmouth. Self-contained 6-berth caravan at Caister Beach Caravan Camp, nr. Gt. Yarmouth. Details from Mrs. N. E. Barefoot, 23 Marlborough Road, Southall, Middx. Tel. 01-574 5067.

Lessingham, Norfolk. Well-appointed 6-berth caravan. Sea 100 yds. Vacancies. Apply Mr. P. White, 12 Swallow Gardens, Hatfield, Herts. Tel. Hatfield 63018.

Looe. Bungalow, two bedrooms, spacious accommodation at Millendreath Holiday Village, nr. Looe, Cornwall. Mr. Keith Jackson, 202 Exeter Street, Plymouth.

Looe. Holiday bungalow at Millendreath Holiday Village. Sleeps six. Fully furnished. Further details Mrs. Cook, 19 Winslade Road, Harestock, Winchester. Dates still available

April, May, Sept., Oct.

Mablethorpe. Self-contained 6-berth chalet situated at Golden Sands Estates, Mablethorpe, Lincs. Apply to Mr. Ken Hall, 17 Walhouse Street, Cannock, Staffs.

Mablethorpe. 25ft. self-contained 6-berth caravan. Situated at Golden Sands Holiday Estates, Mablethorpe, Lincs. Details from Mr. J. Cannon, 28 Deerpark Crescent, Wingworth, Chesterfield, Derbys. Tel. Chesterfield 78952.

New Forest. Well-equipped chalet, sleeping six people. Within easy reach of Bournemouth, Beaulieu, etc. Swimming pool, paddling pool, restaurant and playground on site. Details from Mrs. A. Rae, 16 Clifton Road, Lee-on-Solent, Hants. Tel. Lee-on-Solent 550242.

Rhyl. Open plan 6-berth caravan, partitionable into three, situated at the Robin Hood Holiday Camp, Coast Road, Rhyl, N. Wales. Bookings available 1st-May-30th September to Liverpool Association, 46 Manchester Street, Liverpool 1.

Selsey. New well-appointed, self-contained 16ft. x 30ft. 6-berth mobile home for families with spina bifida members. Sited at Selsey, Sussex. For full details please send s.a.e. to Miss G. M. Clarke, Badgers Copse, Rudgwick, Horsham, Sx.

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