Link

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Association for Spina Bifida and Hydrocephalus/ASBAH

July/August 1986 Issue Number 105

Association for Spina Bifida and Hydrocephalus (ASBAH)
22 Upper Woburn Place, London WC1H 0EP

Registered Charity No. 249338 **TEL: 01-388 1382/5**

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Magazines

LIFT — for members of LIFT (young ASBAH)	Free
Causeway — *for contributors to ASBAH's work*	Free

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Editor's Note

A sense of frustration, of being forgotten and of having failed — these were some of the feelings of mothers of very severely disabled young people with spina bifida and hydrocephalus who met recently in Sussex. (The article on page 4 looks at one of these families.)

While the less disabled may be having a go at abseiling, learning to drive, looking for a home of their own, parents of young people who may be overweight, mentally retarded, blind, and have awkward-shaped bodies, are worrying about very basic practical problems.

One mother who attended the meeting said "Social workers are often young and enthusiastic and don't really seem to know how to approach families like us, or to appreciate our difficulties. They made me feel that I was an awful failure because I went to them for help — even though we have struggled on for 18 years. One young worker delivered a real slap in the face when she suggested that they would take our daughter away from us and give her to a family who could cope better".

Communications between this family and the local authority have clearly broken down, and ASBAH is trying to see if it can help.

If you have any views about the needs of 'severely disabled families' why don't you write to LINK.

Sue Gearing, Editor.

* * *

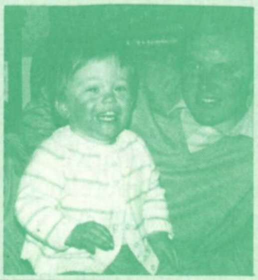
There has been a good response to the LINK readers' Holiday to America. There's another chance to apply provisionally in this issue. (See page 10.)

On the INSIDE

MAIN FEATURES

IN THE NEWS

LIFESTYLE



LEISURE

GENERAL

Stephen, learning to cope on his own in ASBAH's flat in Cwmbran

PLUS

COVER PICTURE

Daniel Lawrence, (not normally very keen to be photographed), captured in a very happy mood, by his father, **David**, a keen amateur photographer. Daniel is one of three children with spina bifida and hydrocephalus adopted by David Lawrence and his wife. They had a daughter of their own with spina bifida who died at the age of 8½ years. (See pages 12/13 for an article about the Lawrences and two other families who have adopted or fostered spina bifida children.

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 August 10. Send to the Editor at National Office.

Caring for the severely disabled

Other people's success can add to sense of frustration

"I FIND all this talk about young people being independent very frustrating, and it makes me wonder where I went wrong with my daughter" said Betty Claris, from Hailsham in Sussex.

Betty has coped on her own, looking after her daughter Sally, who is severely disabled with spina bifida and hydrocephalus, for the past 12 years, after the death of her husband.

Sally cannot read or write, or be left on her own for any length of time. She also suffers from epileptic fits which occur about once a month and can be as severe as grand mals. Fortunately they happen less frequently now than in the past.

Betty's life revolves around Sally, getting her dressed — "She could probably just about manage most of it herself, but it would take over an hour" — lifting her, taking her out, being Sally's friend and companion. This is, of course, in addition to running the house.

It can be very wearing.

"Sally talks nineteen to the dozen and is very repetitive" said her mother.

"She has a very poor short-term memory, but can remember fairly detailed events from way back, and she has a marked lack of co-ordination."

Betty is clearly very devoted to her daughter, wouldn't want her to live away from her, and doesn't complain about the enormous amount of care she needs. But she feels that given the facts about Sally's disabilities, she is never going to achieve any significant progress.

The attainments of more and more young people with spina bifida and/or hydrocephalus who are travelling, living on their own, getting married, even abseiling, are completely out of Sally's reach. They give Betty the feeling that somewhere down the line she has failed her daughter.

One of the main problems is Sally's complete dependence on her. She has no friends or relatives nearby, and the only other person who really understands is Mr Stan Newman, to whom Betty is getting married this year. He works at the training centre, Firstfields in Hailsham, where Sally goes four days each week.

"She tries to do craft work there, but never finishes anything. But she gets a wage packet and this is important to her" said her mother.

Betty has had the support of ASBAH since Sally was small, and she and her late husband George were very active in the development of the Kent Association when they lived in Thanet. When Betty moved to Hailsham — to be near Sally's school, Chailey Heritage — she joined the Sussex Association.

Betty does try to keep in touch, but because of the distances involved she doesn't get to many functions which are frequently held in other parts of Sussex. The effort of getting Sally out to a meeting, or finding someone to look after Sally, is also daunting. The social functions may involve discos where the flashing lights disturb Sally.

Sally enjoys music, television, shows, and coach outings, and on Sunday afternoons goes to a swimming club for the disabled in Eastbourne. She has had only two holidays — at Walsingham House, Hove — and hopes to go again this year with assistance from Sussex ASBAH.

ASBAH's fieldworker in the area, Sheila Wilkinson, keeps in touch and helps as she can, and the local authority have proved very supportive. They installed a stair lift and completely on their own initiative volunteered to replace it for a more modern version.

"In many ways we are very lucky," says Betty. "It's just this feeling of frustration that no-one really understands the problems involved with constantly caring for someone who is severely disabled, and will think I am an over-protective mother."

"And where do you get someone to care for a severely disabled young adult when the carer has to go into hospital?" asks Betty, remembering the troubles she had when she had to stay in hospital. In the end Sally's old school, Chailey Heritage, agreed to have her back, but it didn't prove a great success for Sally. The place had changed.

The recent meeting of families in Sussex with severely disabled young people, had given Betty a bit of a lift, and the realisation that she is not entirely alone. She hopes they may meet again and perhaps some kind of mutual support will develop.

HRH The Duchess of Gloucester, ASBAH's Patron, talking to Zem Rodaway from Haywards Heath, Sussex, at the Computer Industry's [illegible] at the Hilton Hotel, London, in Ju[illegible] Zem presented the Duchess with a bouquet of flowers.

The Ball was held in aid of ASBAH and was attended by about 600 people from the computer industry. Among the guest celebrities were two of ASBAH's Vice Presidents, Clare Rayner, and Michael Aspel accompanied by his wife. There was a cabaret during the evening with international singing star, Marion Montgomery.

Also in the photograph is ASBAH's Chairman, Mr Robin Mackenzie who was accompanied by his wife, the Lady Jean Mackenzie.

ASBAH CONFERENCE

Sorby Hall, Sheffield University
September 5-7

Plans for the Conference progress apace. Over 70 delegates have now registered and ASBAH is receivi[illegible] many more enquiries. Remembe[illegible] that places are limited so do contact Susie Dobson if you are interested in attending. As well as papers on Hydrocephalus, Educational Toys, Portager, Mobility and a discussion on the future structure of ASBAH there will be the opportunity for discussion groups. Specifically ASBAH is arranging a discussion session for older people (25+) with spina bifida and hydrocephalus.

24 hour wheely

CAN you do a wheely? How about doing it for 24 hours!

That was the aim of 21 year old Simon Smith from the Kent Association.

He was aiming to complete 24 hours — in 1 hour sessions with a 10 minute break between — on July 5, and so beat the record. The aim was also to raise money for the Asssociation.

LINK will let you know next issue whether or not he was successful.

British Rail — are they really getting there?

LINK readers may wish to comment on the following, as I am sure many of you have had similar experiences. If so, I would like to hear about them.

As a result of a journey to and from Manchester for the LIFT weekend, with a group of 27 LIFT members, 13 of whom were in wheelchairs, I wrote to Sir Robert Reid, Chairman of British Rail, listing the following complaints.

- At Euston Station, there was lack of knowledge of our party's travelling arrangements, even though BR had received confirmation of our booking.
- Some of the porters refused to use ramps to push wheelchairs into the train. One said they were 'too dangerous'. Instead those people in wheelchairs were bumped up the steps!
- Those who were unable to transfer were given a space in the first class carriages — fair enough. However, the rest of the party were in second class accommodation, *EIGHT* carriages away from the rest of the party.
- On the return journey from Manchester Station the porters were willing to use ramps, but did not know how to operate them. I and a colleague had to show them how!

I also pointed out to Sir Robert that because it is impossible for people in wheelchairs to get into the aisle of a second class carriage this means that people have to be 'manhandled' out of their wheelchairs into the seats, not a very comfortable or elegant experience!

I suggested that when parties such as ours travel together, they should be permitted to use one whole first class carriage. This would enable the party to be together for the journey, and, most important of all, people in wheelchairs would be able to go down the aisle, as there is more space in first class accommodation, and transfer directly into a seat.

Sir Robert replied and did express concern. He agreed that our experiences were indicative of very serious failures on the part of some of the BR staff.

He accepted my point that it is the staff who actually deal with the disabled, who need training in how to deal with people who are wheelchair bound. His Area Managers have been asked to examine this.

HRH the Prince of Wales meets Maureen Wingrove at Euston Station where British Rail were demonstrating their facilities for the disabled last year.

However, I am particularly concerned about his comment concerning accommodation in first class and I quote:

"In regard to your suggestions, only the first class carriages are of a suitable design to accommodate those who need to remain in their wheelchairs, and this can only be accomplished by removing a seat near the vestibule. This places a limit on our ability to cope with such cases, although we do endeavour to do everything practicable based on prior notice and special arrangements.

"This does necessarily involve the separation of large groups if other members of the party are travelling second class. Passengers who arrive in wheelchairs, but are able to be transferred to rigid seats for the journey will normally be placed very near the entrance and are accommodated according to the type of ticket purchased in first or second class accommodation. There are no plans to change our policy on this, which works well for the majority of our disabled people."

He does not see the need to change their policy. He has not explained why a first class carriage cannot be reserved for a large group of disabled passengers.

On both the outwards and return journey, I noted there were approximately three passengers in each of the three first class carriages.

I believe very strongly that there is no reason why it should not be possible to reserve one of the first class carriages for a large party of disabled people. Some people may say that this would mean BR would have to charge first class prices. But, why should they? If second class carriages continue to be inaccessible to those in wheelchairs, disabled people do not have any alternative but to travel first class. They should be allowed to do so until BR improve their stock.

I found the whole experience rather ironic, as a year ago, I was at Euston Station with a young woman who has spina bifida and we were invited to look at the facilities for the disabled on the occasion of a visit by the Prince of Wales.

That day RAMPS were in prominent use — as well as other aids to assist those people in wheelchairs. Something has gone drastically wrong since then!

I am in contact with other voluntary organisations to find out if they have experienced similar problems with BR. There is a Disability Committee set up by BR, and I am lobbying members to put as much pressure as possible on BR — to enable them to get there sooner — *not later*.

DENISE DUNNING
Education, Employment and Training Officer, ASBAH.

Letters

Why the Americans have got it right

I am writing in response to the article "Macro America v Micro England" in a recent issue of LINK.

We are an Australian family with an 8-year-old daughter who has spina bifida and two other "normal" children (6 and 3). Because of my husband's career we get the opportunity to travel and live in other countries and so we have experience of life in the US, in England and also of course in Australia.

Our most recent trip to England and the US was in 1984. We travelled extensively in the US and then spent six months living in Cheshire, and touring around the country at weekends.

My feelings are those of the article — the macro approach is to be preferred over the micro. In the US physical access for disabled people is a right. It is easy, taken for granted and always there.

Visiting museums, etc, is a positive breeze. Also, access to education is accepted as being the right of the disabled — if you want mainstream education for your child you can get it with all the appropriate aids and facilities. One doesn't have to feel one is begging for favours in such a system.

In England we found that the physical access *is* there but it might be round the back and involve an attendant showing the way through a goods entrance say.

I find this sort of situation less easy to accept than the US system. I like to be independent and cope as any other mother and children. I like to be able to walk in the main entrance like everyone else. *And, more importantly, that's what I want for my daughter as she grows up.*

Where education is concerned, we had a marvellous experience in Cheshire with a local headmistress who was happy to take on Amy even though it was only for one term. The school was more or less accessible (one or two steps and a very slippery playground in the wet) and Amy had a lovely time there.

So education, from our experience, seemed very accessible. However, it seems that we might have been lucky (reading of other families experiences) and that it varies very much from area to area. But I guess that's true of the US too — some States are better than others.

Macro America v Micro England

Jan, Amy and Laura Manchester at the Tower of London in August 1984.

As a reference, I'd like to say that Australia falls somewhere between England and the US. Access to buildings *is* often round the back, though *new* government and public buildings must be accessible.

Access to "normal" schooling is very much on an individual basis — find the right headmaster/mistress and you are in, *or* vice versa! Theoretically there is an integration policy (positive) for schools, but funding, manpower, and willingness to take on disabled children all need to be increased before it becomes fact.

In closing, let me add that public transport systems *everywhere* are hopeless for disabled people. In fact I am very impressed with the lift access to railway stations in England. How I wish we had it here!

BARBARA MANCHESTER
Turramurra, New South Wales
Australia

63 years old — and still the struggle goes on

Thank you for your article in LINK about Macro and Micro. I have been fighting for this sort of thing since I was born in 1923 and I am still fighting. I have been barred from very many functions the whole of my life.

After the death of my second husband I found that I was unable to walk. I could not reach the cupboards and shelves or get in or out of my rented council house. The 'Housing' would not help and I could not even get my legs under the sink.

The only way I could get anything done was to buy the house, which I did. Then I had a second mortgage on it and had the interior altered and a stair lift fitted.

What I can't get over now is I have this lovely 3 bedroom house, but the problems go on. The ramps cover up all the steps but they are so steep I can't begin to get to my car to drive it, it is all hand controlled. I have even purchased an electric chair but I can't leave this in the middle of the road when I want to go out in my car.

The garage is so small I can't get the electric chair in to it. The chair has no covering and every time I go out I get soaked. In fact I can't even get the electric chair in or out of my front door.

Now I am pennyless and I can't afford to have it altered.

I have waited now for many months for a Bathaid but I have been assured it's on its way.

My son gets married this year. God knows how I am going to get up the steps to the church, or even into the reception. It means my daughter will spend her day pushing and pulling me everywhere.

I think life is a mess in a wheelchair.

I tried to get into my son's basement flat, and between my son and daughter I will never know how they did it. My

Decline in spina bifida: The debate continues

"IS SPINA bifida really on the decline?" (LINK, March/April 1986): I find Mr Forrest's question difficult to understand when I have shown from official statistics in considerable detail what a collossal decline has taken place since 1972. This decline applies both to the number of births with spina bifida and also deaths from spina bifida.

In my article I pointed out that in 1972 there were 1580 babies born with spina bifida in England and Wales. This figure dropped to 422 in 1983. The figure for 1984 is now available and it is 378, indicating a further progressive, substantial fall. The figures for 1985 are not yet available but the indication is that the trend continues. In other words there is a true and continuous decline which, of course, is naturally shown also in the number of new babies arriving at treatment centres.

I wonder if Mr Forrest could tell the readers of LINK how many patients have been referred to him year by year since 1972?

Official statistics clearly indicate that the fall in spina bifida births has been as substantial in the London area as in other large cities.

Death from spina bifida and hydrocephalus also continues to decline. Official statistics for 1984 so far only give total deaths from spina bifida and from hydrocephalus (without spina bifida) at all ages — this is 283 and compares with 345 deaths only a year earlier. This trend also continues.

In other words, spina bifida really is on the decline, but I am glad that Mr Forrest also emphasised the need for continued alertness and reinforced my recommendation that all known preventive measures should be used to avoid possible future reversal of this trend.

Mr Forrest is right that spina bifida is not a thing of the past but, as for newborn babies, we are approaching this highly desirable objective. It is possible to achieve this objective.

Naturally, there will remain a substantial number of persons with spina bifida surviving, growing up into adults and who will require all the help and services of ASBAH and the medical profession to make their lives as full and as happy as possible.

I give below a short table which might make the figures easier to digest:

SPINA BIFIDA BIRTHS
IN
ENGLAND AND WALES

1972	1,580
1976	704
1982	491
1984	378

PROFESSOR JOHN LORBER, MD, FRCP

Professor Lorber is one of ASBAH's Vice-Presidents.

DUNCAN FORREST, FRCS, Chairman of ASBAH's Medical Advisory Committee, comments:—

I am sorry that Dr. Lorber has taken the title of my article to mean that I do not believe that there has been a decline. I do not deny that for moment. I was not criticising his article in the May/June LINK of 1985. The facts which he presents there cannot be denied.

What I do disagree with, however, is the conclusion he draws from these facts, set out in his article in the Archives of Child Health in November, 1985, provocatively entitled "Spina Bifida — a vanishing nightmare?", and which I will quote again word for word:— "If the present trends continue, then the virtual disappearance of spina bifida from the United Kingdom is now a real, not too distant possibility".

This conclusion ignores other data he presents which by his own admission shows that we cannot completely explain the decrease as being due to the preventive measures now used in many centres, and he reports that in other countries, notably Hungary and Australia, there is once more an upward trend. The fact is that we just do not know whether or not there may be a similar trend in the UK. Indeed, in East Anglia where previously incidence was the lowest in the country, figures for the past years have shown a definite increase, from 9.0 per 10,000 births in 1980 to 10.3 in 1983 and 11.8 in 1985.

I am delighted that spina bifida has disappeared from Sheffield, and devoutly hope that it may not return. My own experience in London, however, has been less encouraging. In one of my hospitals, Queen Mary's, Carshalton, numbers dropped dramatically from about 70 per year in the late '60s but they have levelled off at between 10 and 20 per year from 1977 onwards, and my other hospitals show similar trends. Patients which are referred to me now are mostly infants whose mothers have not been screened, those in whom screening has failed to reveal the defect or those who have refused termination of pregnancy. I cannot see how these numbers will ever diminish to zero.

The unfortunate result of publishing articles with such dramatic disclosures is that the press, radio and television eagerly seize on the more sensational statements while ignoring the more cautious qualifying remarks. This occurred when the *Times*, not a notoriously sensational paper, carried a feature on Professor Lorber's paper. It did not misquote, but succeeded in giving quite the wrong impression, with the result that many people telephoned the ASBAH offices with wildly inaccurate ideas. Professor Lorber would serve the cause of spina bifida best by confining his writings to sober statements of fact.

Don't forget to send in your letters to LINK if you have any views or comments that may interest other readers.

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continued from previous page

chair, only a junior model with a 14 inch [illegible]t could not go into the kitchen, God knows how I will ever go and have dinner with them.

Very often we have a well known symphony orchestra visit Brighton but unless I can get someone to come with me I have to miss it. Once there, however, there is plenty of room for wheelchairs.

Things are getting better but most of all I would love a house I could go out of and get back to, and a car into which I could put my own chair.

I am a prisoner and I can see no way out unless I win the pools or become very rich.

It will take years and years for us to have access everywhere. I enjoy historic places but I must be content to watch them on the box.

I don't like moaning but life gets such a struggle and at 63 years my arms aren't very strong any more.

MRS IRENE DILNOT
Brighton

They've both got problem feet. But the one wearing adimed sports shoes doesn't have to bear the additional handicap of looking different.

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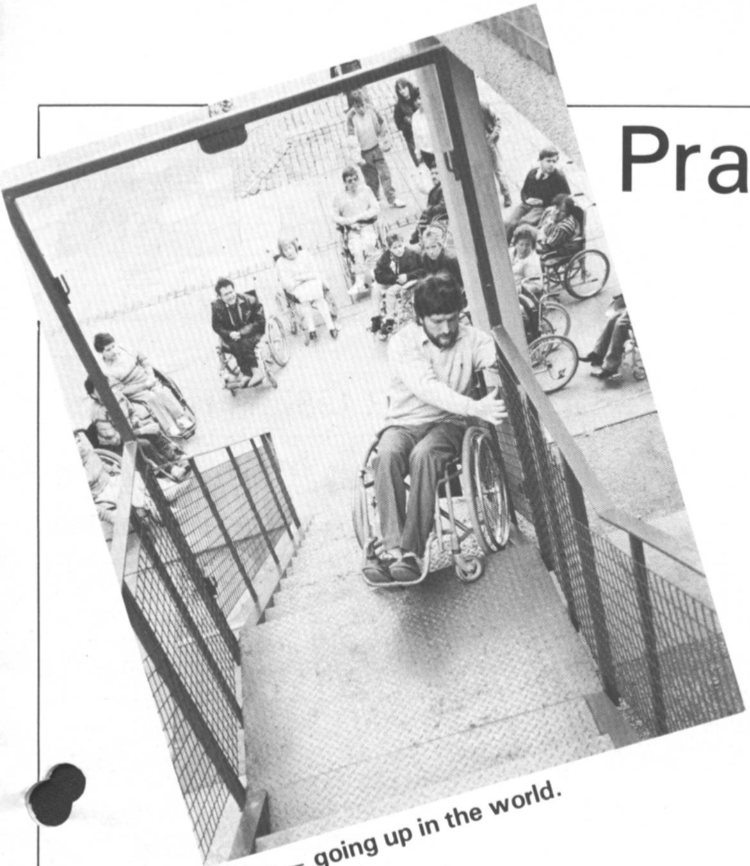
Practical wheelchair workshops



Owen — going up in the world.

AS these pictures highlight, it is possible for some people to be extremely mobile in a wheelchair.

To show these possibilities was the aim of two recent wheelchair workshops organised by LIFT, at its Spring Weekend, and at National Office in June, under the direction of Owen McGee a physiotherapist from Elizabeth Fry School, London, and his colleague, Kay Owen.

He said that the most important thing was to make the best of your chair, and to be as mobile in it as if you were walking. It shouldn't become a handicap.

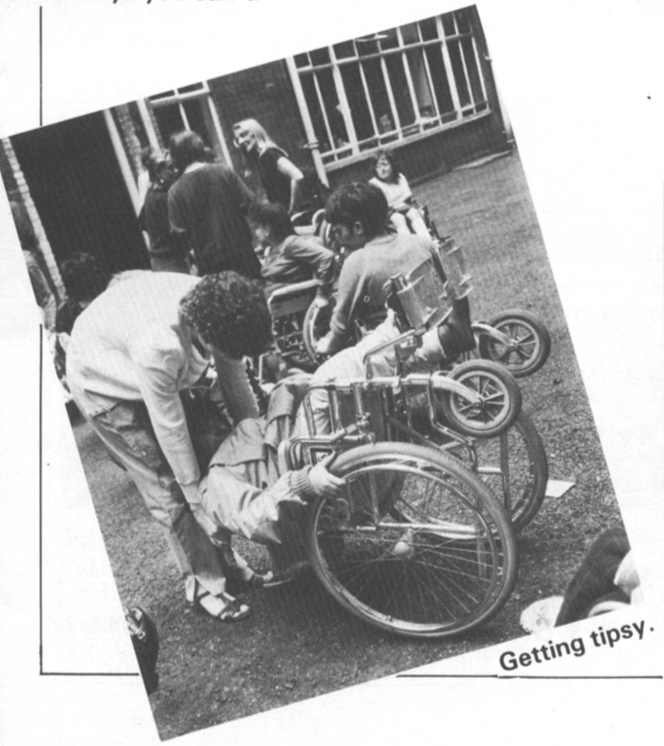
He demonstrated the correct way to get up and down kerbs and ramps, how to do wheelies and to get up and down steps.

Owen explained the pros and cons of various DHSS chairs. Sadly the majority of young people at the workshops were being impeded in their mobility by their wheelchairs.

There will be two follow up days later this year — for beginners, and for those who want to tackle wheelies, escalators and stairs. Contact LIFT for details.

Who says you can't!

Antoinette doing her kerb drill.



Getting tipsy.

Follow me.

Especially for LINK readers

Two centre holiday in

FLORIDA, USA

16 DAYS IN OCTOBER 1987

To include

★ 3 days Disney World ★ 1 day Sea World ★ 1 day Circus World
★ 1 day Cypress Gardens ★ 1 day NASA Space Centre
★ 1 half day Busch Gardens, Tampa ★ 3 days at Clearwater Beach

THIS first ever LINK reader's holiday was advertised in the last issue and there has been a very encouraging response. We are publishing details once again to give those who missed them a second chance to apply.

LINK is joining forces with a leading travel service agent, Panovista, to organise 'a holiday of a lifetime' — a two centre, 16 day holiday to Florida during October 1987. Details are being published early in order to give people the chance to start saving!

The idea has been prompted by the success of a holiday organised by Panovista in October 1985 for 68 members of Sunderland ASBAH, including 15 people in wheelchairs. The LINK holiday will be very similar.

Chairman of Sunderland Association, Mrs J Shepherd, said that the holiday had been a wonderful way of uniting members and bringing the association together. This could also work on a national scale, giving ASBAH members a chance to meet others in a different part of the country, and to make new friends.

Mr J. Brown of Panovista is in Florida now getting firm prices from hotels, attractions and the airline and coach operators, and it should be possible to have a total holiday cost in September. It is likely to be about £700 per adult, £450 per child. This price includes everything listed below, except for food, which is very reasonably priced.

Applications are invited not only from families and friends travelling together, but also from individual young adults provided that they are independent.

If you think you might be interested please fill in the form below as soon as possible. It puts you under no obligation. More details can then be sent later — prices, dates, travel arrangements. As the response seems to be equally divided between North and South, it should be possible to arrange flights from Gatwick and Manchester.

Included in the 15 night package are all the attractions listed at the top of the page plus:

★ COACH TRANSFERS at pre-arranged picking up points, to MANCHESTER AND GATWICK, and RETURN
★ FLIGHTS by British Airways 747 to ORLANDO and Return, & Airport tax
★ ALL COACH TRANSFERS to and from hotels and attractions
★ 10 NIGHTS accommodation at the NEW CONTINENTAL ROYALE HOTEL, near International Drive, Orlando. Conveniently situated hotel. La[illegible] swimming pool, restaurant. A[illegible] conditioning in all rooms, private bath, WC and shower, colour TV and telephone. Lifts to all floors. Each room has two double beds
★ 4 NIGHTS accommodation at the CARIBBEAN GULF HOTEL, Clearwater Beach on the Gulf of Mexico. 5 star hotel with superb beach side position. Bay or beach views. Free inhouse colour TV movies, bath, shower, WC. Air conditioning, Lifts to all floors. Each room has two double beds or 1 king size bed. Choice of hotel restaurants, entertainment lounge and disco, buffet at the hotel poolside
This is a wonderful spot to enjoy three clear days either relaxing on the beach or sightseeing locally
★ 6 STAR FLIGHT VALUE FREE: inflight movies and stere[illegible] flight bag, duty free vouchers, bar service during flights, flight pack, wine with meals

During the stay in Orlando and Clearwater there will be other optional tours available.

To: LINK Readers Holiday, Panovista Travel, 78 Sea Road, Fulwell, Sunderland SR6 9DB.

Please would you send me, without obligation, further details about the proposed LINK readers' holiday to Florida.

There may be. . . . . person(s) interested in the holiday (please give approx. numbers)

We would prefer to fly from Gatwick, Manchester (please cross out as appropriate)

Name: . . . .

Address: . . . .

. . . .

If you need further information about the holiday please contact: Mr J. G. Brown at Panovista. Tel: 0783 494444 or Mrs Sue Gearing, Editor LINK. Tel: 0934 862279.

Local Association Round-up

Bristol

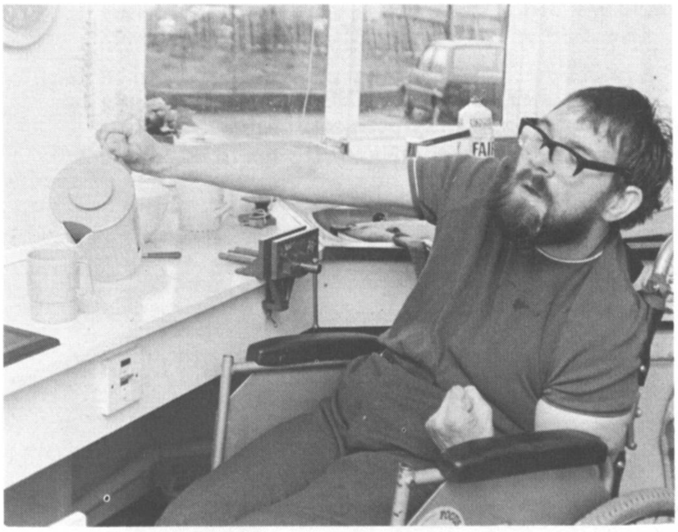
CONGRATULATIONS to Helen Cooper of Warminster who recently added six more gold medals to her collection of over 30 cups and trophies. She is so keen on sport that she has a go at any event, although swimming is favourite. Her recent medals were won at the Southern Regional Athletics in javelin, shot putt, discus and wheelchair racing.

Essex

STEVEN Ashton, 14, of Elm Park, Romford, was one of nine people to be presented with an award for courage by the Mayor of Havering recently. Steven was chosen because of the way in which he kept cheerful despite his handicap, and 18 months in plaster after an operation.

Isle of Wight

THE ASSOCIATION has bought a small car for the use of its oldest member who has been having difficulty getting out and about — Mrs Margaret Spencer (the spina bifida great grandmother — LINK May/June). Because of cataracts she no longer drives, but she has friends who can take her out.



Gwent

STEPHEN Ciesielski, 32, having a go at living alone in the ASBAH flat in Cwmbran. The flat was opened earlier this year in the Taliesin complex at Maendy Way in Cwmbran, and aims to give disabled young adults like Stephen — who has cerebral palsy — the opportunity to make the transition from being dependent on someone else to being more or less self-reliant.

Stephen was a resident for four years in a home for the disabled in Monmouth, and wanted to try to get a place of his own: "I was terrified of coming in because I had never cooked — but now meal times come around and I do it without even thinking" he said. "Of course, it's mostly frozen, but when you think I'm boiling and draining vegetables with one hand, it's remarkable no hot water has ever spilled on me".

After a few weeks in the flat, Stephen was offered a permanent flat of his own in the Taliesin complex by the United Kingdom Housing Trust.

ASBAH rents the 'training flat' from the Trust and several young adults with spina bifida and hydrocephalus have spent periods of about six weeks getting a taste of independence.

ASBAH is keen to offer the accommodation to other disabled young adults. Contact Mrs Teresa Cole at National Office.

Kent

TAKING part in the Junior Games at Stoke Mandeville this month (July) will be 14-year-old Karl Walton from Paddock Wood. Karl who is a pupil at the Valence School, Westerham, broke a new record in the 60 metre swing through when taking part in the regional selection games.

Wirral

IN MAY the Association celebrated its 21st Anniversary with a reception attended by the Mayor and Mayoress of Wirral. At the same time the 21st birthdays of spina bifida members were also celebrated. Two of the founders, Les and Betty Dean are still on the Committee.

Ilkley

MARATHON men line up for the camera after 48 hour non-stop darts which has been acknowledged as a World Record. The marathon was organised by the Rotary Club of Ilkley. The players were sponsored in aid of ASBAH.

Is there any news from YOUR Association? If so LINK would be glad to hear from you.

A letter from Coventry

MY NAME is Henrietta Collins, and I have been chosen as well as fifty three others to represent Great Britain in The First World Games for Disabled Youth. As you can imagine I am very proud to have been chosen for such a great event.

I do not know as yet what I am doing at the event, but I hope it will be something like shot put, discus, short distance dashes, wheelchair slalom, breastroke and finally back crawl!

The Games do not actually take place until August 29-September 8, but my mum has made sure that I will train every day and most evenings!

I first became interested in sport when I joined the Coventry Sports Association for the Disabled about five years ago, when I was eleven. I have been all over England with the junior section of the C.S.A.D. I also learned to swim when I was three at Sherbourne Fields School (a special school), when I was six, I joined the Phoenix Swimming club and have been swimming with some success with both the Phoenix and the C.S.A.D.

Last year I competed in the Junior National Games at Stoke Mandeville, where I won a gold in the shot put. I also won a gold in the discus, and beat the existing record with a throw of 8.42m. I am going to Stoke Mandeville to defend my title in July.

Anyway, back to the Games; the whole thing will last a week, with one day sightseeing in Nottingham, where the Games are to be held, three days of coaching, followed by three days of stiff competition.

I think, altogether, there are about twenty countries taking part. It will be fun just trying to communicate, never mind competing!

I am really looking forward to this event and I hope the Great Britain team will be able to uphold England, and bring back the most, if not all the Gold Medals.

Henrietta Collins

Adopt handica chi

There are always a great ma handicapped children needing looks at two very different f children with spina bifida and h who have become foster paren

David and Una Lawrence's first child was Nina, who was severely disabled with spina bifida and hydrocephalus. She died at the age of 8½ years after many operations.

What made them decide to adopt three children with spina bifida and hydrocephalus, having had an able-bodied son of their own after Nina?

LINK went to see them at their home at Walton-on-the-Naze in Essex to find out.

The Lawrence family — David and Una with Clare, Daniel (centre), David, and baby Sophie.

The family of our choice

DANIEL, 11, was sitting on the doorstep of the Lawrence's chalet bungalow blowing soap and water bubbles and enjoying the late afternoon sun. Clare, his younger sister, aged 7, was waiting in the doorway in her wheelchair, keen to show me in. That was my introduction to the Lawrence's close and happy family — albeit an unusual one.

The family is made up of David, a police sergeant, and his wife Una, their able-bodied son, David, 14, and three adopted children with spina bifida and hydrocephalus — Daniel, Clare and baby Sophie, who only recently joined the family.

David and Una talked about the nightmare of learning that their first born baby, Nina, had spina bifida. They struggled to give Nina as good a life as possible despite her severe handicaps. She had spina bifida and hydrocephalus, many problems with the valve and scoliosis which led to a spinal fusion operation. It was a fight — a fight to find the best treatment, a struggle to learn as much as possible about spina bifida, and to cope with Nina's near death on several occasions, and eventually to come to terms with the fact that she really was dying. "After so many operations, her body seemed to give up" said David.

"While Nina was dying we were wrongly advised to go ahead and have another child straight away. We were also told that the chances of having another handicapped child were 1 in 1,000. Had we known the real odds we might never have gone ahead with a second pregnancy" said David. It was when Una was about seven months pregnant that they read an article in LINK and discovered the real odds. The rest of the pregnancy was an agonising time and they couldn't believe it when David was born fit and well. He is now an active 14 year old.

David and Una decided not to risk another pregnancy. Una had trained as a nursery nurse and she and David had often spoke about adopting even if they had children of their own. Adoption now seemed the natural thing to do.

Why did they take the decision to find a child with spina bifida? Why not a normal baby badly needing a home?

David explained: "While we were caring for Nina we learned so much about spina bifida and hydrocephalus and made a lot of useful contacts. We went through the shock of having a handicapped child of our own and learned the hard way how to do our best for her. It seemed right to use this experience to help another child with the same handicaps".

They applied to Tower Hamlets Social Services who gave them a good deal of help and advice and eventually they were told about 15 month old Daniel in the care of another authority. They really went in at the deep end. They hadn't bargained for the way in which this particular local authority would ha[illegible] Daniel over to them — with no prop[illegible] introductory period, and no information about his background or the extent of his handicaps. He had been neglected, and it wasn't until he was six that by chance they managed to persuade a hospital to give him a proper brain scan and a hearing test. The tests confirmed what Una and David had long suspected, that he had brain damage — due to uncorrected hydrocephalus — he was deaf, had a hernia, and sight problems.

Although the damage was done, operations have improved his condition, and today he is a loving and happy little boy, getting on well with everyone at the special day school he attends in Clacton — the Winsor. A close watch has to be kept on his valve because he is unable to communicate properly if he is feeling unwell. On the plus side, Daniel can walk with the aid of short calipers.

Despite the problems with Daniel, David and Una decided to go ahead and

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many physically and mentally ing homes of their own. LINK t families who have adopted d hydrocephalus, and a couple rents.

apply for another handicapped child. The experiences they had gone through had drawn them even closer together as a strong family unit and they felt able to take on another child.

They again approached Tower Hamlets and everything went almost perfectly. There was a slow introduction [illegible]r about 10 days during which time [illegible]e Lawrences stayed with 2 year old Clare at the children's home, gradually taking over the tasks of caring for her. They were able to find out all about her.

She is a confident and outgoing little girl, going by taxi each day to a local normal school — Hamford School — where thanks to the headmaster, she has been welcomed. Care is provided for her during the day at school. Clare has made many friends, is a brownie, and generally enjoys life.

David and Una acknowledge the help they have received in bringing up their unusual family — help from London hospitals, particularly the Westminster Children's, the local authority, the local chemist and the local community in general. One of the reasons for moving to Walton was the proximity of the special school and other good local schools and they have all proved supportive, and Una's family who live in the area have given tremendous backing and encouragement and welcomed all the children into the family fold.

They have gained a great deal from belonging to the the local ASBAH in Suffolk — David is the honorary secretary — and are pleased with the help and advice they have had from National ASBAH via its publications, and from the fieldworker, Meg Garnett.

Their chalet bungalow is in the process of being extended and will be suitable for the children's needs. It is situated in a residential road alongside the beach, and is therefore an ideal place where young children can grow up.

Their secure, loving environment was another reason why David and Una took the decision to apply for a third child. The other children were consulted and were happy — son, David said he didn't mind so long as she wasn't ugly, and Clare's only stipulation was that she couldn't talk. So baby Sophie joined the family from a local Barnardo's home. She is very pretty, and only nine months old and cannot talk — so she fulfills both requirements! Sophie has a valve, and there is hope that she may be able to walk when older. Her arrival has had an effect on Clare in particular — helping her to move up from being a baby to being a responsible little girl, and she is delighted with her new role.

David and Una have been asked on several occasions to talk to other couples thinking of adopting a handicapped child.

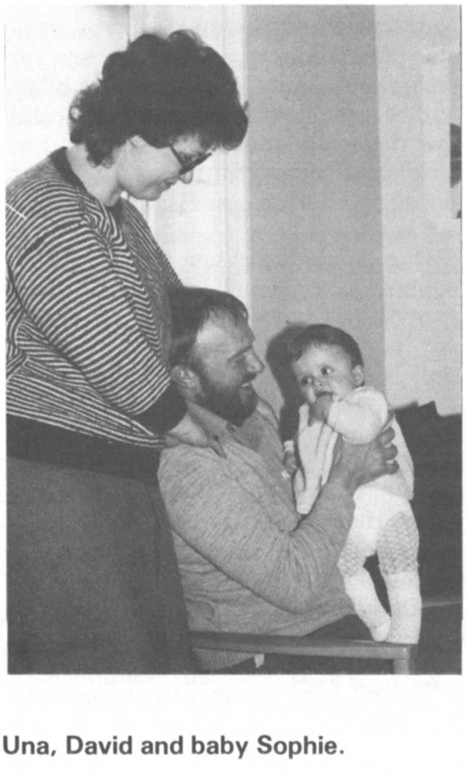
"It's a lot easier to adopt a handicapped child than to have one of your own. If you have had a child with handicaps, you have gone through all the shocks, and have had all kinds of things to put up with. You have had to feel your way. Adoption is not a shock, because one chooses the situation. This is true whether one has 'gone through the mill' beforehand or not. Many couples who have no experience of handicap take on a handicapped child; slowly they may fully realise the responsibility, and other shocks may be in store for them, but they never experience the real shock that takes unprepared parents by surprise. It is also easier to fight for an adopted child. You don't feel selfish and you can have a good battle on their behalf. I feel as we are saving society thousands each year, authorities have a duty to help us. We feel much freer than if the children were our own," said David.

"We love each of our children. Love is different for each person in our lives. It is different towards Nina, towards David, Daniel, Clare and Sophie — not better or stronger, just different. We don't feel it is important if one child is adopted and another a natural child. That is simply the way they came.

"Daniel, Clare and Sophie will grow up knowing that they are adopted. We feel that's important, and if they ever want to trace their roots, then we will help and guide them over what may be a very harrowing experience.

"We wouldn't have wanted to adopt a normal child — we have learnt to enjoy and value the special place of handicapped children in our home" added David.

Turn to next pages for more about adoption and fostering.

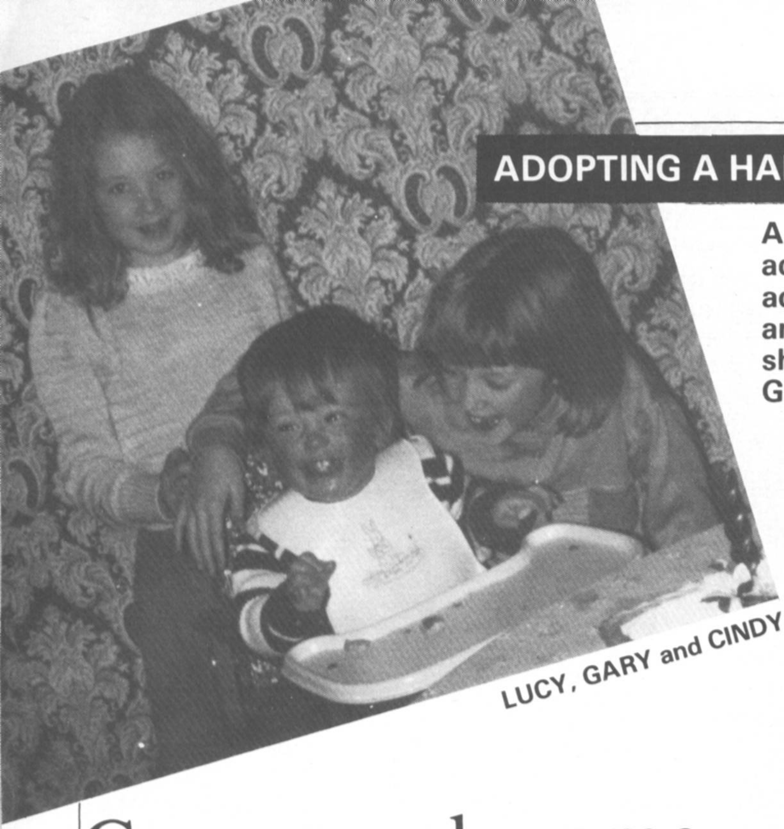


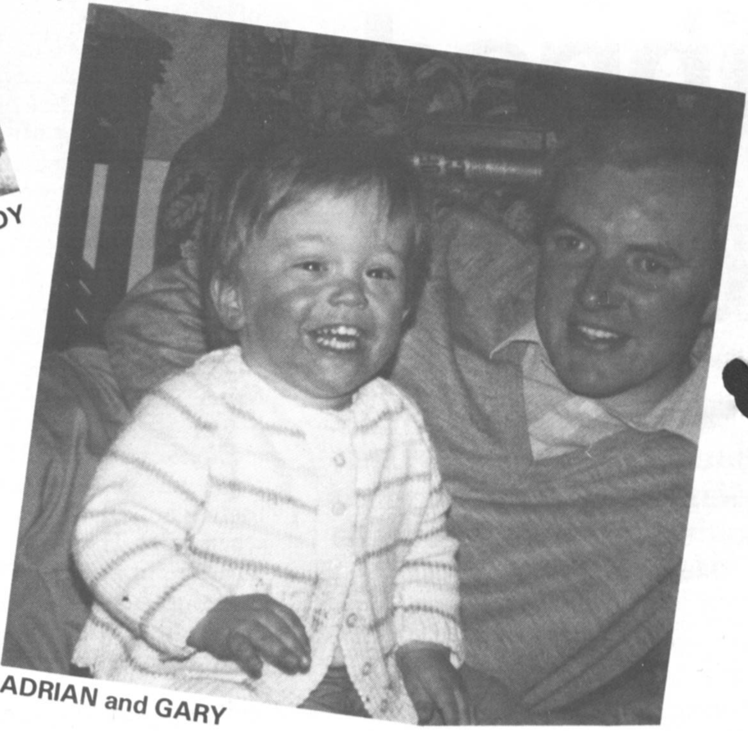
Una, David and baby Sophie.

A proud moment for Clare — her enrolment in the brownies.

ADOPTING A HANDICAPPED CHILD

Adrian and Anne Axford didn't particularly want to adopt a handicapped child — but they did want to adopt Gary, who just happened to have spina bifida and hydrocephalus. Anne Axford writes about how she and Adrian and their two daughters welcomed Gary as a permanent member of the family.


LUCY, GARY and CINDY


ADRIAN and GARY

Gary soon became a true member of the family

WE first saw Gary in the children's ward of the local hospital when he was just six months old. We had been asked to foster him for about a year, and then he would be adopted by someone outside the area.

He had spina bifida and hydrocephalus, and we were unsure if we could handle his severe handicaps, even for a year.

We needn't have worried. Nearly two years later, we have just adopted him ourselves.

It became obvious soon after he came to us that he was not just another child — we'd fostered several children, and we felt different about Gary. He was a true member of our family in every way, and we soon realised that we did not want him to leave — we started to think about adopting him ourselves.

- Yes, his handicaps would give us problems.
- Yes, we would probably have quite a struggle at times.
- Yes, we wanted to do it.

Convincing the professionals took quite a long time. "Why do you want to adopt a handicapped child?" they asked, suspiciously.

Our answer was that we didn't — we wanted to adopt Gary, who happened to be handicapped. We felt that with the problems he would face throughout his life, the least we could do was offer him a family he could call his own, with the security he needed.

Gary is now just over two, and his hydrocephalus is under control. He has had many months in a splint for a dislocated hip, a soft tissue release for a badly deformed foot, and is now awaiting an operation for a squint. We are also embarking on the long road to mobility, with his first set of calipers. We realise that there is a lot of work ahead, but we are pleased to say that, at least in our area, the support from professionals is without fault.

It is, perhaps, easier for us, having adopted Gary, to make full use of the support services offered. We do not have any feeling of guilt about why his handicaps happened, nor do we have to cope with feelings of loss over the healthy child that was expected. We are lucky, too, that our own two daughters (Cindy 9, and Lucy 8) are both completely happy that Gary is with us.

We hope that Gary can lead a happy, useful life in the future. He has a bubbling personality full of fun and mischief which has given far more to us as a family than we can ever give to him.

We can honestly say, to anyone who wonders if you can love an adopted child in the same way as your own children — YES, you can! Some people have commented on how "brave" or "good" we are to take on a handicapped child. We can only say that we do not feel either. We feel very privileged to have the chance to share Gary's life, and enjoy every minute of it.

Having said that, I must admit th[illegible] when we first started fostering, [illegible] specifically said that I didn't feel we could cope with babies or handicaps — it just shows how wrong you can be about your capabilities!

If you would like to find out about the possibility of adopting a handicapped child, contact: The British Agencies for Adoption, 11 Southwark Street, London SE1 1RQ. Tel: 01-407 8800. They will put you in touch with local agencies.

Barnardos run a successful Homefinding Project — London Office, Tanners Lane, Barkingside, Ilford, Essex LG6 1QG. Tel: 01-551 0011.

There is also a 'Be My Parent' book which is kept up-to-date and contains photographs and information on 200 children needing homes. Some of these children will be disabled. To find out where the book can be seen in your area, telephone: 01-407 9763.

Shared disability helps us understand each other

FOSTERING A HANDICAPPED GIRL

Alan and Margaret Twyford — a married couple with spina bifida — became convinced that they wanted to foster a child with the same disability. Here they write about how they set about it.

Alan and Margaret are active members of ASBAH. Alan is a member of the Executive and they are both on the Disabled Living Advisory Working Party.

WE married in 1971, and decided not to have children as we both have spina bifida. We knew there was a risk of our producing a baby with the same disability.

Nevertheless after about four years we offered to be "aunt and uncle" to a child at weekends, but our Social Services Department said they didn't have a suitable child. Undeterred, we got involved in visiting, at weekends, a ward for handicapped children, whose parents were having a break. This we loved doing.

In 1979 we went to ASBAH's residential home "Five Oaks" in Ilkley, to help on a week's independence course. There was one little resident, awaiting fostering, whom we loved. We approached ASBAH for advice, but the degree of handicap seemed so severe, we felt that the difficulties of coping would outweigh the security we could have given had we been accepted as foster parents.

Two years later we helped on another independence week, vowing not to get involved again. The youngster allocated was 16 with no family. She lived in a children's home in the country, although born in London.

After the course ASBAH recommended that she should return to London, and asked if we would befriend her at weekends. She stayed with us at weekends, for about 18 months, with the expected ups and downs. Then she spread her wings, and moved to another area, although we are still in touch.

This experience convinced us that we wanted to foster a spina bifida child. We specifically wanted to foster a child with spina bifida because we thought in that case our own disabilities would not be a hindrance.

We approached ASBAH again, and they agreed to see if there were any children at boarding schools who might need holiday fostering. Later they told us about three children but, for various reasons, we felt unable to help them.

Alan works at nearby council offices and approached the fostering officer of that authority. Ironically at that same time the fostering officer received a letter from another Social Services Department.

They wanted foster parents for a 13-year-old girl with spina bifida whose children's home was closing. They said they would accept her being holiday fostered and attending a boarding school.

Finally, in September 1984, shortly after introduction to us, she moved to her boarding school, and we officially became her foster parents from the November, after the usual approval procedure.

Since then we have had tremendous support, from the school particularly, and are given confidence in what we do. We feel very much part of a team.

After initial trepidation our foster child has settled in. She now realises that despite life's natural trials and tribulations she is very much loved.

As we all have spina bifida it has helped us understand each other. She realises that we understand, from our own experiences, many of her difficulties and we can share the frustrations which inevitably arise.

It has been an interesting time getting to know each other and welcoming her into our routine. We felt strange at first to have a child sharing our lives and belongings but that is becoming second nature. She is very independent and healthy and does not require lifting.

Fostering is hard work, frustrating, and demanding, but very worthwhile. It can offer much to people who love children. If you expect nothing in return, then everything is a bonus. Whether you are disabled or not, if you feel you can cope, by providing a secure home, it would add an extra dimension to your own, and your foster child's lives.

Our foster daughter has added the following description of how she views things:—

"I come home every other weekend and for school holidays. When I first met my foster parents I was afraid of being away from my boarding school. I feel happy now when I am with them. When I am with them I cook, clean, and wash up, and it really makes me busy and tired, I am really getting to be independent.

My bedroom is a bit like a bed-sitter, because I have my own sink, and a seat you can make into a bed. It has a nice pink wallpaper and it is really bright and cheerful. I don't mind being fostered, but at first I did not like the idea."

Paul needs a home

When Family Finders, an organisation looking for adopters, heard that LINK was publishing a feature about adoption and fostering of handicapped children, it approached us and asked if we could help in their search to find a home for Paul . . . .

Paul, described as a very sociable and likeable boy of 11, needs an adoptive home. Paul has spina bifida and hydrocephalus. He is in a wheelchair in which he is extremely mobile and active. He has a valve and is doubly incontinent, but is reasonably independent. His righthand is slightly bent back so this hinders his independence to a certain extent.

Paul goes to a special residential school in Barkingside, Essex, and at weekends and holidays goes to his grandparents.

As they get older they realise the importance of finding permanent new parents for Paul. However they would always like to maintain contact. His natural parents have another disabled child and weren't able to cope with Paul as well.

Family Finders, the agency concerned with Paul, say that a couple who have had experience of caring for a handicapped child would be helpful, but not essential. What is more important is that the prospective adoptive parents and Paul should get on well together.

Paul is an active boy, enjoying cricket, is a great West Ham fan and loves computers.

For more information contact: Peter Turner, Family Finders, 12 Moulsham Street, Chelmsford, Essex. Tel: 0245 351567.

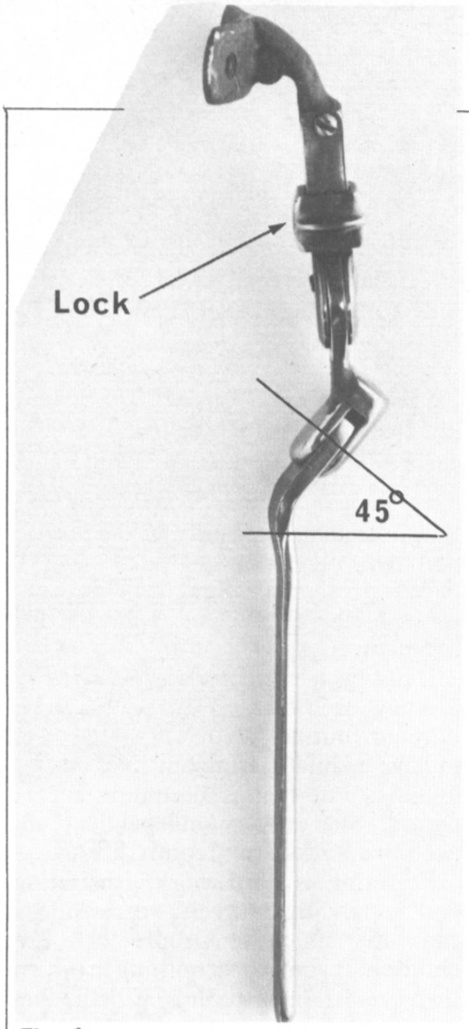


Fig. 1

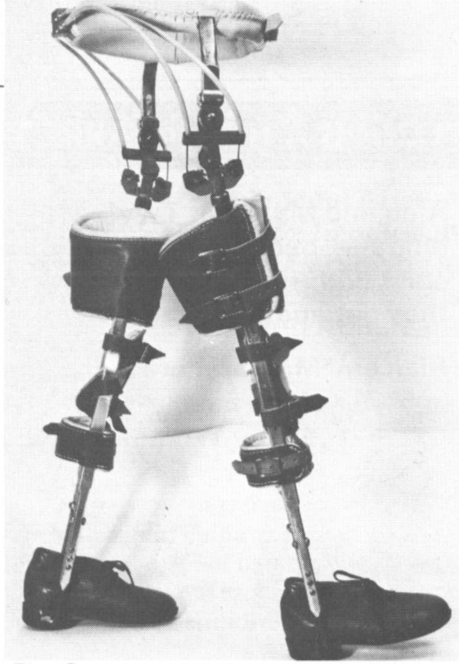


Fig. 2

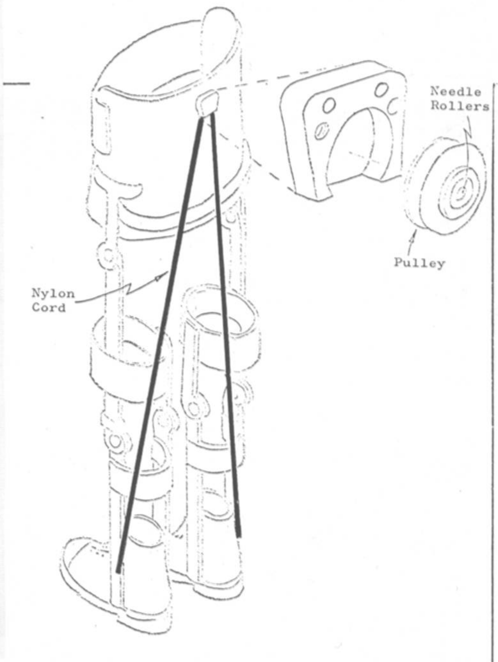


Fig. 3

JOHN FLORENCE'S letter (LINK, May/June 1986) about reciprocal walking systems has aroused a lot of memories. David Scrutton, Superintendent Physiotherapist at the Newcomen Centre, Guy's Hospital has written in more detail about what was going on in England and Canada twenty years ag He says he can be fairly certain of th details because he wrote down such facts as he could establish at the time (reference 1).

Reciprocal Walking Systems: A look at some of the early steps

DURING 1963, working at the Cerebral Palsy unit at Queen Mary's Hospital, Carshalton, I had two cerebral palsy children who were in full length calipers. Without a pelvic band their legs scissored and their feet turned inwards (from the hips). This could be prevented by a pelvic band (frequently used in spina bifida).

However, in normal walking we transfer our weight onto the leading leg by rotating our pelvis (about 10°) and the ordinary hip hinge in the caliper does not allow this, as movement is in the one plane only (backwards and forwards). Thus, although the normal hinge appears to *allow* the movements of normal reciprocal walking, it actually imposes artificial and inefficient restrictions.

To overcome this problem I designed a hinge (based on a doll's hip) which was angled at 45° and so rotated the pelvis 8° for a 30° step. The orthopaedic workshops at Carshalton made me a pair in 1964 (Figure 1) — and more as a joke I called them "polyplanar" hinges. Unfortunately the children were simply unable to use them and I put the idea aside.

In 1966 I was treating a couple of spina bifida children at Guy's Hospital and it struck me that we locked (for standing) and unlocked (for sitting) *both* their hip hinges, whereas for normal walking we "lock" only *one* hip at a time when walking. How could we get a brace to do that?

Obviously we needed some form of reciprocal connection between the left and right hip hinges; and the first one I made used Hillman Imp pneumatic throttle controls. Very exciting, but not a success (it was too spongy), *but* it did demonstrate that not only could we get stable standing or/and reciprocal hip movements, but that the standing leg *could power the swinging leg.* A more positive interconnection was needed and in 1967 we made our first twin cable system and it was obvious that now the polyplanar hinge could be controlled it might have a use (reference 2) (Figure 2).

However, during 1967 three further systems were quite independently being developed, two by Wally Motloch at the Ontario Crippled Childrens' Centre, Toronto, and one by Mr Hartley in England.

1 Reciprocating gait attachment (Figure 3) using a nylon cord to *allow* reciprocation and prevent bilateral hip flexion (Wally Motloch).

2 Reciprocal gait brace (Figure 4) which had two meshed spur gears at lumbar spine level, which created stability for standing and *powered* the forward swinging leg (Wally Motloch).

As far as I could find out (reference 3) neither of these systems was developed any further.

3 The Hartley brace (Figure 5) (reference 4). I have not asked the designer, but the reason for the parallelogram arrangement can onl have been to control the foot positio relative to the ground. Once th parallelogram was moved from the feet (Figure 6) it became an encumbrance using eight hinges in the reciprocal system instead of two and created inherent frictional problems without imparting a benefit. As John Florence wrote, further development failed to make this system effective.

Financed by the DHSS, about ten sets of polyplanar reciprocal calipers were made for spina bifida children, with the help of Moyna Gilbertson (then at the Hospital for Sick Children, Great Ormond Street) and Tom Towers of Pryor and Howard. The results were written up in 1971 (references 5 and 6). Contrary to popular belief, they were a great success for two or three of the children, and (here I disagree with John Florence) did "provide power" to the legs; by the child pulling himself forward over the standing leg (with his crutches), he extends the standing leg which

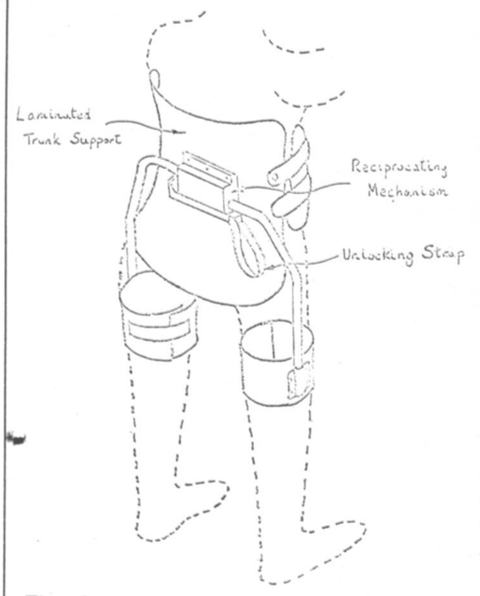


Fig. 4

(through tension on the front cable) automatically swings the other leg forward.

Children without *any* muscle power in their legs could walk reciprocally using elbow crutches at a speed faster than any other method except swing through — but they could still swing through if they chose. The major disadvantage was the width of the brace, owing to the angled hinge and the projection of the cables.

From 1971 to 1974 the DHSS (who were very helpful throughout) financed a part-time three-year project for myself and Bill Bond, an engineer, and the Polytechnic of the South Bank. Our main aim was to design out the faults in the polyplanar system, but also to develop other aspects of lower limb bracing (reference 7). The final reciprocal brace is shown in Figure 7.

Like John Florence, I am delighted that some others are now taking an interest in reciprocal gait and may be able, in the next few years, to take things a step further. However, I think that several points need bearing in mind.

1 Reciprocal gait, whilst cosmetically attractive, is unlikely ever to be as efficient functionally as swing through gait.

2 In standing, the hips tend to flex and the trunk fall forwards. A pelvic band does not have the lever arm to combat this and to *control hip movement* a thoracic level support is usually necessary.

3 To be efficient and cosmetic, reciprocal gait requires pelvic (and trunk rotation. This can be allowed for by loose fitting apparatus but we have found that, reciprocal systems work best when the body and the brace are closely applied and follow each others actions precisely; and this needs designing in (Figure 8).

4 Any system which transmits the movements of one leg to another also transfers *lack of movement:* if one leg cannot extend then it will prevent the opposite from flexing. These systems work best for those with no muscle spasms and no fixed deformity at the hips.

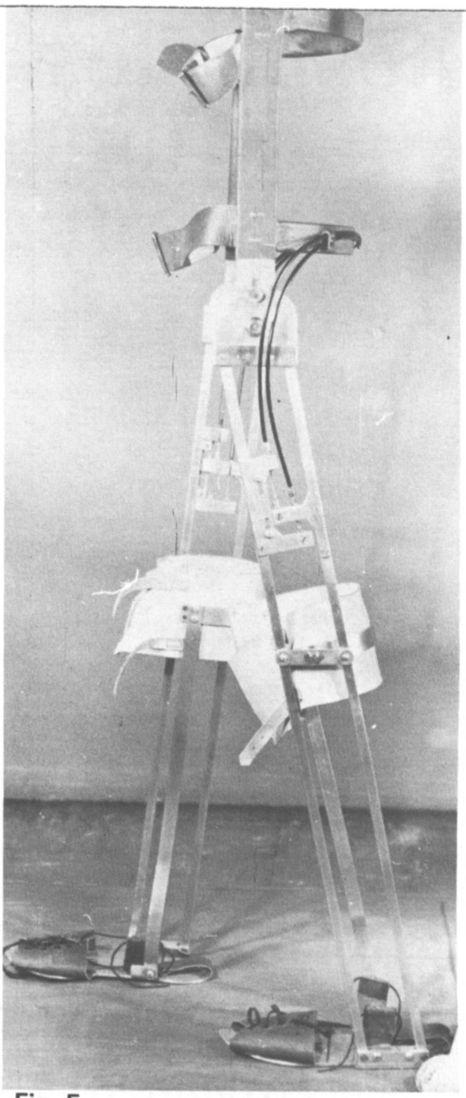


Fig. 5

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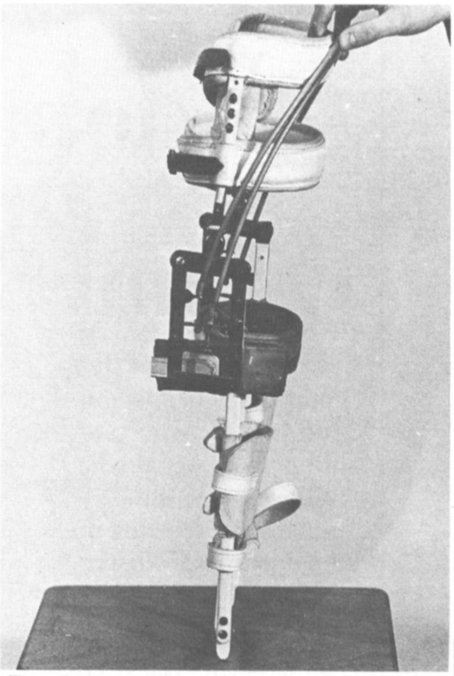

Fig. 6

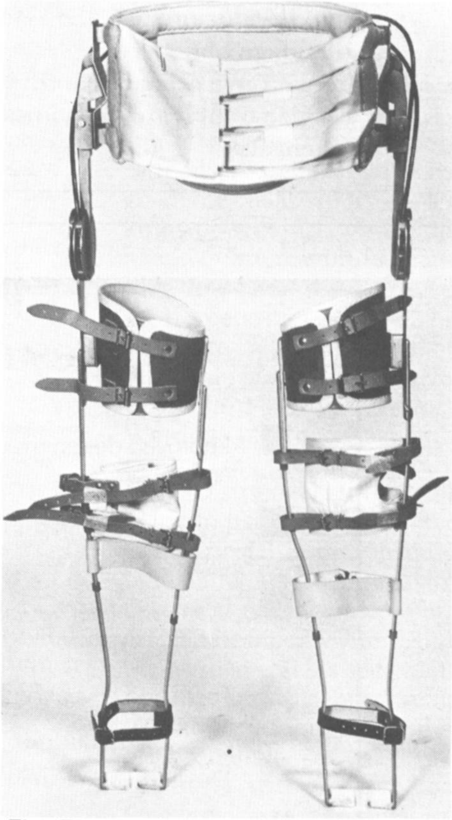

Fig. 7

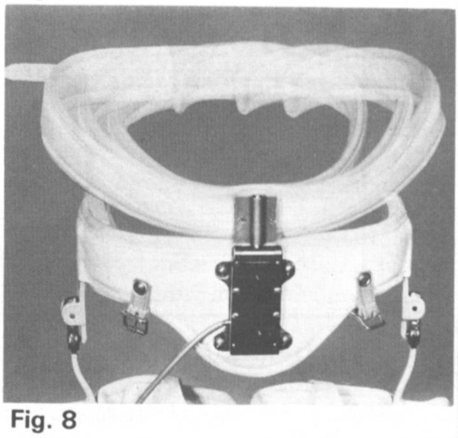

Fig. 8

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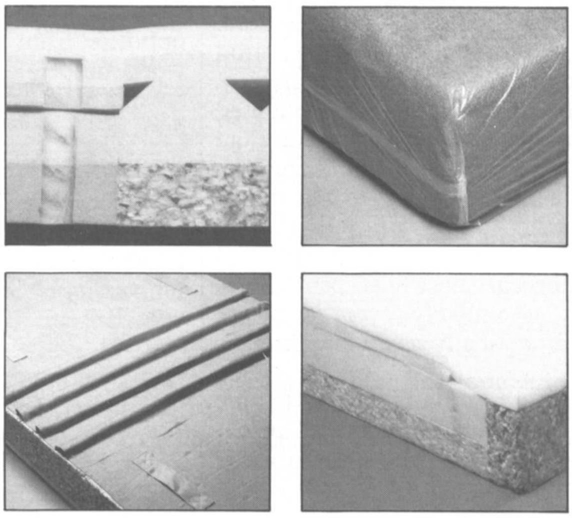

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Newslines NEWSLINES Newslines

Kate Holmes — a lady who talked her way to a title — that of Conversationalist of the Year 1986. Seventy competitors took part and their conversations were judged for wit, content, lucidity and staying with the subject.

Lucy said "I sell insurance for a living, so it's also part of my job to talk to people each day. I concentrate on puting people at their ease". The competition, held annually by ASBAH, took place at the Glaziers Hall in the City of London, and raised several thousand pounds. It also, once again, provided ASBAH with good publicity in the local and national media.

PLANS to provide hostel accommodation in London for disabled people have ground to a halt, largely because of bureaucratic hold-ups, and complaints by local residents.

A number of charities formed a consortium to help meet the need of disabled people for low-cost accommodation in London. They created The London Hotel for Disabled People (LHDP).

It was a response to the fact that only 50 hotel beds in London are suitable for wheelchair users, and these are in the more expensive hotels, beyond the reach of many people.

The consortium has already helped to provide ten easonably priced rooms at e London Tara Hotel suitable for disabled people.

In 1983 it met with the Youth Hostel Association and together they came up with a plan to adapt one of London's youth hostels. Both organisations offered to meet the costs. Hopes were high.

But trouble loomed in the shape of bureaucrats and local residents. The bureaucrats led the consortium through a maze of planning problems, form-filling and official enquiries. The residents, meanwhile, got together to block progress.

The consortium hasn't enough money to meet the gal cost of challenging the pposition and so the scheme cannot proceed.

But the consortium plans to fight on. Chairman, Charles Moore, says: "We are prepared to do all that is necessary but we need help — help to find useable sites or buildings in central London, help to persuade authorities of the justice of such plans, help to raise money, and help to get over to everyone the need to do it ***now***."

ASBAH supports the aims of the consortium. If you would like to add your support write to: William Barnes, LHDP, Juxon House, 94 St Paul's Churchyard, London EC4M 8EH. Tel: 01-248 9155.

● Disabled people are not after all going to be banned from going to the cinema. A proposed ban on disabled cinema-goers met with so much outcry that the Home Office has stepped in saying it will not allow restrictions other than those which say that wheelchairs must not be put in gangways where they will block exit routes. If you were one of those people who registered your complaint at the proposals after perhaps reading them in LINK Nov/Dec 1985 then you should be feeling pleased that your voice was actually heard!

● A register of reputable driving instructors all over the country to whom suitable disabled people can be referred for driving lessons is in the process of being compiled by the Mobility Information Service based in Shrewsbury. The plan for a register has come about because of the Service's concern about complaints from disabled learner drivers that they were 'ripped off' or actually discouraged from learning to drive by some driving schools. The address of the MIS, is Copthorne Community Hall, Shelton Road, Shrewsbury, Shropshire. Tel: 0743 68383.

● Disabled visitors to the National Garden Festival in Stoke-on-Trent this year might like to send for a list of accessible accommodation in the area. It has been compiled by D.I.A.L. Stoke on Trent, Trent Centre, 645 Leek Road, Hanley, ST1 3NF. Tel: 0782 269744.

● An exciting 'Learning for Living' course is being run at Nash House — the extended education unit for physically handicapped students of 16 and over — at Coney Hill School, Hayes in Kent. There are places for 32 students on the course which leads to a national recognised Certificate of Pre-Vocational Training.

Students will have a chance to take City and Guilds Numeracy and Literacy, RSA Typing, First Aid and Music exams, learn to drive and to develop their skills in crafts, home economics and leisure pursuits. Alongside this will be work experience and self-care training in the independent living flats.

Students will also help make and sell 'Nash House Productions' — jewellery, woodwork, cookery and horticultural produce.

More details are available from the Head Teacher, Mrs D. E. Hobbs, Coney Hill School, Croydon Road, Hayes, Bromley, Kent, BR2 7AG. Tel: 01-462 7419.

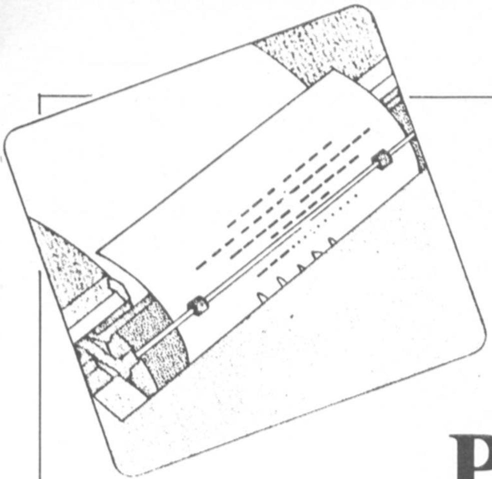
● The Youth Hostels Association is organising 'Handicapped Special Friendly Face Weekends', on every weekend in August, where handicapped hostellers will be given the chance to try out all kinds of activities, visit local places of interest or do whatever they like.

"If a person in a wheelchair wants to reach the top of Kinder — we will carry them up" said Dave Teare, Warden of the Castleton Hostel in the Derbyshire Peak District where it is all going to happen.

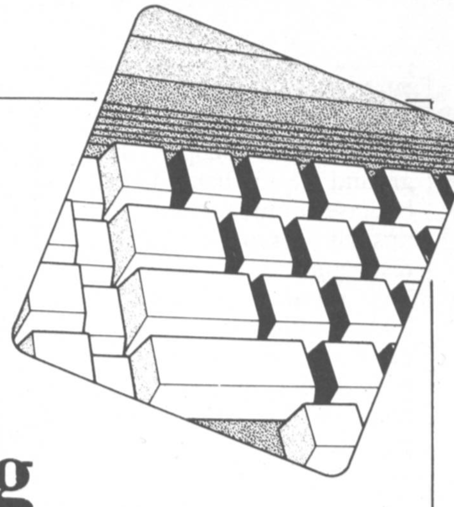
The hostel is not purpose built and its facilities are described as not being perfect for handicapped visitors, but the warden and his staff want to encourage people with disabilities to join in the fun of hostelling so they are making a special effort and throwing open an invitation for the 'Friendly Face Weekends'. The staff at Castleton are experienced in helping handicapped people, and the caterers can cook for special diets.

The cost is £17.50 (21 and over), £15.50 (16-20 years), £12.50 (under 16), plus standard hostel fees.

For details contact Dave Teare, Castleton Youth Hostel, Castleton Hall, Castleton, Sheffield S30 2WG. Tel: 0433 20235.



Continuing his series of articles on the education of children with spina bifida and/or hydrocephalus, John Costello asks how important good handwriting is. He looks at other ways of communicating in writing.



Put it in writing

— the modern way

POOR handwriting has become recognised as an important difficulty for many children with spina bifida and/or hydrocephalus. The excellent booklet* on this topic, available from ASBAH, suggests that this may not be the most obvious feature of the disability. It is, of course, true that incontinence and impaired mobility are much more apparent problems, but the ability to write legibly and at a reasonable speed is a serious handicap in education, and may be particularly frustrating for children whose level of intelligence and ability is otherwise good.

Producing written work is a very large part of education in British schools — perhaps unreasonably large. As children become teenagers most school subjects involve a lot of writing; and a lot of examinations both at school and in higher education demand answers in the form of written essays. This kind of work no doubt develops skills in finding, organising and using information, and these abilities are likely to prove useful in many aspects of life. On the other hand, it is hard to argue that the actual presentation of a carefully written essay is itself a valuable skill — it is a task to which very few people ever return once they have completed formal education. In practice, many teachers use written work to assess children's progress; and, even if the content of the work is good, its untidy appearance may give teachers an unreasonably bad impression.

A lot has been written about why children with spina bifida and/or hydrocephalus have handwriting problems. These children often have weak muscular control and poor hand-eye co-ordination, which together produce a clumsy style of writing. Whatever the underlying causes, however, it is clear that many children have difficulties both in writing neatly and legibly and in writing at a reasonable speed.

It is not easy to say what good writing is. We can say that it should be easy to read, but that does not mean it should have a standard pattern like a printed page. The best handwriting has its own individual characteristics. What makes writing unacceptable is a generally cluttered appearance with words badly spaced and letters irregularly formed. Teachers are likely to be reluctant and sometimes unable to disentangle the words from amongst what looks like a scribbled mess. It is difficult for children to take a pride in what they write if they cannot make it look attractive or even acceptable to other people.

Many children with spina bifida and hydrocephalus write very slowly. In some cases it may be possible for children to improve the legibility and general appearance of their writing only by reducing the speed considerably. Having to write slowly is a serious problem when taking notes in class. But it is even more frustrating, particularly for more creative children, to write slowly when producing individual work. Ideas may come, but the unbearably laborious process of writing them down may prevent children from expressing these ideas. Slowness in writing can result in children who are imaginative and orally articulate, producing short and over-simplified written work in order to avoid the physical effort of writing. Such children's ability is likely to be under-rated.

You might think that there are two possible answers to these difficulties. Either we try to teach our children to write better and more quickly; or we try to avoid written assignments and provide typewriters, word-processors, tape-recorders or whatever other means of communication seems appropriate. But neither approach is likely to be satisfactory by itself — we need both. Perhaps it is worth pausing for a moment to think why.

There does not seem to be any sensible reason for encouraging children who can write, however laboriously, to give up handwriting altogether, as it will always be a necessary skill. On the other hand there are undoubtedly some children for whom writing will always be a slow and painful process, and for these we ought to look for an alterntive.

There is no doubt that children can be systematically taught to write. This does not mean just giving them copying tasks — this is one situation where practice alone does not make perfect. Poor handwriters can spend hours of every day writing and still be poor handwriters. What is needed is careful attention to, and advice about hand movements and about the precise way in which letters are formed. The relative size of letters and the spacing between words are also important features. Help and advice of this sort can produce a real improvement, but it has to be recognised that for some children (with spina bifida) writing will still be very difficult and, therefore, it must be questionable whether it is worth spending a great deal of time and effort on it.

Some severely disabled people are able to express and record their thoughts only by using a tape-recorder. Some can take examinations only by dictating the answers for someone else to write down; and there are those who have 'written' books by dictating the text. These are rare and exceptional situations, but they emphasise that the satisfaction of writing lies in the creation and expression of ideas and not in the physical activity. In all but a very few cases, however, such extreme forms of assistance are neither necessary nor valuable.

An important part of setting out our thoughts in writing is that we can keep looking back over what we have written so far and review our ideas. Dictation, particularly into a tape-recorder, makes

Continued from page 20.

this much more difficult. For most people, using some kind of typewriter or printer is a better alternative to writing.

It is sometimes argued that children whose writing is poor are unlikely to develop useful keyboard skills, since such skills also need fine co-ordination. Fortunately, this does not seem to be the case. Manual dexterity is a complicated mixture of skills; and children who write badly may well develop delicate motor skills of other kinds, perhaps in playing a musical instrument or some kind of craft work or even controlling a wheelchair or an electric vehicle.

My own son, Timothy, has to write very slowly to make his work readable, but he copes expertly with some of these other manual activities. Poor writers can sometimes become fast and accurate typists.

These are not just practical considerations. If people whose movements usually appear clumsy and uncontrolled can find situations in which they can operate with precision and a certain gracefulness, this can be a source of great emotional satisfaction.

Writing is a very personal aspect of human activity, and one in which we all have individual needs and purposes. If you have problems with this you can do two things — you can get help and advice to improve your writing, or you can look for technological aids to avoid writing.

**The Handwriting of Spina Bifida Children. (See inside front cover of LINK).*

Parking spaces in London

A FEW MORE parking places have opened up for Orange Badge holders in Central London.

Following respresentations from the Joint Committee on Mobility for the Disabled, Westminster Council has modified its policy of barring Orange Badge holders. It will allow holders to park in any of 18 specially designated on-street parking spaces:—

Duke Street (North from Oxford St), West side, outside Selfridges — 3 spaces.;

Orchard Street (North from Oxford St), West side, outside Marks and Spencers — 3 spaces;

Marylebone Lane (North from Oxford St), West side, outside Stratford Court Hotel — 1 space;

Vere Street (North from Oxford St), West side, outside No. 6 — 2 spaces;

Vere Street (North from Oxford St), East side, outside St. Peter's church — 3 spaces;

Leicester Square — opposite Odeon cinema — 2 spaces;

Chapel Street (East from Edgware Rd), North side — outside Marks and Spencers — 2 spaces;

Howick Place (South from Victoria St), North side, outside the Army and Navy — 2 spaces.

The City of London, Kensington & Chelsea and Camden — except for one area — still do not allow Orange Badge parking. The Camden exception is an area north of the Euston Road.

ASBAH NEWS

Seminar

ASBAH's first seminar for older people with spina bifida and/or hydrocephalus (pre 1956) took place in June, and 25 people attended from as far afield as Cornwall and the Isle of Wight.

They heard about ASBAH's range of services, and the session on incontinence proved of particular interest.

During the day, Miss Moyna Gilbertson, ASBAH's Executive Director, spoke about the survey of older people which ASBAH had carried out in 1984.

At the end of the day one lady said she had learnt more from this seminar than she had during the rest of her life. There was a request for another meeting — maybe to span a weekend.

Staff change

ASBAH recently said goodbye to a valuable member of staff:

Beverley Holland who worked in a variety of ways over 8 years to build up ASBAH's information department left in June to further her career as Information and Development Worker for Islington Disablement Association.

Beverley, as Information Officer, built up ASBAH's stock of material, especially a range of Factsheets, and was responsible for the bi-monthly Bulletin to local associations.

She was also instrumental in helping to set up two support groups — the Hydrocephalus Support Group, and SATFA (Support After Termination for Fetal Abnormality).

Exchange

An ASBAH group of young adults with spina bifida and/or hydrocephalus is due to go to San Francisco next year (May 28-June 16) as part of an exchange contact which LIFT has made with disablement groups from San Francisco's Bay Area. This contact came about after a Seminar in California to promote exchanges, attended by Paul Cooper, Development Officer at Five Oaks.

It is hoped that the group will be able to go on from San Francisco to the International Federation for Hydrocephalus and Spina Bifida Conference being held in Denver from June 17.

Sue Gregory, Senior Dental Officer in North Bedfordshire and a member of the Executive Committee of the British Society of Dentistry for the Handicapped, gives some simple guidance for healthy teeth especially for LINK readers.

The whole tooth — and nothing but the tooth

HEALTHY teeth are important to all of us. They help us to:—

- enjoy our food
- speak clearly
- face the world with a smile
- avoid toothache

All of us would prefer to keep our own teeth for life. For those with hydrocephalus or spina bifida it is even more important to maintain a healthy mouth and to avoid the possiblity of infection.

There are two major dental diseases — periodontal (gum) disease and dental caries (tooth decay). So we have two battles to fight. Most of that fighting can be done at home just following some basic rules, whether caring for your own teeth or one of your family.

Keep the mouth clean

You will probably have heard of the term PLAQUE. This is a sticky film of bacteria which forms every day on every one's teeth. If this film is not brushed away thoroughly at least once a day, it will cause periodontal disease.

Plaque is normally white and difficult to see, but by staining the teeth with a harmless dye (available from most chemists) it becomes obvious and thus can be removed more efficiently. Choose a toothbrush with a small head and flexible nylon bristles.

It is important to clean every surface of every tooth, which is difficult to manage if you brush haphazardly. Use a system, start in one corner at the top, brush all the way round the outside, back around the inside and then the biting surfaces. Same again at the bottom.

If you are helping someone else to brush their teeth, it is usually easier to do it from behind then, for example, a person in a wheelchair will find their head well supported against your tummy.

Always use a fluoride toothpaste.

Eat the Right Foods

Everybody likes sweet things and they can be difficult to avoid. Remember it is the number of times per day that the bacteria in the plaque are fed with sugar which matters.

So if things containing sugar are eaten:—

- try to avoid them between meals
- remember the best time to have them is directly after meals
- try to think of an alternative.

Fluoride

Many water supplies now have fluoride added to them. If your local water supply is not fluoridated, ask your dentist's advice. Fluoride supplements are especially beneficial for handicapped children's teeth and can be taken in tablet or drop form.

Visit your Dentist Regularly

Most people's first line of contact with a dentist is to the local General Dental Practitioner. If you have problems in obtaining the care you require the local District Dental Officer may be of help in providing you with information on any specific dental facilities available within your district.

The District Dental Officer's telephone number should be listed together with all the other District Health Authority numbers in your phone book.

Many Districts do offer more specialised facilities, for instance for people in wheelchairs, via the Community Dental Service.

Remember you are not alone in this fight.

A snack sheet, with ideas for suitable, healthy snacks that won't ruin your teeth, had been produced by the Community Dental Service, North and South Bedfordshire Health Authorities and the Nutrition and Dietetic Service of South Bedfordshire. It is available free from: The Health Education Centre, Luton, and the Dental Health Education Department in Bedford.

Mobile units

Two new mobile dental units (above) are now in action in Bedfordshire. The 24-foot-long vehicles are being used by the community dental teams in the county — one unit covers North and Mid Bedfordshire, and the other covers South Bedfordshire.

They were developed by North West Thames Regional Health Authority in order to improve the community dental service for people living in rural areas of Bedfordshire.

Great care has been taken in the design so that the special problems of handicapped children and adults and the disabled elderly are taken into account. There is a special lift for easy entry and exit. A Hatrick Recliner is available for patients who have to be treated in a wheelchair.
Photo: Dental Practice.

Advertising

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rate: £2.50 for 30 words max; £3.75 for 30-45 words; £5 for 45-60 words. Cheque or postal order payable to 'ASBAH'.

Adverts for next LINK (Sept/Oct) should be in by August 10. Send to: The Editor, Mrs Sue Gearing, The Gables, Long Lane, Wrington. Avon, BS18 7NE. Tel: 0934 862279.

HOLIDAY ACCOMMODATION

HEYSHAM, Nr. Morecambe. Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 5 Roman Way, Whitchurch, Shropshire. Tel: Whitchurch 3691.

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

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

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GREATSTONE, Kent. 3 bedroom bungalow. Lounge, kitchen, well equipped large bathroom with hoist. Large garden. Close to safe, sandy beach and shops (200 yds). NE London Association (NELASBAH). Details: Mrs Pierson. 18 Kingsley Rd., London E7 9PP. (Sae please).

COLWYN BAY (near). 6 berth luxury holiday home. Fully adapted for wheelchair users. Quiet family run site. Details: Mrs C. Hughes. Tel: Abergele 824673.

SELSEY, Sussex. Purpose built 7-berth mobile home. Fully equipped for wheelchair users. Cot available. Licensed site. Details: Mrs M. Holmes. 11 Grove Road, Ashtead, Surrey. KT21 1BE. Tel: Ashtead 76730.

CENARTH, W. Wales. Luxury chalet adapted for wheelchairs. Sleeps 6. Colour TV. Heated pool, restaurant, shop, launderette. Details: Mr T. Noon, 14 The Chase, Leicester LE3 2WA. Tel: 0533 895691.

WINTERTON-ON-SEA, Nr Great Yarmouth. Chalet-bungalow. Sleeps six. 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. J. Morris. Tel: 0494 32184.

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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.

CHAPEL ST LEONARD'S , Nr Skegness, Lincs. Specially designed accessible bungalow, in own grounds with children's play area. 4 bedrooms, sleeps 8. TV. Fully equipped. Good local shops and safe beach. Skegness 6 miles distance. Details: Mrs J. Brook, 11 Standiforth Road, Dalton, Huddersfield HD5 9HD. Tel: Hudd. 21776.

LOOE, Cornwall. Self-catering bungalow, suitable for wheelchairs. Sleeps 4/7. Well furnished and equipped. Colour TV. On holiday site with facilities. From £45 per week. Details: P. Cash, Farriers, School Road, Bransgore, Christchurch, Dorset. Tel: 0425 72055.

CLACTON ON SEA, Essex. Hylands Chalet Park. 6 berth chalet. Outdoor pool, shop and clubhouse. Equipped with electric cooker, fridge, TV, shower. 5 minutes walk village with supermarket, shops and banks. Tel: Mrs J. Bashford, 01 735 5489.

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Complete set of Bekker hand controls to fit Austin Allegro. £25.

Also set to fit Talbot Horizon. £25. Both in excellent condition. Tel: Barry (0446) 736135.

Nippy 3 wheeler scooter, driven from adapted wheelchair or can be fitted with a seat. Honda 80cc engine. Only 205 miles. (Cost over £2,000). Complete with Everest & Jennings wheelchair: £1,500 o.n.o. Tel: 0244 376597.

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Mrs P Keyes,
Pinfold, Chapel Lane,
North Scarle, Lincoln.
Tel: Spalford 781.

**LINCOLNSHIRE
N.E. & S. HUMBERSIDE**
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ASBAH Centre,
Hainton Avenue,
Grimsby.

LINCOLNSHIRE SOUTH
Mrs P Mason,
67 Boston Road,
Heckington, Sleaford.

LIVERPOOL
Tudor House,
Wood Lane,
Liverpool L27 4YA.
Tel: 051-488 0246.

LONDON, CENTRAL & NORTH
Mrs Christine King,
30 Derwent Road
London, N13 4PU
Tel: 886 7286.

LONDON N. EAST
Mrs B A Pierson,
18 Kingsley Road,
Forest Gate, E7 9PP.
Tel: 01-472 8605.

LONDON N. WEST
Mrs H Prentice,
37 Milton Road,
Hanwell,
London W7 1LQ.

LONDON SOUTH
Mrs S Cudd,
15 Woodvale Walk,
Elder Road,
W. Norwood, London SE27.
Tel: 01-761 2400.

MANCHESTER CENTRAL
Mr G Watson,
8 Bushnell Walk,
Manchester M9 2QH.
Tel: 061-795 0029.

**MANSFIELD, WORKSOP &
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Mrs E Freeman,
23 Melbourne Street,
Mansfield Woodhouse, Notts.

MIDLAND
Mrs D Britt,
14 Court Road,
Sparkhill, Birmingham 11.
Tel: 021-771 0371.

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

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

OXFORDSHIRE
Mrs Pam Jarvis,
71 Woodfield,
Ruscote, Banbury.
Tel: Banbury 58124.

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

ROTHERHAM & DONCASTER
Mr & Mrs D Barringer,
21 Coppice Gardens,
Broom Riddings,
Greasbrough,
Tel: Rotherham 56686.

ST. HELENS & DISTRICT
Mrs N Maddocks,
236 Rainhill Road,
Prescot,
Merseyside L35 4LD.
Tel: 051-426 3921.

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

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

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

SOUTHAMPTON & DISTRICT
Mrs H Vaughan,
6 Lumsden Ave, Shirley,
Southampton SO1 5EL.

STAFFORDSHIRE
Mrs J Davies,
8 Oakhill Avenue,
Stoke-on-Trent, ST4 5JN.
Tel: Stoke-on-Trent 45365

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Jesolo,
Lea Croft,
Shortwood Common, Staines,
Middx. Tel: Staines 50854.

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1 Brookside Avenue,
Offerton,
Stockport.

SUFFOLK
Mr D. J. Lawrence,
69 Woodberry Way,
Walton on the Naze,
Essex CO14 8EW.
Tel: 02556 6245.

SUNDERLAND
Mrs A Shepherd,
115 Holborn Road,
Sunderland.
Tel: 0783 283 568.

SURREY
Mrs J Straker,
Squirrels Leap,
Woodfield Lane,
Ashtead.
Tel: Ashtead 72009.

SUSSEX
Mrs M White,
Averys, Rusper, Horsham,
Tel: 029 384 217.

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

TRAFFORD & SALFORD
Mrs T Gaynor,
Moorefield Annexe,
Council Offices,
Crofts Bank Road,
Urmston, Manchester M31 1UD
Tel: 061-748 4000. Ext. 293.
Mornings.

WARRINGTON & DISTRICT
Mr P Gosner,
22 Sage Close,
Padgate,
Warrington WA2 0UG.
Tel: 0925 819943.

WESSEX
Mr T Poole,
123 Gerrards Green,
Beaminster, Dorset,
DT8 3EA.
Tel: 0308 862614.

WHITCHURCH & DISTRICT
Mrs D R Calder,
3a Bridgewater Road,
Whitchurch, Shropshire.

WIGAN, LEIGH & DISTRICT
Mrs Margaret Mort,
27 Park Road,
Hindley, Nr Wigan.
Tel: Wigan 56361.

WIRRAL
Mrs M Hudson
28 Stavordale Road,
Moreton, Wirral,
L56 9PR.
Tel: 051 678 4409.

WORCESTERSHIRE
Mrs G Doleman,
9 Pelham Road,
Droitwich, Worcs. WR9 8NT.
Tel: 0905 775862.

YORKSHIRE NORTH
Miss F M Seward,
45 The Paddock, York YO2 6AW.
Tel: 0904 798653.

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde
Mr John Dewhurst,
62 Edmonton Place,
Bispham,
Blackpool.

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

Cannock & Walsall
Mr Ken Hall,
17 Wallhouse Street,
Cannock, Staffs.
Tel: Cannock 4847.

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

Consett & District
M Broadley,
15 Girvan Close,
Burnside, E. Stanley,
Stanley, Co. Durham.

Derby & District
Mrs A Hewitt,
St Merryn, 20 Burley Hill,
Allestree, Derby.

East Anglia
Mr P Grantham,
7 Ash Close, Downham Market,
Norfolk, PE38 9PS.
Tel: 0366 382200.

Gainsborough & District
Mrs M. Hawkes,
10 Turpin Close,
Gainsborough, Lincs.
DN21 1PA

Isle of Wight
Mr D J S Sprake,
Springfield, Town Lane,
Chale Green, Ventnor, I.O.W.
Tel: Chale Green 234.

**Lancaster, Morecambe &
District**
Mrs M Dyson,
25 Royds Avenue,
Heysham, Lancs.

Rochdale
Mrs Ann Lawton,
20 Spencer Street,
Chadderton, Oldham,
Lancs.
Tel: 061 652487.

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

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

OTHER AFFILIATED ASSOCIATIONS

WALES

LLANELLI
Mr P Williams,
8 Glasfryn Road,
Pontardulais,
Swansea, SA4 1LL.
Tel: 0792 841930.

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

NORTH WALES
Mrs E Boddy,
Canolfan Yr Orsedd,
Fford Orsedd, Llandudno,
Gwynedd. Tel: 0492 78041.

SOUTH WALES
Mrs Brenda Sharp,
38 Redbrick Crescent,
Barry Island, S. Glamorgan.
Tel: Barry 735714.

SCOTTISH SPINA BIFIDA ASSOCIATION

Executive Officer:
Mrs Audrey Smith,
190 Queensferry Road,
Edinburgh EH4 2BW.
Tel: 031-332 0743.

NORTHERN IRELAND

Mr J. Rippey,
Long Eaves,
24 Tulleywiggan Road,
Cookstown,
Co. Tyrone.
Tel: Cookstown 62290.

IRISH ASSOCIATION

Mr Michael Neville,
Old Nangor Road,
Clondalkin,
Dublin 22.
Tel: Dublin 01-572326.

Please will all local Secretaries who want entries changed contact: Mrs Sue Gearing, LINK Editor at National Office: ASBAH, 22 Upper Woburn Place, London WC1H 0EP. Tel: 01-388 1382.

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