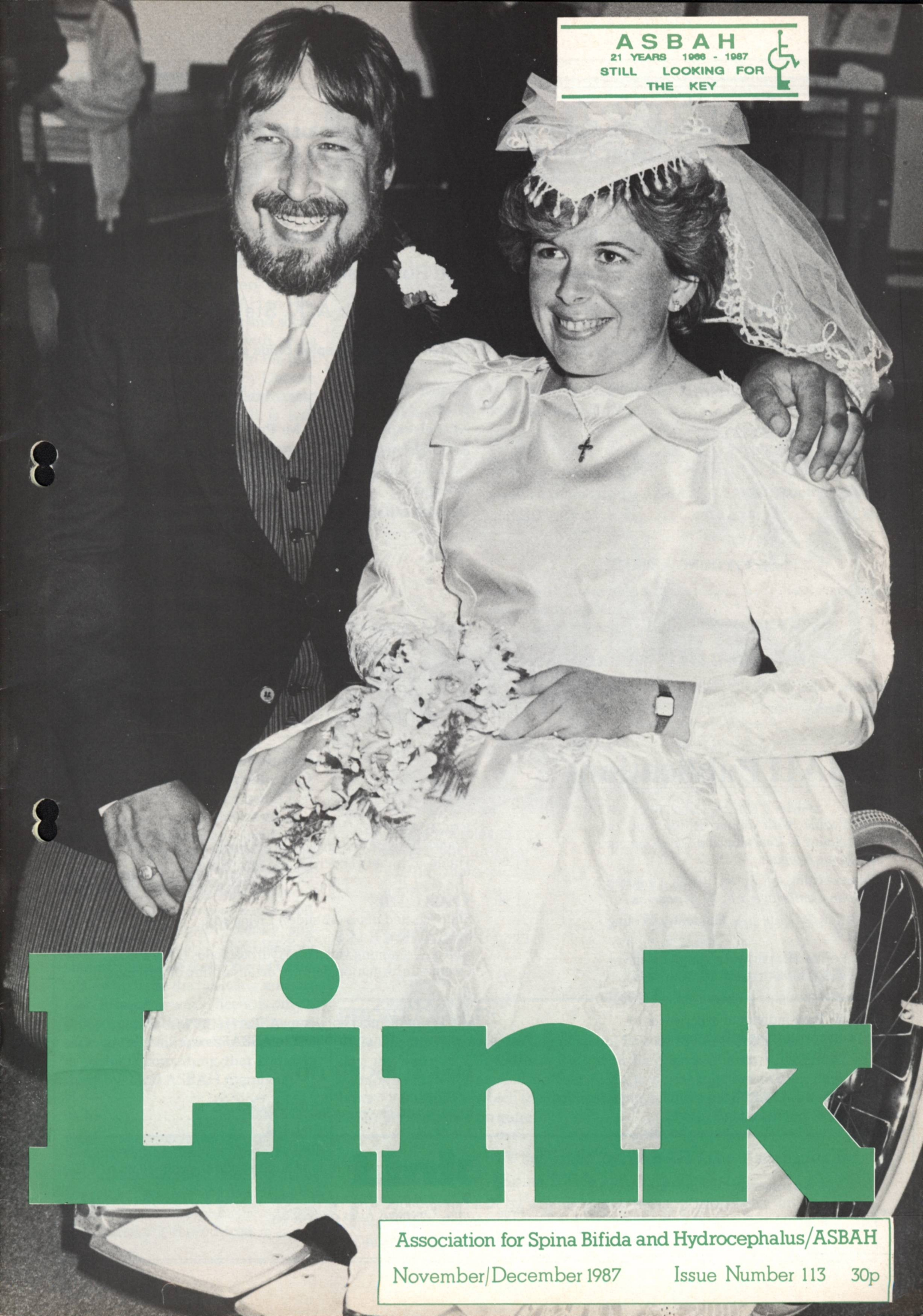
ASBAH
21 YEARS 1966 - 1987
STILL LOOKING FOR
THE KEY



Link

Association for Spina Bifida and Hydrocephalus/ASBAH
November/December 1987 Issue Number 113 30p

Association for Spina Bifida and Hydrocephalus(ASBAH)
22 Upper Woburn Place, London WC1H 0EP
Tel: 01-388 1382

Registered Charity No. 249338

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ASBAH Publications

All available from National Office
Cheques payable to "ASBAH"

Young People with Spina Bifida and/or Hydrocephalus — Learning and Development (1985) *Leonie Holgate*..................	£1.60
The Handwriting of Spina Bifida Children (1979) *Joan Cambridge, Eliz M. Anderson*...	£1.60
Spina Bifida & You - A Guide for Young People (1985).........................	£3.50
Sex for Young People with Spina Bifida or Cerebral Palsy (1984)..................	£1.75
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Video — Training video on Hydrocephalus (May 1987). Contact Information dept for details of hire or purchase.

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LIFT - for members of young ASBAH (LIFT)...........	Free
Causeway - for contributers to ASBAH's work..........	Free

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Editor's Note

LOOKING FOR THE KEY: SPECIAL LINK INSERT

THIS LINK contains a very special insert: the history of ASBAH and the improvement in treatment and social attitudes towards those with spina bifida and hydrocephalus in the past 20 plus years. It is written by Duncan Forrest and based on his address to our AGM in September. It is well worth keeping.

Since Mr Forrest's address, ASBAH has had a number of enquiries about programmeable valves. Very few valves have been used in this country so far but we hope to publish an article in the not too distant future.

NAME THE HELPERS

Can any reader think of a more appropriate name for *"a helper "* - i.e. someone who accompanies a disabled person on a special course or holiday etc. to participate and help. We feel that the word *"helper"* is rather weak and out-dated. Any suggestions please?

CONVERTIBLE TAXIS

More and more taxis are being converted to take wheelchair passengers (ASBAH's information department can give you a full list covering the whole country). Now the movmeent has started it is important to keep it going The Joint Committee on Mobility for the Disabled recently suggested that local organisations should pressurise their District Councils - which are the licensing authorities - to issue new taxi licences only to those operators who agreed to provide wheelchair accessible taxis. This is perhaps something that could be done by local ASBAH members.

Sue Gearing
Editor

On the INSIDE

MAIN FEATURES

LEISURE

IN THE NEWS

DAILY LIVING

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GENERAL

FRONT COVER:

A flashback to the happiest day of Jacqui Bowkett's life - September 12 -the day she married Clifford Marshall at St Stephen's Church, Cinderford, Gloucs. They will be spending their first Christmas together in their new home - a bungalow which they are restoring. Jacqui's proud mother writes about her daughter on page 9. Photo: Bristol United Press

Link is published by ASBAH (The Association for Spina Bifida and Hydrocephalus).

Contributions to LINK by way of letters, news, photographs, articles and opinions are warmly welcomed. The closing date for the next issue is December 5. . Send to the Editor at National Office

ASBAH AND CONDUCTIVE EDUCATION

Visit to Hungary

ASBAH is very concerned about some of the claims that are being made about the use of Conductive Education for children with spina bifida and hydrocephalus. These claims are fairly new and there is little information yet available about the results of using this system of management with children with spina bifida and hydrocephalus.

ASBAH is anxious to be in a position to give families and professionals accurate and informed advice. We are, therefore, very pleased that Miss Carole Sobkowiak will be travelling to Hungary to assess the claims that are being made and to review other services available in Hungary.

Carole is Superintendent Physiotherapist at the Child Development Centre at Darlington Memorial Hospital and a member of ASBAH's Medical Advisory Committee. She has had a great deal of experience in all aspects of the management of children with spina bifida and cerebral palsy. (See Carole's article on the facing page). We hope that she will undertake her journey in the Spring of 1988, and a report will be published as soon as possible after this.

FOR SALE

New

ASBAH T- Shirts

Good quality. 100% cotton. White, with attractive green/grey and black elephant motif.

Includes wording:
"ASBAH - Association for Spina Bifida and Hydrocephalus".

Prices:

28" and 32" chest	£3.25
Medium adults	£3.50
Large adults	£3.75
Extra large adults	£4.00

10% discount for orders of 10 or more.

Money with order. All credit card orders welcomed.
Please give credit card number and expiry date.
Cheques/p.orders payable toASBAH

Send to Mrs Joan Chapman, Appeals Department, ASBAH, 22 Upper Woburn Place, London WCIH 0EP.

I have SPINA BIFIDA

This new book from Franklin Watts in the series *I have...* looks at the life of 12 year old David Purcell from Essex who has spina bifida. It aims to give schoolchildren an insight into disability. ASBAH's Executive Director, Moyna Gilbertson acted as consultant for the book which is beautifully written and illustrated with colour photographs. More details about the book and price in the next LINK.

The use of language to encourage and train disabled children is central to Conductive Education

CAROLE SOBKOWIAK describes a British project which uses similar techniques..............

Talking it through

CAROLE SOBKOWIAK is a member of ASBAH's Medical Advisory Committee and Superintendent Physiotherapist at the Child Development Centre, Darlington Memorial Hospital.

ACKNOWLEDGEMENT
To my friend and colleague Miss Dorothy Hodgson, the teacher who shared the project with me and who continued to work on a day to day basis with dedication.

This article is written with parents and young people in mind and I have chosen the title "Talking it Through" to describe to you some of the work which I started in one of our special schools in October 1983. This was a joint venture with a very experienced teacher of physically handicapped children.

The aims of the project were for the children to work as a group, being aware of each other, organising themselves in space, improving right/left orientation and movement and thought sequencing, to try and improve auditory and visual memory and to develop their co-ordination skills. As a group it was hoped to increase friendly competitiveness and develop leadership. We planned eventually to transpose these aims into different environments.

As you will know the learning difficulties of children with spina bifida are largely due to their associated hydrocephalus and the fact that many need to have valves inserted. Both of these factors can cause changes in the nervous system which we as therapists and teachers try to remediate. The signs and symptoms are extremely complex and it is for this reason that I would like to describe to you our methods of remediation.

Other workers in this country will use similar methods. We all work from basic principles of neurology and education but obviously as individuals we will have a slightly different method of getting the end result. I often compare this to cooking; we can all start off with the basic ingredients, ie. the recipe, but the art is in the mixing and the blending.

Research

We have become familiar over the years with the numerous problems our children have. There are too many to mention here without getting totally bogged down. What I would like to emphasise to you is that the work described here is a direct result of a good deal of research which has taken place in this country into children's problems with spatial and perceptual concepts, right/left disorganisation, handfunction, learning difficulties, to mention but a few. Some of you will have listened to papers given and discussions held at the various ASBAH Study Days.

I see the brain rather like a computer; information is punched in by pressing buttons, it is then processed, followed by a print out. We as therapists and teachers, and you as parents, press the buttons sending in the information. This may be quite simple to you and me because on the whole when you and I receive information, we process it in order to give an output. If however there is a disturbance in the system due to the presence of hydrocephalus or a valve, then routes and pathways may be disturbed, blocked or even non-existent.

It is this central disturbance which interests teachers and therapists. We know that these areas are in particular those which control spatial awareness, sequencing, body image, right/left confusion or reversal, planning, short term memory, abstract concepts of mathematics and so I could go on.

Instead we need to look at other parts of the computer which are perhaps better controlled and to use these better parts of the brain in an attempt to compensate with remediation programmes. There are three areas in particular which we have used - language, music and rhythm.

Increasing memory

The language area of the brain is often intact and this is why our programmes contain a high proportion of time aimed at getting the children to talk to themselves about the movements they areperforming, in other words "Talking it Through". This may require endless repetition in order to build up a basic motor skill or follow a set of instructions eg. to get to the toilet "I turn right, right again and then left" or "I must remember my bag, towel, toothbrush, toothpaste to go to the bathroom.

As you will see the information punched in can increase in the number of digits, thereby increasing the auditory and visual memory. When we started our project some children could only remember two digits but with training we managed to increase this.

What some children find difficult is to sort out all the jazz within the central computer in order to produce an

Continued on next page

Talking it through

continued

output - we have all seen them sitting there endlessly trying to work it out. For this reason we press our buttons carefully and select the channel albeit auditory, visual etc. in order to give the children time to assimilate the information. In our group, most of them needed the booster of the language area. I often say to parents that it is a bit like having a central heating system where in order to boost it one switches on the pump. There are added boosters in the form of rhythm and music. We learned at school through chanting time-tables and jingles to remember the alphabet and then went on to develop reasoning skills for learning.

I am not able here to describe the programmes in detail but they included competitive activities eg. team games, relay races, slaloms and obstacle courses. We were then able to expand this to include mathematical concepts such as measurement, distance, timing abstract addition and subtraction, making shapes, concept of size and weight. Outdoor activities were arranged to local places of interest like Durham Cathedral. We discussed our journey as we went along and at the destination, information and questionnaires were given out. Observations and the children's drawings of the environment were recorded on worksheets. This gave us a record of how the children could orientate themselves in an unfamiliar environment.

Internalising language

In summary I cannot emphasise sufficiently the use of language to direct motor tasks. There is nothing new in this as many workers in the field have been applying these principles for years. To begin with our children could be seen to be "talking their way through tasks" when receiving information. Finally they could internalise language. This meant that they could be given a complex instruction, appear not to struggle with it, reduce the amount of time required and more effectively carry out the complexity of the instruction. On the whole we found that we had to take them back a few stages in new set-ups, eg. orienteering and map reading in the park or in the supermarket in other words they were learning to transpose skills.

This approach to working with children learning motor skills in an education framework requires much patience and repetition but we found that the children improved in their right/left discrimination, increased their auditory and visual skills, were better organised in space and time, could keep to a rhythm and remember tapped or clapped sequences and therefore became more co-ordinated.

What is more important their confidence was built up and as a result they became happier with an increase in their independence.

In conclusion we found the use of language to direct motor skills to be of great value in our programmes and felt that it did pay to "Talk it Through".

Calling all local associations..help to make it an occasion to be remembered:

LIFT WEEKEND 1988
MARCH 25 - 27

Next year LIFT is celebrating its 10th Birthday, and as part of those celebrations there will be a Conference at Owens Park, Manchester University. To make this an extra special occasion we are hoping that every local association will sponsor at least one young person to attend so that members from all parts of England and Wales can come together.

The LIFT Working Party recently met to draw up a programme and we are now contacting speakers, negotiating a price with Owens Park and making all the other necessary arrangements to make it a successful weekend.

By the time you read this, we may have more details so if you are interested in helping to make LIFT's 10th Birthday Weekend an occasion to remember, please contact: Andy Neale, LIFT Organiser, LIFT Office, ASBAH, 22 Upper Woburn Place, London WC1H OEP. Tel: 01 388 1382

ASBAH and RESEARCH

THIS RESEARCH SUMMARY APPEARS IN ASBAH'S ANNUAL REPORT 1986/7.
FOR A COPY OF THE FULL REPORT AND ACCOUNTS PLEASE CONTACT ASBAH'S PR

ASBAH aims to promote, encourage and conduct reseach into the causes and treatment of spina bifida and hydrocephalus. This was an important object 21 years ago and the importance of research has in no way diminished. In fact, as new problems and possibilities emerge, the importance of research is heightened.

When an application is received it is scrutinized by our Medical Advisory or other relevant committee; as can be seen from the projects described, not all of ASBAH's research projects are medical. If the examining committee decides that a project is worth supporting , ASBAH endeavours to ensure that sufficient funds are available to cover the costs. This can be a limiting factor when there are so many demands on a very small research fund. Donations earmarked for specified projects, or for research generally, are always welcome.

Over its twenty-one years ASBAH has supported research into a wide variety of issues relating to spina bifida and hydrocephalus, and this has helped to increase knowledge and understanding and has led to improvements in services to individuals and their families.

Current research projects are:

Dr Ruth Maxwell in Bristol is studying the differences in cerebrospinal fluid flow between hydrocephalic and normal children. Once completed we hope that this project will give us an increased understanding of hydrocephalus, its effects and treatment.

Dr Jean Bowyer in London is conducting a project investigating why children and young people with ventricular atrial shunts - that is shunts which drain excess fluid into the heart - are prone to pulminary hypertension. This is a problem which is a great worry to parents, young people and the medical profession and we hope that Dr Bowyer's research will identify why the problem occurs so that an effective treatment can be produced.

Dr Brian Tew, in Cardiff is researching the educational achievements of children with spina bifida and/or hydrocephalus. We are aware from previous research of many of the educational problems particularly linked to hydrocephalus - but our knowledge of the very severe learning problems is not complete and as more and more young people are integrated into mainstream education a fuller knowledge is vital. We hope to be able to provide professionals in education with a great deal of information so that they are better able to cope with the problems these children and young people present.

Dr Roger Bayston who has worked closely with ASBAH for a great many years continues his work on the treatment of hydrocephalus and the safety of shunting systems. Dr Bayston receives as much support as resources allow. He also provides a very valuable advisory and practical service to ASBAH and families.

Dr Martin Bax and Dr Andrew Thomas in London are studying the needs, problems and the provision of services for young adults. We have, for many years been concerned about the lack of medical and social provision for young people once they leave the paediatric services. So great was our concern that in 1982 ASBAH conducted its own survey into needs and provisions for this group. A paper was presented to the Society for Research into Hydrocephalus and Spina Bifida.

The preliminary study by Dr Bax and his team only identified a few of the problems and we know that much more remains to be done. We are pleased to be able to support Dr Bax and his team. A great many problems and needs are being uncovered, and we hope the research will enable us to press more effectively for improvements in all services to young people.

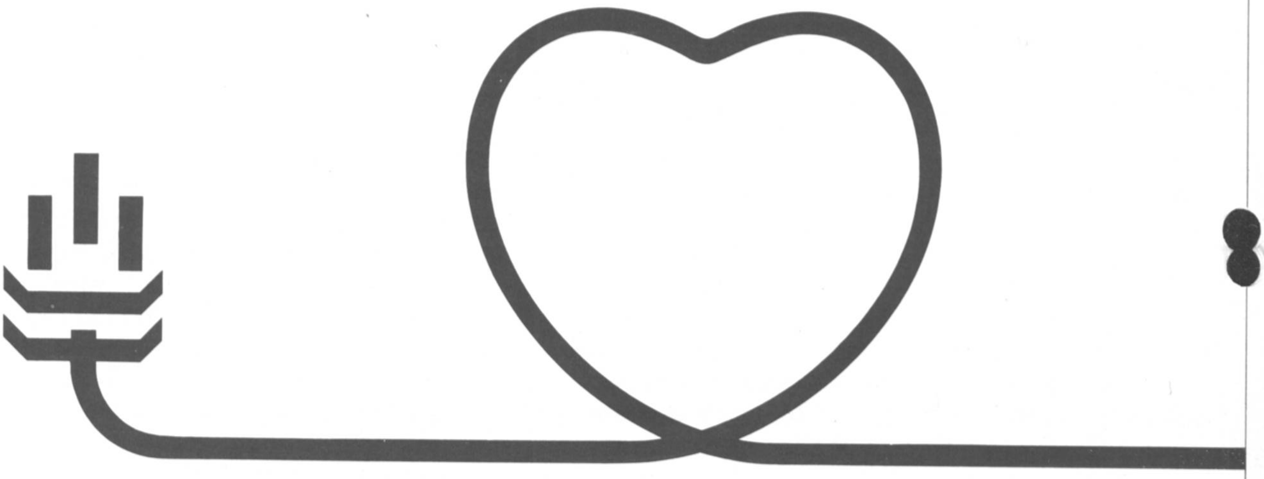
The ASBAH Driving Courses which are held at Five Oaks our centre in Ilkley have provided a great deal of information enabling Psychologist, **Barbara Simms** to research the mobility problems of people with spina bifida and hydrocephalus.

We are anxious to find ways of helping these young people to achieve mobility, and also where suitable to drive .

Two new research projects which ASBAH has just approved are:

A new approach to the Neuropathic Bladder -
Mr David Thomas in Leeds, and

Investigation into the morphological characteristics of the ependyma in normal and hydrocephalic states -
Dr Patricia Collins in Southampton.



THE FREEDOM OF AMERICA

LINK EDITOR SUE GEARING REPORTS ON THE FIRST EVER READERS HOLIDAY................

THE LINK READERS HOLIDAY TO FLORIDA in October and November this year not only provided access to the wonders of Disney, blue skies, and the Gulf of Mexico, but it also gave access to a much freer life for those in wheelchairs.

Everyone was able to move freely into shops, restaurants, cinemas and practically all of the attractions. There was an abundance of public toilets (rest rooms) not only accessible but very, very clean.

"I think we shall all miss this ability to go anywhere when we get back to England" commented Alison Baker from Princes Risborough. "I was amazed at the friendliness and hospitality of all the Americans we met and their eagerness to help" said Alison Jenkins from Jacksdale, Nottinghamshire.

They were both on the first holiday - which departed from Gatwick at the beginning of October, and which I accompanied.The second group, which left from Manchester, are heading back as I write this, and details and pictures of their holiday will have to be left until the next issue.

There were 55 of us who left Gatwick and headed for the delights of Florida weather - in the eighties most of the time and not at all humid. There were about 25 in wheelchairs and we were made up of family groups and young adults travelling with a friend. Many had managed to find the money for the holiday themselves -others were sponsored or had been given the opportunity of this holiday of a lifetime as a result of local fund-raising efforts.

The flight by British Airways jumbo was much as most of us had been led to believe - rather cramped and virtually impossible for anyone who couldn't walk to get to the very small toilet. But everyone had been forewarned and somehow managed the 9 hour flight without undue incident! The staff were very helpful and the food was good so that counted for a lot.

The first ten days were based at The Continental Royale Hotel in Orlando. We all had rooms on the ground floor near the swimming pool. The rooms were very good and easily accessible like the rest of the hotel, but the bathrooms could have been larger. It wasn't easy for some to have a bath, and this complaint about small bathrooms was even more true at the second hotel at Clearwater.The Orlando hotel kindly removed bathroom doors for two of our group and this largely solved the problem. Certainly there weren't any more complaints - everyone was so busy having a good time generally and storing up memories.

The memories are of the professionalism ofDisney World - where the atmosphere and showmanship captivated everyone even those well above Mickey Mouse age; of; Epcot which for many proved the high spotof the holiday. We will remember the silver globe of Spaceship Earth and the journeys into the world of tomorrow; the highwire acts and the wonderful range of restaurants and pavilions from around the world. We shall also remember the fantastic firework and laser show across the lake at Epcot which concluded one of the days. That particular day had been very very wet - hurricane Floyd was on its way, but actually never came to anything where we were - but when the fireworks started the fact that we were all soaked to the skin didn't matter at all. There were other attractions, too - and everyone will have their own particular memories - Sea World with an amazing show by Shamu the killer whale, Cypress Gardens with lush tropical plants and water ski shows, and Bush Gardens where some of us braved the rapids, and at least one person went on the roller coaster,but unfortunately where many rides weren't accessible. However the Hospitality Tent with free beer partly made up for it.

The second stage of the holiday - four days on the Gulf of Mexico at Clearwater - gave us the opportunity to rest from sight-seeing and flop around the swimming pool and jacuzzi overlooking the Gulf. The hotel -Adams Mark - was luxurious and welcoming; restaurants in Clearwater were inexpensive and helpings generous; the weather smiled on us; and the cocktails enjoyed on the terrace listening to the steel band, or the

Photos on next two pages. Story continued on page 18

FRONT COVER:

Here Mrs Jean Bowkett of Cinderford in Gloucestershire writes about her daughter Jacqui who is featured on her wedding day on the front cover of this LINK:

I just had to write and tell you that our daughter Jacqui who has spina bifida and is confined to a wheelchair was married to a wonderful man in September...He is very kind and most considerate and caring about her problems. Jacqui is now 26 and we have been ASBAH members all these years and have always admired all the work and progress made towards getting them a better standard of living.

The newly weds are getting along fine and Jackie is managing very well in her new kitchen... They are buying their bungalow which is old and has great prospects. It is detached and is in a quiet but yet central part of the town.

We feel very happy for them and in all our wildest dreams we never thought we would have such a wonderful day as we did in seeing Jackie married.

When she was born she was given just four days to live and had many operations at Great Ormond Street and Frenchay Hospital, Bristol.

She was Head Girl at her school, and was the first girl to obtain the Queens Guide from a wheelchair in the whole of England. She led 2,500 guides at a Thanksgiving Service at Salisbury Cathedral. There have been manyother wonderful days of joy. Her father and I do feel terribly proud of her.

FLORIDA '87

Pictures of the first group holiday

taken by LINK Editor, Sue Gearing,

and

Tom Wilson from High Wycombe

Report on the holiday on pages 9 and 18

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1

3

PHOTOS:

1 First day at Disney World - Gill Butcher (left) and Alison Baker in the main street

2 The Woollard family from Ipswich - Lionel, Rosemary and son Andy - enjoy relaxing around the swimming pool at the Continentale Royal in Orlando

3 Debbie Taylor meets Minnie

4 At Epcot. Spaceship Earth is in the background. Left to right: Clare Fitzgerald, Debbie Taylor, Edna Wilson, Julie Morby and sister Suzanne (in the chair), and Tom Wilson

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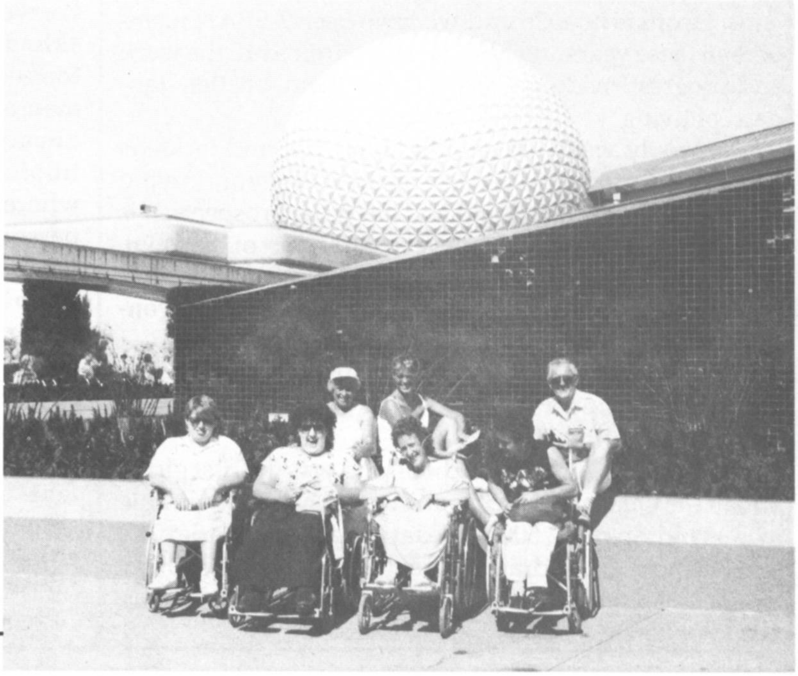

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FLORIDA '87

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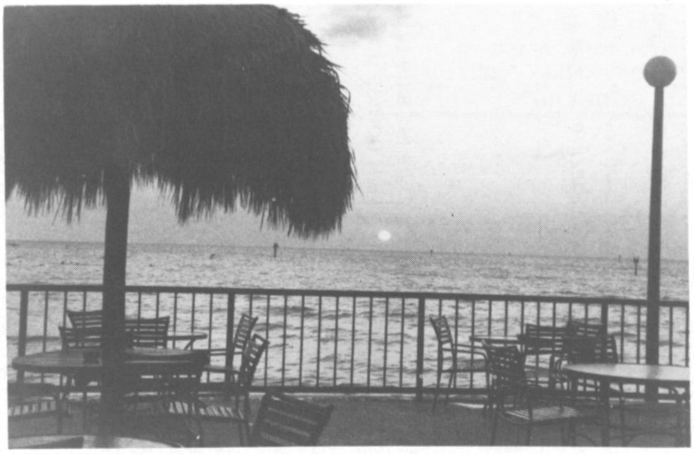

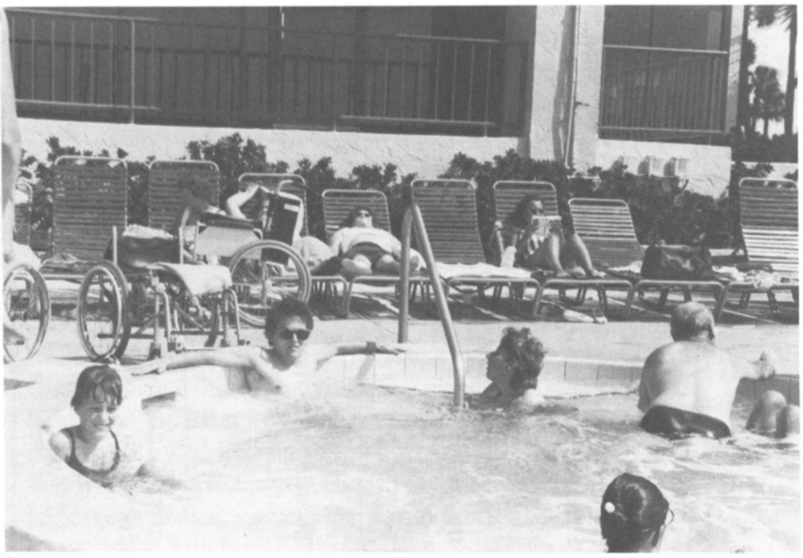

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5 The Atkins family from Gravesend, Kent - Trevor and Linda with Debbie, baby Nicola and Paul who has spina bifida

6 Sunset over the Gulf of Mexico - view from the terrace of Adam's Mark hotel, Clearwater

7 The warm bubbly water of the jacuzzi on the terrace at Adam's Mark attracted many of the group including Mark Phillips (with the dark glasses)

8 At Kennedy Space Centre - Melanie Harthill protesting about the camera with from left to right - Alison Baker, Melanie's son, Simon, Trudy Anne Bush and Clare Fitzgerald

8

9 Left: The start of another day - getting into the buses. J-J is in the background; in the foreground are Alison Jenkins (left) Gill Butcher and Trudy Anne Bush

The Passage of a Public Bill Through Parliament

This chart shows the passage of a Public Bill through Parliament. LINK thought it might be of interest to readers as an instant guide when they read that a certain bill is at a certain stage. There are two types of Public Bill — a Private Member's Bill and a Government Bill. Both have to go through the same Parliamentary procedure, outlined below. There are a few differences between the two types of Bills. A Public Bill implements Government policy and is introduced by the Secretary of State of the relevant Department. The Private Member's Bill is introduced by an individual MP and unless the Government wishes to facilitate its passage it is unlikely to go through all the stages and become an Act due to lack of time for later stages.

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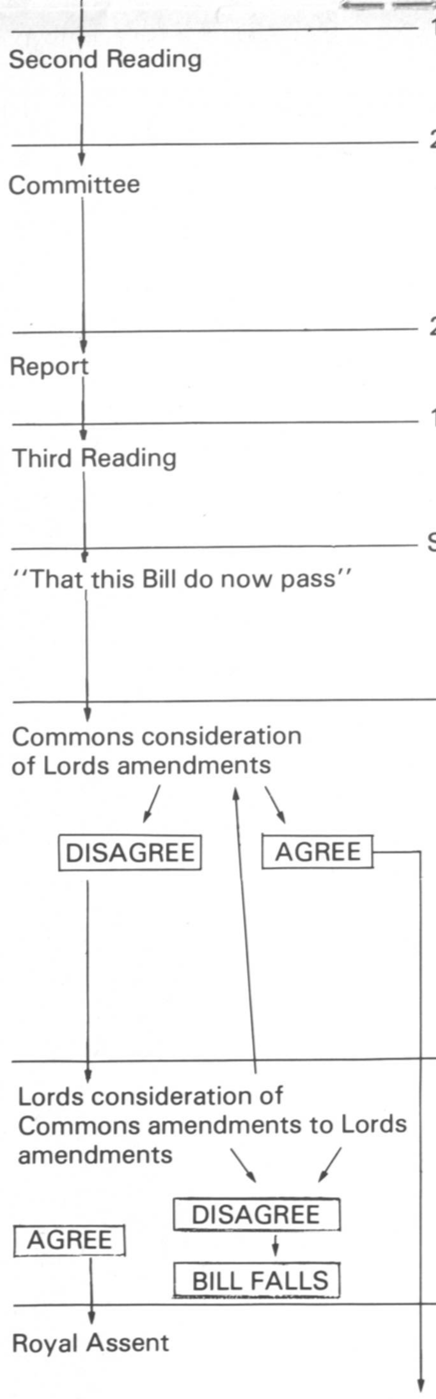
Name of Stage	Time Between Stages (Approximation)	Type of Discussion	Comments
House of Commons First Reading		A mere formality; the Secretary of State of the relevant Government Department announces the Bill in the House of Commons, and it is printed.	MPs and others interested, such as outside organisations, can read a copy of the Bill before it comes up for Second Reading.
	a few weeks		
Second Reading Majority Vote VOTED DOWN		Formal debate on the floor of the House, open to all MPs.	This is a wide-ranging discussion on the principle of the Bill and what should or should not be included in its provisions. A motion that the Bill now be read a second time is voted on. The Government is highly unlikely to be defeated on this vote, given it has a majority in the House Outside organisations may try to get coverage for their views during the debate.
	Immediately		
Committee		Each Clause is discussed in detail by a group of 20-30 MPs from all parties in a Committee Room. The number of MPs from each party reflects the vote carried at Second Reading. The Committee meets 2 mornings a week (it can include 2 afternoons if they become pressed for time) for 2-3 months. An MP may speak as many times as he or she wishes on an amendment.	Amendments aimed at either improving the Bill or initiating a discussion on a particular point are tabled. Outside organisations will ask MPs to table amendments on their behalf. Amendments may be voted on or withdrawn according to the circumstances. Any amendments passed become part of the Bill. No fixed length of time is given for this stage but should the Committee spend too long discussing small detail and not get through the Clauses, the Government may set a timetable for completing the Committee Stage. This is called a ''guillotine''.
	1-2 Weeks		
Report		The Bill is returned to the floor of the House for a debate on further amendments. MPs may speak only once on any one amendment.	An opportunity to raise further amendments; outside organisations may again get coverage for their views. Depending on the nature of the Bill 1-3 days be allocated for Report.
	Often on the same day		
Third Reading Majority Vote VOTED DOWN		A short debate on the floor of the House; usually no more than a formality.	This is a debate on the principle of the Bill. Unlike Second Reading it focuses entirely on the contents of the Bill. It may be followed by a vote.
	1-2 Weeks		
House of Lords First Reading		As in Commons.	As in Commons.



	1-2 Weeks		
Second Reading		As in Commons.	As in Commons, but, unless the Bill is highly controversial [a[illegible] the Local Government (Interim Provisions) Bill]no vote is taken.
	2 Weeks		
Committee		Unlike the Commons this takes place on the floor of the House and any peer wishing to participate may do so. Any number of days from 1-5 may be allotted, depending on how complex and/or controversial it is.	As in Commons.
	2 Weeks		
Report		As in Commons.	As in Commons.
	1 Week		
Third Reading		A short debate on the floor of the House.	The Third Reading is agreed to, and after this further amendments may be tabled to the Bill which may be voted on.
	Same day		
"That this Bill do now pass"		Often a formality; although the motion may be debated.	The motion is particularly likely to be debated if amendments were tabled at Third Reading. It is voted on only in exceptional circumstances.
Commons consideration of Lords amendments		A debate on each amendment made by the Lords takes place on the floor of the House of Commons.	The Commons decide whether to agree or disagree with amendments made by the Lords. They may vote on a controversial amendment. If they agree with the Lords amendments the Bill awaits the Royal Assent. If they disagree they may either propose an amendment in lieu or insist on their disagreement and draw up a Reason for this. The exchange between the Lords and Commons can continue so long as the Commons propose an alternative to the Lords amendment. However, should the Commons insist on their disagreement with the Lords for a second time the Bill is lost for the session.
Lords consideration of Commons amendments to Lords amendments		A debate on the floor of the House of Lords on the Commons amendments to the Lords amendments.	If the Lords agree with the Commons amendments or accept their Reason the Bill awaits the Royal Assent. If not, the amendment goes back to the Commons either with a Reason for insisting on their amendment or with an alternative amendment.
Royal Assent		Formal announcement in each House.	The Bill becomes an Act of Parliament with the force of law behind it. This need not be immediate. The Bill may specify a date from which it becomes law and different parts may come into force at different times.

A Public Bill usually starts in the House of Commons. However, a few start in the House of Lords and when they do, exactly the same procedure is gone through in each House.

Looking for the key

the first 21 years of ASBAH (1966-1987)

by Duncan Forrest, FRCS, Paediatric Surgeon,
Founder Member of ASBAH and
member of the Executive Committee

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The early days

I first came into the field of hydrocephalus and spina bifida in 1954 under the influence of my teacher George Macnab, a humane and modest man who treated hydrocephalus and spina bifida at the Westminister Children's Hospital and Great Ormond Street at a time when most surgeons felt they could do nothing and dismissed their patients without offering any practical help. Though we did not have much to offer in the way of effective operations, at least we could keep the patients on the books and give what aid and reassurance was possible. I well remember some of those pathetic early cases with uncontrolled hydrocephalus, twisted, paralysed limbs and hopeless incontinence. As Dr Michael Laurence showed at that time, as many as 16% of untreated spina bifida patients survived, but some of them had grotesquely enlarged heads and impaired faculties. Their numbers were not great, however, and they were widely scattered in the community without any mutual support.

I clearly remember a discussion I had in 1956 with Michael Laurence who was at that time Research Fellow in Pathology at Great Ormond Street studying the spinal deformity in spina bifida and the causes of hydrocephalus. We agreed that the current policy of leaving the raw wound on the back to heal slowly did not give the best chance of the nerves of the back to preserve their function and that led to thoughts about the best way to tackle patients at birth. Similar thoughts were going on in a few other centres, notably in Sheffield under Mr Robert Zachary and Liverpool under Mr Peter Rickham

Research Society

At the same time new ideas about the pathology and treatment of hydrocephalus were being aired, and out of this was born the Society for Research into Hydrocephalus in 1957. There was a small membership consisting primarily of Paediatric Surgeons and Pathologists and some Neurosurgeons but only one Paediatrician, Dr John Lorber. At first we were occupied with the numerous problems of hydrocephalus, but later, the other aspects of spina bifida received more attention and the Society was renamed to include spina bifida in its title.

Spitz Holter Valve

At about this time, in the United States, Dr Eugene Spitz was beginning to have success with a valve to control hydrocephalus by draining fluid into its natural place which is the venous bloodstream. Up till that time, attempts to do this had been frustrated by the lack of suitable materials, but when silastic became available, the situation changed. This new synthetic rubber is chemically and biologically inert, so it can be left in the body indefinitely without harm. But it was still necessary to have technical know-how. Dr Pudenz had also been working with silastic tubes but didn't have the engineering knowledge to make a workable valve. By good fortune Dr Spitz obtained the help of John Holter, an engineer whose son Casey had hydrocephalus. Together Spitz and Holter devised a valve that was so advanced in design that it is used almost unchanged to this day. Pudenz finally made a valve which also works satisfactorily though it is not of such logical design.

In 1958 Mr Macnab and Mr Rickham went to the United States to visit Dr Spitz and came back determined to try the new valve. Mr Macnab had the foresight to return with a valve in his pocket and so has the credit of being the first to insert a valve in this country. After that the demand increased. At first there was difficulty with payment for these expensive devises. The Department of Health ... toyed with the idea of manufacturing them ...before deciding that we should be allowed after all to import them from the United States.

Treatment at birth

The policy of encouraging early and active treatment was given a huge boost when in 1960 the Sheffield group published figures which seemed to show that infants whose backs were closed surgically within a few hours of birth actually gained some improvement in the power of their legs. This naturally encouraged many of us to operate on almost all cases at once and throughout the sixties paediatricians sent us all their cases. When we operated on them the intention was to save the function in the damaged nerves, not especially to save life. However, since they were given the best nursing care in specialised neonatal surgical units they often survived when they would not have done so with less skilled treatment. Consequently the sixties saw a huge increase in the number of survivors.

The beginning of ASBAH

In centres where active treatment was being undertaken, groups of parents had begun to come together for mutual support and information, seeking the help of professionals such as doctors, nurses, physiotherapists and social workers for the expert advice they so desperately needed. They were a group of parents with young handicapped children almost all under five years of age and mostly with all the problems of spina bifida, many of which had not yet been solved. Those few parents whose children had hydrocephalus alone felt a little remote from the main body. Local groups were formed and began to correspond.

It was in this atmosphere that ASBAH was born. I cannot remember exactly when our first tentative meeting took place, but it must have been early in 1965 and I remember a meeting in Mr Zachary's home in Sheffield where we had long debates about such important subjects as our title. We had to decide whether to use the term "spina bifida" which in those days was not widely known, or to use the more usual term "myelomeningocele" which some thought more precise but was certainly something of a mouthful and difficult to spell! I am glad that we eventually settled for "spina bifida". Mr Zachary who is good at word games, juggled the wording of the title round to give the acronym "ASBAH".

Another vital decision was over the structure of the Association. We debated whether there should be a ruling body with a number of branches around the country, but eventually chose to have a federal structure with local Associations keeping their independence but affiliating with and having a voice in regulating the national body.

At first we sought to call ourselves "The National Association" or "NASBAH", and we worked closely with the Scottish Association which had already formed. Unfortunately, Scotland eventually decided to go their own way, a great pity in my view, so we had to drop the word "National" in our title.

With all the details which had to be agreed, a constitution to be drawn up and an application submitted to the Charity Commissioners for charitable status, I am amazed on looking back, how quickly and with what good will it was all achieved.

The Association was officially incorporated in April 1966 under the rules of the Companies Act, we at first were obliged to call ourselves ASBAH Ltd. Eleven subscribers were named, guaranteeing to underwrite the Association in the event of its winding up. Three of us, Mr Zachary, Dr Lorber and myself represented the medical profession. The other eight were parents and other concerned persons with a number of professional skills, but, most of all, plenty of determination and good will. Some names such as Mrs Keeling, Mrs Foster, Mr Bartlett and Mr Hinchcliffe will be familiar to many of you.

Structure of ASBAH

An Executive Committee was formed and met for the first time on May 8, 1966 under the Chairmanship of Mr Zachary. The Minutes of this first meeting make fascinating reading. Much of the structure laid down then has survived to this day. Publicity, Editorial, Medical and Education sub-committees were formed. Methods of collecting and spreading information were agreed. The official journal was already in existence though as yet unnamed, and 5,000 copies of the first issue was ordered. A month later the name "Link" had been chosen.

Although there was only £250 in the bank, it was confidently agreed that we should aim for a target budget of £100,000. Forty thousand Christmas cards were ordered. Plans were laid for paid staff to be engaged by the beginning of 1967.

The response from around the country was enthusiastic. By November, fifteen local Associations had been affiliated. The wisdom of the decision to form a federal structure was clear when we discovered the fierce independence displayed by the local Associations. It took a great deal of diplomacy to show them that ASBAH had no claims on their autonomy or territory but existed only to give professional assistance.

With the arrival of new members the executive was strengthened by the addition of nine more including Mrs Cotsford, Mr Tallamy, Mr Breeze, Mr Frank Armour who became the first Secretary and Mrs Raymond who became the first Treasurer, soon to be followed by Mr Pointer.

We established cordial relations with other bodies and became a member of the Central Council for the Disabled.

First Secretary

The next landmark, only a year after our founding, was the employment of our first paid secretary and the renting of offices in Craven Street, Charing Cross, the whole enterprise to be funded by a campaign organised by professional fundraisers. By 1968 we had outgrown the Craven Street office and had moved to larger, but rather scruffy premises in City Road . It was just as well that at that time we had no physically handicapped members. It was difficult enough even for the able-bodied to fit into the lift and negotiate a rabbit warren of stairs and corridors! By then we had 34 affiliated associations. In the same year, the Rt Hon Horace King, later Lord Maybray-King, one-time Speaker of the House of Commons, became our Patron and later our President. For many years, almost till his death in 1986 at a very respectable age, he enlivened and disciplined our Annual General Meetings.

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In 1969 we appointed as General Secretary Miss Mary Oughtred, who, until her retirement in 1976, carried us through many crises both financial and political.

Research

It had always been our intention to encourage research into medical, educational and other aspects of spina bifida so to fund this expensive field the Spina Bifida Trust was formed. By the end of 1968 the Trust had approved requests for research grants totalling £120,000. From the first, the Medical sub-committee worked closely with the Society of Research into Hydrocephalus and Spina Bifida and it still draws heavily on the expertise of its members for advice.

Fund raising

Fund raising soon became too onerous for unpaid members. The first salaried Appeals Director was Mr Browning. He was followed by a resourceful and energetic young man married to a belly dancer. He had a passion for animals which proved incompatible with our aims. He set up a mobile zoo which he proposed to tow around the country to help us raise money. Unfortunately the connection between zoo animals, belly dancers and children with spina bifida was not obvious to the paying public and his expense account was always high. He left to work for a wild life organisation - more congenial pastures!

We were luckier after that with Mr Relph and then Mrs Kate White who put fund raising on a truly professional footing and made us financially secure.

With the new emphasis on active treatment and mobility, investigation and spread of information about equipment and appliances was important. An Appliance sub-committee was formed with Mrs Olwen Nettles, a Physiotherapist with vast experience, as Appliance Officer.

Working in the community

From the first, parents complained that nobody in the community understood their problems. It was obviously unrealistic to expect health visitors, social workers, general practitioners or district nurses to be experts in all aspects of care, and it was most worrying to parents to be given conflicting advice from all sides. Therefore, an early priority was research into welfare needs and this was set up in 1969. As a result by 1970 six local Associations had appointed Welfare Research Workers funded locally or centrally according to means. One of the best things we ever did was to appoint Mr H D Macfarlane as Liaison Officer in 1971. 'Mac' became one of the best known and loved characters in ASBAH, and long after his retirement in 1980 continued to be much in demand for his valuable advice and experience.

Royal Patron

In 1972 we received the Royal assent when Her Royal Highness the Duchess of Gloucester graciously consented to become our Patron.

The growth of ASBAH

Though fortunately we have never been torn apart by civil war as has often happened to other developing charities we have had heart searchings - such as over the purchase of Five Oaks, a valuable asset which has also at times been something of a financial millstone.

Much of the credit for the growth of the Association must go to all the paid and unpaid officers who worked so hard in the early days. Mention must be made of Mr Stubbs, Chairman of the Management Committee and Vice Chairman of the Association, of Mr White who ran the Appeals Committee, Mr Hinchliffe of the Training and Employment Committee, Dr Cohen and from 1975 Lady Jean Mackenzie of the Welfare Committee and Dr Lorber who chaired the Medical Committee for many years and wrote some of our early handbooks. Frank Armour, one of the first members, served as our first Honorary Secretary and then became the first salaried Financial Director until his retirement in our 18th year.

We have been most fortunate in our Chairmen, for the first eleven years Mr Zachary who masterminded our formation, then Mr Coleman, and Mr Bryant who stayed on long after personal commitments became pressing. I don't need to emphasise how lucky we are to have today a thriving Association headed by our new President, Sir Hugh Rossi, our Chairman, Mr Mackenzie and an Executive Director with the energy of Miss Moyna Gilbertson.

Changing needs and new problems

When the Association was formed the first need was to assure active treatment country wide for an infant population and to introduce what was then an unknown disorder to an ignorant and apparently uncaring public. At that time we believed, rather naively as it turned out, that active treatment and training throughout childhood would result in much diminished handicap. It was hoped that in most cases hydrocephalus would eventually become spontaneously arrested, so that shunt problems would disappear and intelligence be preserved, that early closure of the back, orthopaedic operations, calipers and physiotherapy would permit independent walking and that early care of the bladder would prevent kidney damage and make continence possible.

In 1970 it was becoming abundantly clear that these early hopes were much too optimistic. Early closure of the back did prevent paralysis from getting worse, but it did not lead to any real improvement. Many children as they got older found walking became an added bar to mobility. Most often the hydrocephalus remained shunt dependent and complications resulting in temporary blockage often caused more brain damage. Moreover, even if no complications occurred it became increasingly obvious that intelligence was often impaired in specific ways.

Many children with hydrocephalus were for the first time seen to have a poor attention span, experience difficulty in retaining lessons just learnt and to have trouble in sequencing, appreciating spatial relationships and co-ordinating hand and eye. All these defects combined to make education difficult and resulted in many children being labelled lazy or stupid. The natural frustrations of adolescence are often aggravated by feelings of inadequacy. Recently we have had a few worrying cases of deviant behaviour in young adults.

However, there has been one undoubted bonus from early shunting of hydrocephalus. We have been successful in preventing the grotesque growth of the head we used to see in untreated cases.

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In spite of every attention to the bladder, some children's kidneys progressively deteriorated, leading eventually to kidney failure. Diversion of the urine to an ileal loop was for some years the standard method of achieving control of the urine and preserving the function of the kidneys. However, ten and twenty year follow up studies seemed to show that kidneys still failed in spite or perhaps because of the operation so it fell into disfavour.

Massive surgery to correct paralytic deformities of the spine and lower limbs failed to produce efficient walking in spite of vigorous physiotherapy and improvements in the design of calipers.

Dr Lorber reported all this from Sheffield in 1970 and suggested criteria by which bad cases could be recognised at birth. This led to a rapid turnabout on the part of many paediatricians round the country who started selecting patients at birth and withholding treatment from those they considered too badly handicapped to survive. Consequently the number of babies treated actively fell dramatically.

Screening

The next step was the development of methods of screening for spina bifida before birth. Some of this research was sponsored by ASBAH. For the first time parents had the agonising necessity of choosing between having the pregnancy terminated or continuing it in the knowledge that their baby would be born handicapped. This has been mistakenly called 'prevention', but of course it is no such thing.

Prevention

The first attempt at true prevention was trying to isolate factors in the mother's diet that could poison the fetus. An early claim that blighted potatoes were to blame received a great deal of publicity but did not stand up to impartial testing.

A more realistic idea was first investigated by Dr Laurence who received a grant from ASBAH as long ago as 1968 to try to find out the role of folic acid deficiency in producing spina bifida and other neural tube defects in humans. Professor Smithells in Leeds further tested the theory by giving a vitamin cocktail containing folic acid to mothers before conception and for the first three months of pregnancy.

The outcome seemed to show clearly that it is possible to prevent spina bifida. The Medical Research Council is now attempting to prove the theory beyond doubt in the hope that the Department of Health will be persuaded to prescribe vitamins for all potential mothers. They have just taken the first step of making Pregnavite Forte F available on prescription.

All these developements have generated grave ethical problems which have led to agonising debate, often aggravated by ill informed coverage in the press and other media. ASBAH has always taken the view that we cannot take official sides in these debates. In order to continue offering a service to all who need help, we must remain neutral, while trying to understand and sympathise with any reasonable viewpoint of our members.

Those being born today

At the present time the number of patients being born with spina bifida is about one tenth of what we saw in the 60's. The hope that it is a dying disease is unfortunately, not realistic. There will always be mothers who have no ante natal care, those who refuse termination of pregnancy, or those whose screening fails to reveal the defeat. Nevertheless, we can be confident that we will not see another epidemic such as the one that occurred during the early days of ASBAH.

The diagnosis of hydrocephalus on its own was often difficult in the early days. The development of sophisticated ultrasound equipment has made pre-natal diagnosis common and post natal supervision much easier. Ultrasound is no use after the skull had completely closed, but new methods of imaging with the CT scan and more recently Nuclear Magnetic Resonance have made diagnosis and monitoring of hydrocephalus and spinal deformities much easier and more accurate in children and adults. This has been a huge step forward.

Into adult life

In the past five years we have been conscious that we have not succeeded in treating and educating our young patients well enough to made the best of their potential. Now that many of them are reaching adult life, our task is to try to fit them into an independent life in the community. Some will never achieve this, but I am certain that, with the experience we have gained from the first generation, we can find ways to do better in future. One way we have tried to help the young people is to encourage them to run their own affairs by creating their own subsidiary of the Association, LIFT. This has successfully demonstrated that, with the right kind of help, they are fully capable of remarkable achievements.

One problem that has not been solved results from the fact that for historical reasons, several of the most active treatment centres in the country have been based in Children's Hospitals because paediatric surgeons have been the prime movers. That arrangement works well for children by concentrating all treatment under one roof with only a few separate specialists involved. It makes life difficult though when the children grow up and have to move to adult units which, because there is no local expertise among adult specialists, are often unsatisfactory. We have been aware of this for some years and the Department of Health has offered help, but nothing can be achieved until we can enthuse selected suitable centres with the need for an integrated service and staff them with properly trained staff. In other places, where neurosurgeons have given the initial treatment for the spinal lesion and the hydrocephalus, well planned Spina Bifida Units have arisen, able to make the transition from child to adult care more smoothly.

Hydrocephalus on its own

It is now becoming clear that the needs of those people who have hydrocephalus, with or without spina bifida, though not so obvious are just as intractable and need detailed study. Furthermore the number of new cases of hydrocephalus on its own does not seem to be declining, mainly because of the number of very premature babies that now survive. We are trying, by forming a Hydrocephalus Support Group to bring this section into closer contact and we have just completed a new video film devoted to the subject.

The future

Several new ideas for treatment have been on the stocks for some years and are now reaching the stage of practical application. In the treatment of hydrocephalus, we have learnt a great deal about the two main complications, blockage and colonisation and are more successful in recognising them and preventing their ill effects. Dr Roger Bayston has worked for many years, partly as our Research Fellow, on the subject of colonisation and is still very active.

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There are now many different makes of valves to choose from. They all work on the principle of the original Holter or Pudenz valves with a pre-set pressure rating to suit the individual patient. However, an infant may need a low pressure valve but be more suited to one of higher pressure as he grows. Usually we have left the original valve in place and the patient usually compensates fairly well. Perhaps we should change to a higher pressure valve more often. The search for a means of changing the pressure rating of a valve without an operation has at last resulted in two makes of programmable valve which are now being tried in a few patients. This looks like a major breakthrough and I predict that they will soon be the accepted choice for insertion in infancy. Thus, we should in future be able to avoid some of the complications seen in today's teenagers.

Orthopaedic operations, after a period of disillusionment, are becoming more rational and well thought out. Correction of spinal deformity, formerly a major undertaking necessitating months of immobilisation, is now much less traumatic and more successful. Mr David Scrutton in his speech at ASBAH's AGM in 1986 gave us a very clear picture of the possibilites for ambulation. The use of computerised electrical impulses to stimulate the leg muscles is still a dream. It may possibly be applicable to a few patients one day.

Much progress is being made in the realm of bladder control. Intermittent self catheterisation has received much publicity and, when it works, is certainly life enhancing but it is successful in less than 50% of cases, so there are many who require other methods. The artificial sphincter has been around for many years gradually being improved and refined until now it is a very practical proposition, rather handicapped by its price tag of £2,000. Again, it is suitable for only a minority and the necessary operation is by no means always successful, but increasing numbers of patients are treated.

We are about to set up a research project which I hope will eventually give us some information about long term results. There are bound to be further developments along these lines as well as in other operations to improve the function of the bladder. For many years Dr Brindley of the Institute of Psychiatry has been working to perfect a method of encouraging emptying of the paralysed bladder by stimulating the spinal cord directly with an implanted electrode. He has succeeded with some adults with certain forms of acquired paralytic disease. I believe that some spina bifida cases may eventually prove to be suitable for this treatment.

ASBAH's slogan in its 21st year is "Still Looking for the Key". I think that really we should say that we are still looking for a whole bunch of keys. We are sponsoring research into the causes of spina bifida and hydrocephalus, we are looking hard at methods of genuine prevention, as well as improved forms of treatment, training and care. In all these fields there is no single answer, but a whole spectrum. Though we have certainly come a long way, there is still further to go in many directions.

There is no doubt that ASBAH will have an important role to play in the next century. It is our job to start planning it now.

This article follows closely the address given by Mr Forrest at ASBAH's 21st AGM in September, 1987

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Letters

Limited access to Pump Rooms and Roman Baths

This letter from Architects, Feilden Clegg Design of Bath , follows earlier correspondence in LINK concerning lack of good facilities for disabled visitors to Bath's major attraction

Mr Hunt of Bath City Council has passed on a letter of July 14 in connection with disabled access to the Pump Rooms and Roman Baths.

We have been looking into this issue in some detail and believe that there should be no problem in obtaining access to the Concert Room which is the main entrance to the complex, the Pump Rooms and the Terrace around the Great Baths. This should enable wheelchair users to get a reasonable view of the Great Bath and there will be possibilities of views of Kings Bath although this will be rather more restricted.

As architects for the scheme we have done our best to improve the situation, but I regret that there will still be no access to the lower levels. I hope that this information is helpful.

Richard Feilden
Feilden Clegg Design,
Canton Place, Bath.

Hydrocephalic children: problems with toys or learning equipment

I am completing an In service B.Ed degree in Design and Technology at the West Glamorgan Institute of Higher Education in Swansea. As part of the course I have to undertake a problem study related to the area of Design and Technology.

As the father of a three year old hydrocephalic son, I am particularly interested in researching the handicaps/disabilities commonly associated with hydrocephalus and brain injured children and my project aim will be to identify a specific need or problem encountered by these children and then design an 'aid ' to help resolve it.

I would very much like to hear from parents of hydrocephalic children what problems or needs they feel their children have encountered with either toys or educational learning equipment and how they feel such toys/equipment could be improved.

I. Raymond
14 Somerset Road, Bridgwater
Somerset, TA6 5NT

DHSS Equipment Evaluation:

Wheelchair Cushion Summary

I am updating the 1984 wheelchair cushion report by Peggy Jay, and would welcome assistance from your members or readers.

The main requirements are:

1. They should be wheelchair users
2. The wheelchair should have a sling seat
3. The wheelchair is in use for a minimum of 30 hours per week
4. The wheelchair should not be reclining or semi-reclining
5. They should be using a cushion (including DHSS foam) or have need of a cushion.

The study will also include bath and WC (toilet seat) cushions, and cushions for children's wheelchairs so any information from users would also be welcome.

I will be carrying out an evaluation study so am looking for suitable participants in the London (Home Counties) region. I would be happy to visit them in their homes. It is hoped that the project will be completed by January 1989.

S E Tuttiett
Research Occupational Therapist
Westminster Hospital, Dean Ryle St
Horseferry Road, London SWIP2AP

Toy libraries can help

I was interested to read the letter from Carol Sloane in Link (July/August) entitled "Make sure your child can cope with the toys you buy". I was pleased that she was able to find such helpful assistants in the toy shop.

May I draw your readers' attention to another source of advice about toys suitable for children with special needs? The first toy libraries were set up to meet the needs of these children and a large number still do so. An increasing number of toy libraries are providing a service to all families in their area including those with children with special needs. Toy Libraries not only loan carefully chosen toys but provide support for parents and other carers. Many have a regular visit from a professional - health visitor, teacher, physiotherapist, for example. While the majority are set up and run by parents, a growing number are being established in connection with statutory services.

If any readers would like to know the whereabouts of the nearest toy library or are interested in setting one up we would be very pleased to help.

Lesley Houlston
Information Officer
National Toy Libraries Association
68 Churchway, London NW1 1LT

Unorthodox or alternative therapies?

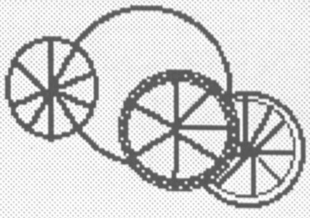
I am looking at the possibility of cataloguing and presenting a new publication with information on 'unorthodox' or 'alternative' therapies that are employed from time to time in the management of children with developmental disabilities or chronic neurological disorders. Any ultimate publication would seek neither to support nor condone such practices, but to inform..........

I will be grateful, therefore, for any information that your members might be able to provide on such therapies (however defined) preferably with the names and addresses of relevant practitioners. I should add that my interest is in therapies that have their origins in developed countries or have significant support in such countries. I undertake to maintain confidentiality in respect of my sources of information.

Gwilym Hosking
Consultant in Paediatric Neurology
Ryegate Children's Centre,
Children's Hospital, Tapton Crescent
Road, Sheffield S10 5DD.

Wheels within wheels

- loading a wheelchair into a car



More and more young people with spina bifida are learning to drive a car and are becoming competent road users but, often, the vexed question remains of how to load the wheelchair into the car, when they are on their own. If all else fails there is nothing wrong in asking someone else to do it providing instructions on how to fold and lift the chair without damaging car, clothes or the helper's back, are competently given. Loading the wheelchair is rarely taught in schools or colleges. Although independent transfers are practised and encouraged, it usually stops there. Naturally, as a result, the impression is given that this skill is for others to perform or that some sort of gadgetry will be necessary. Advertisements or demonstrations of special adaptations are seen and, occasionally, fitted to the car, at considerable expense. Often a simpler method at no cost at all would have been quite adequate.

Many people with spina bifida have strong shoulders and arms although their backs may be weak and this varies from person to person. A great number of disabled people are capable of loading their wheelchairs manually once shown the method. With practice this can be done with a minimum of effort. Some will find this too much of a strain - usually because the muscles in the spine are paralysed and the spine may have a curvature which places them in a position of mechanical disadvantage. It is always worth trying to load the chair manually first because (a) it is the cheapest method, (b) it may further develop muscles thus assisting in other transfers (c) electrical apparatus, no matter how good, sometimes has the knack of going wrong (d) the driver is not limited only to driving his car, providing hand controls are fitted.

The following is a brief description of the various methods of stowing the wheelchair.

There are three requirements to consider before discussing any method, apart from Car Chair..

1. The ability to get in and out of the car unaided ie. independent transfer
2. The ability to dismantle the chair, take off the footplates, fold down the back, fold the chair and remove arm rests if necessary, to reduce the weight and size.
3. Whether to have a two-door or hatch back car. The two-door car has a wider door and space behind the front seats in which the chair can be stowed. If the driver is able to walk a little with the aid of calipers and, or sticks, in a hatch-back car it is possible to sit on the boot and pull the chair into the boot and then walk around to the driver's door.

Manual Loading

Ideally, this should be done from the passenger's side as it is safer being away from passing traffic. Firstly, transfer into the passenger's seat (PS), dismantle and fold the wheelchair and pull the smaller wheels up and over the sill behind the seat. The chair will balance on the large back wheels at right angles to the car. The occupant then moves across into the driver's seat (DS), folds the PS forwards, reaches across and pulls the chair into the car behind the front seat. The seat back is moved upright again and this holds the chair in place. The reverse procedure is followed to unload the chair. If it is rather a stretch to reach the chair to pull it in, a piece of cord tied around the uprights will assist and lessen the gap.

There are one or two adaptations which can facilitate this operation. If the gear selector and handbrake are obstacles to moving from the PS to DS, they can be made to collapse down whilst the transfer is accomplished. Where it is awkward to reach the release catch for the back of the PS from the DS, the two seats may be transposed to bring the release catch within easy reach. A grab stick or a cord attached to the passenger door may assist in closing it from the DS. The seats may be given some lateral travel to narrow the gap between seats, or seat and door, when transferring. The PS may be narrowed to provide a space beside the seat for storing the wheelchair.

NB With some makes of wheelchair eg. Barratt, it may prove easier to pull the larger wheels in first and then to tip or rotate the chair to rest on its back rather than roll it in upright.

Transfers straight into the DS may require the addition of a sliding/swivel seat in order to bring the seat out of the car and leave room for loading the chair. If the driver is slim or fairly agile this will not be necessary - the back of the DS has to be held down with one arm, and the driver is, therefore, squashed between the steering wheel and the seat back whilst pulling the chair into the car. Once the chair is in, all is well and the seat can be slid back to hold the chair in place and allow comfortable arm room for driving.

Some disabled people with strong shoulders and trunks, lift the chair bodily and heave it onto the back seat or PS. If they have a hatch-back, they may climb into the car this way, pull the chair in and wriggle through into the DS: "Chacun a son gout".

It illustrates that physique, size, agility and strength all help to decide which method is most appropriate.

Electric Hoists

If the weight of the chair proves too much (this is where lightweight chairs come into their own) and the back or shoulders are under strain, then a small hoist may be fitted to whichever side or part of the car is most convenient. This will eliminate having to lift the chair manually - it

continued on next page

Wheels within wheels

continued

will only need guiding into position. The hoist is operated by a switch and, if fitted in conjunction with a sliding/ swivel seat on the driver's side, solves the problem.

NB A great deal can be done to seats in size and angle. The seat can be made to slide sideways, swivel, rise and fall; mechanically or electrically.

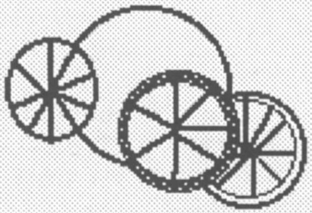
Loading the Wheelchair onto the Door (Autobility)

This is an elegant way of stowing the chair if it cannot be managed manually or with a hoist. A special chair may have to be purchased with the mechanism or an existing chair modified, in order that the nearside wheel may be removed to make room for the chair beside the driver within the car.

Again independent transfers and wheelchair folding skills are necessary for this method to be successful. The only other effort required is in sliding the chair onto the hooks on the door and removing the wheel to stow it behind the seat. The mechanism is operated by a switch. It is slightly awkward having to reach through the chair to close the door but with practice this should not be a problem. It is a snug fit with chair, occupant and hand brake, but this provides stability in the driving position, particularly for those with trunk weakness. The position of the seat and the steering wheel have to be altered and this could affect re-sale value.

Loading the Wheelchair onto the Roof (Autochair, Gottlieb-Zair)

Again there is the common denominator - the ability to transfer and fold the chair. In this method the chair is stowed on the roof of the car under a sleek fibre glass cover thus reducing the wind resistance which will obviously occur with raising the height of the car. The mechanism is easily operated by switches. Perhaps the fibre glass topping is too noticeable for people who do not wish to advertise that they are disabled. However, it does leave the inside of the car free and is particularly good for a family.



The whole apparatus can be moved from car to car when selling. Petrol consumption will be raised but, unless high mileages are contemplated, this should not be too burdensome.

NB Chair-up is no longer in production.

Car Chair

This a a mechanism whereby the chair and occupant are loaded into the car together. The chair has to be purchased as well as the mechanism.

Very few people with spina bifida should require this method of loading themselves and their chair because it is for the very severely disabled ie. people with considerable weakness of shoulders and elbows or severe stiffness, making them unable to transfer. Large people do not find this easy to use because as the chair swings in they have to duck their heads, or be decapitated, and there may be insufficient room for the legs to clear the door pillar at the front. There are, however, a few people for whom this is the answer and will give them total independence or allow a frail companion to assist them into the car as no strength is required to operate the mechanism.

Summary

From this it is clear that it is a case of "horses for courses". Personal advice is essential on these matters and it is as well to consult a Mobility Centre Few people are in a position to discount the cost and often the most expensive method is not the best solution. Certainly, for most people with spina bifida, the cheapest method is the best for reasons quoted. It is often worth asking friends who have worked through the problem. They may allow you to practise on their car. A word of warning - throw an old rug or blanket over the sill of the car to avoid chipping or scratching the paintwork. Also consider the wheelchair itself - is it the best one for your needs or would a lightweight chair be easier to manipulate and load?

Prices

These can vary from nil in the case of manual loading to between £400 - £500 for an electric hoist and seat modifications. Door or roof stowage will cost well over £1,000 and Car Chair starts at £2,300 and may go up to well over £5,000. Exact prices have not been quoted because they change and modifications may require individual tailoring. It will be necessary to discuss the cost with the conversion specialist direct.

Everyone is different and has different needs and different preferences so do give this subject careful thought if it applies to you and SEEK ADVICE.

LEONIE HOLGATE, MCSP
ASBAH Disabled Living Adviser

Mobility Centres

Banstead Place Mobility Centre Park Road, Banstead, Surrey SM 3EE Tel. 07373 51674

Derby Disabled Driving Centre Kingsway Hospital, Kingsway, Derby DE3 3LZ Tel. 0332 371929

Mobility Advice and Vehicle Information Service (MAVIS) Department of Transport, TRRL, Crowthorne, Berks RG11 6AU Tel. 0344 779014

Mobility Information Service Unit 2A Atcham Estate, Upton Magna, Shrewsbury, SY6 6UG Tel. 0743 77489

Vehicles of the Disabled Centre Astley Ainsley Hospital, 133 Grange Loan, Edinburgh EH09 2HL Tel. 031 447 6271

Wales Disabled Drivers' Assessment Centre 18 Plas Newydd, Whitchurch, Cardiff Tel. 0222 615276

Reference Books

'Ins and Outs of Car Choice' published by Department of Transport.

'Motoring and Mobility for Disabled People' by Ann Darnbrough and Derek Kinrade. Published by The Royal Association for Disability and Rehabilitation.

THE FREEDOM OF AMERICA

from page 9

disco in the hotel in the evening will all be remembered. It really was a beautiful place.

It is impossible to go into detail about all that we saw and did. But I must mention those things that made the holiday outstanding - the care and concern of the travel agents, John and Dorothy Brown of Panovista Travel, Sunderland, who were with both groups all the time, and did everthing they possible could to help, and advise. Their knowledge of Florida was invaluable and their patience unending; the personalities, and lifting power of J-J, Bert and Angel, our irrepressible drivers and lifters; the friendliness of the staff at the two hotels - in particular at the Continental Royale, Nothing was too much trouble for them.

The biggest drawback was the fact that we had no accessible transport for our journeys - and at Orlando we went somewhere different almost every day. The cost and availability of transport for as large a group as us proved impossible. So instead, Panovista had arranged for the three strong lifters. With the aid of canvas carrying seats - Transit Seats - they were able to lift everyone in and out. In fact they made such a good 'performance' of it that the lifting process became quite the highlight of the day, especially for the girls! Bert, Angel, and J-J will feature in many of the photographs taken! Nevertheless it did take quite a time and meant that quick trips to restaurants or anywhere else in the evenings became a major task. Obviously tail-lift buses would have been easier, but perhaps not quite as much fun for some. Certainly the transit seats were a boon and are strongly to be recommended to other groups where lifting is necessary.

What else shall we remember? The doggy bags automatically given in restaurants if you can't manage al the steak and wish to take it home; the number of really overweight Americans we saw (it made us all feel quite slim); the strange breakfasts which included sweet toast and grits, wonderful range of food, marvellous shopping malls, cold beer and coke ("easy on the ice, please"), television full of advertisments, Mickey Mouse soft toys; and the frequently heard - "Have a nice day".

Our flight back was a little delayed and we wished we hadn"t had to fly via Manchester, both on the outward and return journeys. It was a tiring flight but the staff were helpful. We pushed those in wheelchairs to the door of the plane and then British airways staff took over and lifted them into their seats. The chairs were stowed away in the hold.We did have one wheelchair damaged on the way out to Orlando but British Airways with the help of Panovista lent the owner- Tim Vicary from Rye, East Sussex- another for two or three days until the repaired chair was delivered to the hotel.

Tim was unfortunate, too, that he was ill for a day or two at Orlando and had to go to hospital for a check-up and some medicine.. It was nothing serious and he was back at the hotel the same day . However, the bill was very high , but fortunately it was possible to pay by credit card there and then, and the medical insurance meant that the family were re-imbursed when they got home. Fortunately Tim soon recovered and was able to enjoy the sun at Clearwater and get the start of a respectable sun tan.

We all came back a different colour, and the scene at the airport when we said goodbye was a very tearful one.

Many have kept in touch since then. It was a unique occasion for ASBAH members from different parts of the country to get to know each other, as well as being an exciting value-for- money holiday.

PHYSIOTHERAPY

HELP US TO HELP YOU

We are receiving disturbing reports regarding the availability of physiotherapy and will be carrying out a survey to estimate the size of the problem. If necessary we will press for improvements in this service.

A questionnaire will be sent with the December Bulletin.

Copies are available from National Office. Please contact Pat Corns or Susie Dobson.

FLAT VACANCY

STEPPING STONES is a new housing project for young people with spina bifida and/or hydrocephalus managed by Trafford and Salford ASBAH.

The development is conveniently situated in Stretford, Manchester, and is due to open in January 1988. There will be four self-contained flats and an office to be used by the local ASBAH. Each flat will have an emergency alarm system and tenants will receive support from the statutory services and the local association.

There is still a vacancy for one of the single person flats. Anyone interested in applying should contact Miss Carolyn Smith, ASBAH's Accommodation Officer at ASBAH in London as soon as they can.

Newslines NEWSLINES Newslines

GCSE: ARRANGEMENTS FOR CANDIDATES WITH A DISABILITY

●Comprehensive guidance notes which explain arrangements for candidates whose disability is likely to handicap them in GCSE examinations, have been prepared by the six GCSE Examining Groups. The Guidance Notes were welcomed by Richard Stowell, Director of the National Bureau for Handicapped Students (NBHS) who described them as 'practical and reassuring'. A Working Party co-ordinated by NBHS has been working closely with representatives of the Examining Groups and played a vital role in collecting information on current good practice which has been included in the Guidance Notes.

The Guidance Notes will be included in documents published by Examining groups and will be available to all colleges, schools and examination centres and will offer information to staff preparing candidates with special educational needs for the new GCSE, as well as students themselves.

The purpose of special examination arrangements is to compensate for the limitations imposed by the handicap, but not otherwise to advantage the student.

The Joint Council has also approved the setting up of an Advisory Committee comprising staff representatives of the Examining Groups and professionals with experience of the needs of disabled students who are handicapped in examinations. The Committee will provide an informed view on the introduction of GCSE as it affects students with special educational needs. It will bring to the attention of the Examining Groups information on technological and other developments, which affect the study and communication methods of candidates with disabilities, will analyse reports from Examining Groups on the implementation of the new guidelines, and make recommendations about any necessary revisions to Joint Council policy in this area. It can be contacted via the Secretary to the Joint Council for the GCSE.

Any organisations or individual candidates or their parents who would like information about provision for candidates with special needs should contact the relevant Examining Group.

More information from Ms Sylvia Simmons, Development Officer, NBHS. Tel: 01 274 0565.

TAKING A BREAK

A guide for people caring at home

Advice on arranging time off for anyone who looks after a relative or friend who is elderly, ill or disabled

●If you are caring for someone at home, write for a free copy of this guide to:

Taking a Break,
Newcastle-upon-Tyne,
NE85 2AQ.

Professional and voluntary workers can buy single coies at 60p each. Bulk supplies available too.

●*Working Together Towards Independence*
by Judith Male and Jean Ward

This publication gives practical information on ways to assist physically disabled school children and suggests how non-teaching assistants (NTAs) can help to encourage their independence. It is written for NTAs but will be helpful to all those working with these children. It is liberally illustrated.

Price £1 plus 20p post and packing from the publishers: *RADAR, 25 Mortimer Street, London WIN 8AB. Tel: 01 637 5400.*

●Alan Hughes who is slightly disabled himself, and therefore has an insight into some of the problems confronting disabled motorists has set up a service offering advice in purchasing a car and help with conversions (any make).

Mr Hughes is at Dartford Disabled Driver Advice Centre, Whitehouse of Dartford, 474 Princes Road, Dartford, Kent DA1 1YT. Tel: 0322 77231

●The National Handicapped Skiers Association has been formed to co-ordinate a structured system of courses for instructors to teach the handicapped to ski, to provide suitable facilities and to develop appropriate aids. Another aim is to integrate the handicapped with able-bodied skiers. The Association believes that people with a very wide range of handicaps can ski and that skiing encourages fitness, provides exhilaration, encourages independence, gives freedom from "the locks of disability' and increased confidence in life.

For the last two years it has run courses for registered instructors, who have taken back new skills to their own dry slope s.

If you would like a leaflet about the Association the address is: The National Handicapped Skiers Association, Harlow Ski School, Hammarskjold Road, Harlow, Essex CM20 2JF. Tel: 0279 21792.

Getting between London stations and out to Heathrow should get easier if you are disabled. Carelink will be relaunched early in 1988 - wheelchair accessible small buses linking the major London stations (and Liverpool Street will probably be included). Airbuses operating every 20 minutes from Victoria to Heathrow are being converted to take two wheelchairs each, and will be in operation any day now.Please try and use both services Contact Pat Corns at ASBAH for details or ring London Regional Transport's Unit for Disabled Passengers
Tel: 01 227 3176 or 3299

Slim Flegg who is disabled through polio tries out the steps leading to the Kennedy Memorial, Runnymede

OPEN HOUSE?

The National Trust has suffered a good many brickbats over the years from disabled people as anxious to enjoy the nation's heritage as the next person, but often only able to get a very second class view of it all.

The Trust is trying to do something positively to open its doors to everyone. Valerie Wenham is a special National Trust Officer for Facilities for Disabled Visitors and visits all parts of Britain each year to look at what the Trust is doing in this direction, and then to set about improving facilities. This includes provision of powered chairs at some properties, good level paths, and liaison with architects to provide as much accessibility and special facilities as possible.

Mrs Wenham said "We have about ten million visitors to our buildings and gardens each year and unknown millions more visit our coast and countryside. .. statistics tell us that ten per cent of these visitors have some measure of physical, mental or visual disability ...it is a vast number of people for whom to cater."

Where possible Mrs Wenham visits the properties with someone who is disabled. "It is quite invaluable to have the advice of someone with first hand knowledge of what disability means when I am advising on access and facilities at Trust properties".

The Trust produces a free booklet *Facilities for Disabled and Visually Handicapped Visitors.* For a copy or for more information from Mrs Wenham, the address is: The National Trust, 36 Queen Anne's Gate, London SWIH 9AS. Tel: 01 222 925I. Please send s.a.e for the booklet.

At the Northamptonshir manor house of Canons Ashby, Brian Scarff of Towcester tries out one of the new wheelchairs given to the National Trust for its properties all over the country by Everest and Jennings.

APPEALS NEWS

Susanne Webb with Postman Pat and cat Jess. The boilermakers Fun Day helped raise money for an electric wheelchair for her -see Bridge Stroll (below). Photo: Croydon Advertiser

LUCKY FOR US

A special gambling evening in the Summer was held at the Edgware Road showroom of Nissan Colindale motors. Friends and clients were invited to try their luck at the roll-a-dice competition and gaming tables to win prizes and raise money for ASBAH

BIKING IN THE RAIN

The third Fun Bike Day took place at Kennett, Newmarket in September. A sustained torrential downpour did not add to the pleasure of the day and attendance as a result was disappointly small.

BRIDGE STROLL

Last year the members of Ruskin House, Croydon - the social club belonging to the General and Municipal Boilermakers and Allied Trades Union - raised a large sum of money for ASBAH by a sponsored walk from Brighton to Croydon. This year they headed for London and walked the London bridges. As a result of which they again presented a handsome cheque to us. In between times they raised money through a Fun Day for an electric wheelchair for the daughter of the Ruskin House Manager, Susanne Webb (see photo)

172 MILES ON EUSTON STATION!

On September 21, Lenny Denton from Southend, who last year pushed an outsize wheelbarrow from John O'Groats to Lands End and thence to London, rode an exercise bike for 12 hours on the main concourse of Euston Station. Several hundred pounds were raised and Lenny 'covered' 172 miles - a really prodigious effort.

BEAUJOLAIS CHALLENGE

All readers of LINK have had opportunities to support this event through sponsorship, and we hope that as many people as possible will respond as soon as possible and return the sponsorship forms if they have not already done so.

STOCKING UP

In addition to the ASBAH shops previously reported we have now acquired new premises in the Southampton suburb Swaythling. Go and visit it if you are in the area - you might find a bargain.You can get the address from ASBAH's Appeals Department of this and any of our other shops.

COO - ANOTHER SHOW AT BLACKPOOL

We have been invited to take at stall at the British Homing World Show of the Year at Blackpool on January 23,24, and of course, we have accepted with alacrity.

TO THE DOGS - AGAIN!

There will be a second charity greyhound meeting for ASBAH at Wimbledon Stadium on Tuesday February 23 next year (1988). More details from ASBAH Appeals office if you'd like to be there.

A RACING CERTAINTY

Richard Poole, one of our Appeals Organisers will once again be planning an ASBAH charity day at Ripon on Saturday April 30, 1988.

LET'S HAVE A GOOD CONVERSATION

The Conversationalist of the Year contest (previously known to most people as the Chatathon) will take place on April 23,24 at Glaziers Hall, London Bridge.

London Broadcasting Company are taking over the sponsorship from Taylor's Port. It is their wish that the event should go 'up market' and that the word *Chatathon* should not longer be used. *Chatathon* is now such a familiar word that we may need the help of a swear box to phase it out!

FOOTBALL MATCH POSTPONED

The hopes expressed in the July/August issue have unfortunately not been fulfilled. Arrangements were far advanced for two matches at Leeds on October 13 - one between teams of old England and old Scotland Internationals and the other between Leeds United and the Scottish Cup holders, St Mirren. Unfortunately, the Scottish Football Association - for reasons no-one else has been able to comprehend - refused permission for St Mirren to appear.

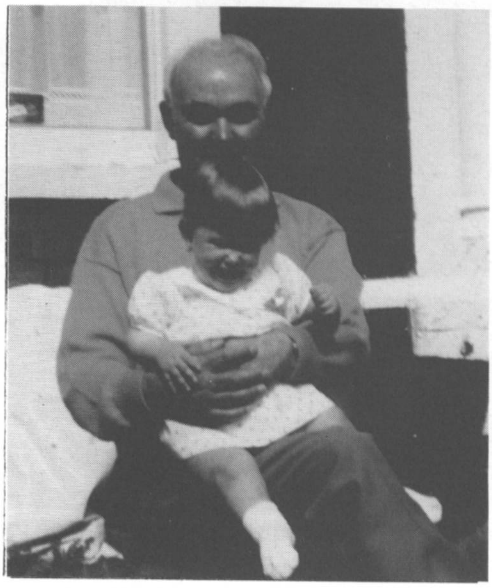
Work is now going on to recruit an English First Division Club to replace St Mirren as opponents for Leeds United later in the year. Please contact ASBAH Appeals Department for details

TO SOPHIE.................

THE PROUD grandfather of Sophie Woodham of Barry, South Glamorgan, wrote a special poem to celebrate her first birthday. Sophie was born with spina bifida and hydrocephalus and her parents were told she would not live 48 hours. LINK has printed part of the poem......

The party's over, the day is done,
You're at the close of birthday one,
And as I look back o'er the year,
That started with despair and fear,
I wonder who would have been so bold,
With confidence foretold,
We would celebrate this Special Day,
"No hope", was all the Doctors had to say.

But here you are now well and strong,
Home at last where you belong,
And though our worries do not cease,
You seem to have an inner peace,
You have an ever-ready friendly grin,
For anyone who may drop in,
And a sparkling, bubbly personality,
With a very special ability,
Instantly to give so much
Pleasure to all whose lives you touch.



Sophie Woodham enjoying herself with grandad

Sometimes with me you'll stay the night,
We'll wake together in the morning light,
You peep at me through the cot side-rail,
No cry from you, no hungry wail,
Just a smile that lights the room,
Dispelling fleeting thoughts of gloom,
A cheery smile which seems to say,
Don't worry grandad - I'm here to stay

from Grandad

Advertising

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

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

Cheque or postal order payable to 'ASBAH'

Adverts for the next LINK (Jan/Feb) should be in by December 20. Send to: **The Editor, Mrs Sue Gearing, The Gables, Long Lane, Wrington, Avon, BS18 7NE. Tel: 0934 862279**

HOLIDAY ACCOMMODATION

BORTH, Nr Aberystwyth. 6-berth de luxe holiday home. Licensed site. Suitable for wheelchair users who live independently. Details: Mrs J. Carter, 1 Meadow Road, Craven Arms, Shropshire.

EXMOUTH, Devon. Fully equipped, self-catering 2 -bedroom bungalow. Sleeps 7. Full central heating. Details: Herts & S.Beds Association. J. Harper, 70 Grove Road, Harpenden, Herts. Tel: 05827 69213

ISLE OF WIGHT. Very well equipped chalet with easy wheelchair access at **Brambles Chine, Freshwater.** Sleeps 6. Indoor heated pool, club, shop.Details: Ring or write: Mrs S. Gully, Old Princelett, Apse Heath, Sandown, Isle of Wight. Tel: 0983 863354

SELSEY, Sussex. Six berth purpose built fully equipped mobile home. Ramp access. Site near sea. Pool, club, etc. Details: Mrs C. Bugden, 27 The Grove, Sholing, Southampton SO2 9LT. Tel: 0703 444921.

WESTWARD HO, North Devon. Holiday Bungalow. Sleeps 6. Excellent beach. S.a.e. to : Mr G.L.Oakley, 12 Farleigh Road, Perton, Wolverhampton. Tel: Wolv. 751484.

WINTERTON ON SEA, Nr Great Yarmouth. Chalet bungalow. Sleeps 6. Fully equipped. Bathroom, toilet. Accessible for wheelchairs. TV. Shop. Take -away. Club room (live music). Children's play areas. Heated indoor pool. Details: Mr R. H. Morris. Tel:0494 32184.

Two luxury bungalows, fully adapted for wheelchairs, set among magnificent pine trees in the heart of Clwyd, yet minutes from old market town of Mold. Lovely private south-facing gardens, patio, barbeque, telephone, etc. Sleep 4/6.
Brochure: Mrs Lynne Dowling, 23 Gleneagles Road, Great Sutton, South Wirral. Tel: 051 339 5316, or 051 355 1005

WHY DON'T YOU
ADVERTISE IN
THE NEXT LINK?

EXCHANGE AND MART

FOR SALE

Braune Battery Car. Good condition, complete with hood. Aprox. 4 years old. £500 o.n.o.
Contact: Mr R Linton tel: 0266 2516.

Malden Minikart
Suit child 3-6 years. In need of repair. £50.
Apply in writing to The Occupation Therapist, Maidstone Children's Centre, 188 Union Street, Maidstone, Kent.

BEC Battery powered wheelchair with kerb attachments. Approx 18 months old and little used. Cost over £1,000, accept £700 o.n.o.
Contact: Mrs J.E.Carter, 131 West Avenue, Maylandsea, Chelmsford, Essex. Tel: Maldon 741007.

BEC Mobility Scoota. Excellent condition. One year old. Includes battery charger, cape and basket. Bought for £1,175. Will sell for £650.
Contact: Mrs B. Harrison, 35 Rookery Crescent, Cliffe, Rochester, Kent ME3 7RH.

Braun Battery Car. Very good condition. New batteries fitted. Covers included. Hardly used. £600.
Please phone: Kings Langley 67872.

WANTED

Electric wheelchair. Must be able to go up kerbs and be in good condition.
Please phone: Kings Langley 67872.

Now is a good time to send in details of your association's holiday chalet or caravan if you would like other ASBAH members to have the chance of booking it during 1988.
Please send in as soon as possible to the Editor of LINK at national office or to her home address (above)

DIRECTORY OF LOCAL ASSOCIATIONS

BARNSLEY
Mrs Marlene Haigh,
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Kendray,
Barnsley, S. Yorks, S70 3AE

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Kempston, Beds. MK42 8PX

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Mrs G. Lanning,
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Christchurch, Dorset
Tel: Highcliffe 3255

BRISTOL
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Knowle, Bristol 4
Tel: Bristol 777942

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Northfleet,
Gravesend, Kent.

HAMPSHIRE NORTH,
W.SURREY & S.BERKS
Mrs Liz Selby,
The Old Police Station,
Woodbridge Road,
Guildford
Tel: Guildford 571736

HAMPSHIRE SOUTH
Mr S R Baker,
12 Moorings Way,
Southsea, Portsmouth,
Hants. POY 8QW
Tel: 0705 819075

HERTS & S.BEDS
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55 Whitehicks,
Letchworth, Herts.
Tel: Letchworth 676706

HILLINGDON
Mrs D. Prince,
6 Cobden Close,
Wellington Road,
Uxbridge, Middx.

HUDDERSFIELD
Mr B. K. Swiffen,
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Huddersfield, HD8 8DP

HULL & DISTRICT
Mrs G D Brown,
233 Cranbrook Avenue,
Hull. HU6 7TX
Tel: Hull 857165

JERSEY, Channel Islands
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Mont-A-L'Abbe,
St.Helier, Jersey.

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North Scarle, Lincoln
Tel: Spalford 781

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ASBAH Centre,
Hainton Avenue,
Grimsby, S. Humbs.

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LONDON N. WEST
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Hanwell, London W7 1LQ

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