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Link

JULY/AUGUST 1977 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)

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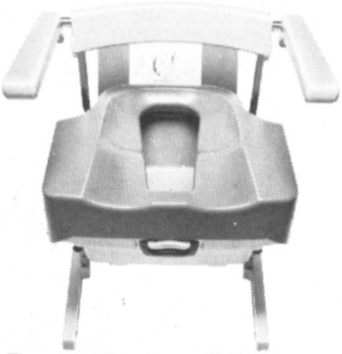

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pages

Opinion

As an older spina bifida sufferer working for the Association I find myself looking with somewhat different eyes on our youngsters. I am one of the lucky ones, not only in having handicaps with which I can cope but also in two other respects. I have been able to achieve my ambition of becoming the Headteacher of a 330 strong infant school and I have been surrounded by people who MADE me lead as normal a life as possible.

If this makes you think that I must have had it easy—not so. I was quite handicapped as a child with calipers etc, have a badly deformed spine plus scoliosis (4 ft 10 in. on my long leg!) and ostoemyelitis in my feet. I enter hospital almost yearly for surgery—school holidays of course.

But it isn't me I want to talk about. I want to talk to you as parents and what I want to say is PLEASE LET GO.

Every person has the right to be an individual, has a personality to develop and a life to lead. Do you as parents let your handicapped child exercise this right? So often I see parents being over protective not only physically but mentally. We all learn by our mistakes but if youngsters are not allowed to make mistakes how can they learn by them?

All teenagers are difficult but so often this is put down, by parents of the handicapped, to their disability not to their being teenagers. When did you last ask your youngster where he would like to go on holiday? If he would like a holiday without you? Five Oaks could be a glorious venue for a teenagers' house party—but not for your child; he wouldn't like it—or would he? Has he been asked?

All teenagers want quite unsuitable clothes—just look at shoes—but they learn. Can I quote myself as an example, I have my shoes made. They are rather ugly alas with one built up. I desperately wanted them made in a rather vivid red. My family suggested they would draw attention to my feet and were not suitable. I pleaded and was allowed to have them. The family were right. They were horrible. My mistake, but I learned by it. We dyed them black!

On the other hand, do you 'pander' to your child, allowing him to rule the house? Many do, but you wouldn't if he weren't handicapped, would you?

PLEASE LET GO. If you don't I can see two alternatives. Either the young person will turn into a rather self-centred, unpleasant adult or he will opt out completely and let you, or anyone else, take decisions for ever.

My family let go. I brought them lots of worry and an awful lot of heartache in my escape. My mother died when I was 11 but my father lived 17 more years to see his rebellious daughter achieve more than he had ever dreamed of or hoped for; more than my two sisters who helped me so much.

FAITH M. SEWARD, BA
Executive Member, Education Sub-committee Member,
Secretary North Yorkshire Branch.

FRONT COVER Wendy Stewart of Cumnock talking to the Queen when Her Majesty visited a new housing estate in Govan, Glasgow earlier this year.

News from all around

Why we must try to walk

An 18-year-old girl with spina bifida felt so strongly about the importance of learning to walk that she sent this letter to *Link*:

'At the Nottingham Conference a parent said to me: "She walks if she wants to. We don't make her. It's very hard work".

'I know it's hard work learning to walk, and I can assure you it is an uphill struggle all the way. But I now realise that if I was not able to walk from my car to my chair I would not be able to work.

'Don't take "no" for an answer because your future may depend on it. You can always get up one step on your own with difficulty if you are walking, but you need help if you have to do the same in a wheelchair. If someone has to help you four times a day they will soon get tired of it.'

Simon gets swim award

Congratulations to eight-year-old Simon Hartill of St Margaret's, Kent who recently gained an advanced swimming award. He had to swim 100 metres, dive three feet to the bottom of the pool to retrieve a small object, dive and swim 15 feet with his face submerged, and swim 25 metres on his back.

Simon is a member of the Dover physically handicapped swimming club and is now aiming for the bronze survival award.

Good News from Belfast

The photograph captures a very happy moment for the Belfast Association — the opening of a splendid new 30 ft clipper caravan, which was obtained with Green Shield Stamps!

The magnificent total of 3,500 books of stamps was collected during the past year from the Belfast area by many friends of the branch.

This luxury caravan is situated at Ballycastle, a well known seaside resort on the Antrim coast and will be used by Association families.

There were enough stamps left over to completely equip the caravan with bedding, china, cutlery, etc. a fridge, two spare folding beds and even a lawnmower.

Star in her own right

Mrs Nancy Scott, the Social Worker with Bucks ASBAH writes:

Joanne Tilly of Windsor was recently awarded the Girl Guide Star of Merit and invited me to the ceremony as one of her six guests. This was an honour and one I was happy to accept.

'As the County Commissioner remarked the Star was not gained easily. Out of all the names put forward only one in twenty got through. Joanne well deserves her Star. She has borne her disability with enormous courage and I have yet to hear her complain. Although confined to a wheelchair she takes part in everything and her sporting record especially in swimming is notable. Congratulations to Joanne and her parents who have supported her'.

Arrow raises £200

Sunderland and District Association has found good friends in the crew of HMS *Arrow*. They recently raised £200 for the Association by direct donation and also from a sponsored walk.

Mr Fagan a member of Sunderland ASBAH painted a picture of the commissioning ceremony of HMS *Arrow* and presented it to the officers and crew.

Information

Mud prize—£1,137

A happy picture—and there's a good reason for being so pleased. A special matinee featuring The Mud at Batley Variety Club raised more than £1,137 for Leeds and Bradford Association. Debbie is pictured with one of The Mud and the very happy man in the foreground is Michael Booth, Chairman of the Leeds and Bradford Association.

'MUSIC—to help disabled children to move'

Although primarily aimed at physiotherapists, this practical and easy-to-read booklet will also be of value to other professionals concerned with the care and education of disabled children, including playgroup and nursery school leaders. Moyna Gilbertson, ASBAH's Chief Executive Officer, who is, of course, an experienced Physiotherapist, and Daphne Kennard, a Music Lecturer, authors of this booklet hope that it will help to 'unlock' the music that may so often remain hidden in us. It shows the value of music for children; it may give them a chance to do something completely independently, be a means of communication or socialising, or provide valuable exercise. The booklet discusses singing, instruments, movement and listening.

Price 40p from: Physiotherapy Dept, Brays School, Brays Road, Birmingham B26 1NS.

ASBAH Launches 'Swop Shop'

As some major items of equipment are very costly an 'exchange and mart' scheme is being set up at National Office so that people can buy and sell second-hand equipment.

If you have any significant items to sell, e.g. an electric wheelchair, please contact the Appliance Officer, Jill Vernon. Give your name, address and telephone number, the exact make and model of the item and its condition, and the price you require. *Please do not send the equipment.*

Advertisements for equipment will appear in Link and/or the Bulletins which are sent to Local Association Secretaries.

'Making Movement Fun'

This booklet gives guidance on movement and positioning for the severely disabled child—movement which will widen the field of vision and thus the child's experience, and also prevent stiffening of joints and contracture of the limbs. It is written by Frederick Mortimore, a remedial gymnast, who believes first and foremost that movement should be fun for both child and helpers.

Price 50p, postage 10p. National Society for Mentally Handicapped Children, Pembridge Hall, 17 Pembridge Square, London W2 4EP.

NAIDEX '77

This year the Exhibition looks like being even bigger and better than before. Until now the Central Council for the Disabled (now BADAR) has been the sole sponsor of this annual Exhibition of Aids for the Disabled. This year it is being joined by Hospital and Social Service Publications Ltd. Naidex '77 is based in London at the Royal Horticultural Society's New Hall at Greycoat Street, Westminster, from 9 - 12 November. Further details from BADAR (British Association for Disability and Rehabilitation)—formerly CCD—, 34 Eccleston Square, London SW1.

Just before going to press *Link* heard how successful a special week of independence training for 12 youngsters from Sussex Association had proved. The next issue of *Link* will carry a full picture report.

Finding footwear

Finding suitable footwear is a headache for a large number of families with spina bifida children.

Shoes should open to the toe, so that the child's paralysed foot can be placed flat in the shoe. This prevents possible damage caused by the foot being in an unnatural position. Shoes should provide good ankle support to prevent the shoe slipping off the foot. Local shoe repairers may be able to add extra ankle straps if necessary.

A firm called F. E. Abbott and Co, make Shoo Shoos, which are a good leather open-to-the-toe bootee, available in children's sizes 2 -). Alterations, such as caliper sockets, for shoes bought privately, are done free under the National Health Service.

If the shape of your child's feet means that it is impossible to buy shoes that fit, then special ones may be ordered, at the discretion of the consultant. There are now two types of boot available under the NHS which are particularly suitable for spina bifida children. These are the Piedro boot, and the Biffabout boot, which may also be purchased privately.

The Stockport Odd Feet Association aims to try to overcome the problem of odd-sized feet. The Association gives information about national retail stores providing an odd shoe scheme, but most firms have an extra charge for this service. SOFA also links members who can swop shoes.

Many spina bifida children seem to wear out shoes very quickly. We need evidence about this problem, so that we can do something to solve it. So, *please* write to us at the National Office, explaining your problem, and telling us how many pairs of shoes you have had to buy for your child during the previous twelve months.

Addresses

(Shoo Shoos) F. E. Abbott and Co, 33 Forest View, Chingford, Essex E4 7AU.

(Piedro Boots) Gilbert and Mellish Ltd, 503 Bristol Road, Birmingham B29 6AU.

(Biffabout Boots) Ken Hall Ltd, 39 Regent Street, Kettering, Northants NN16 8QC.

Stockport Od Feet Association, 3 Chiltern Drive, Woodsmoor, Stockport, Cheshire SK2 7BE.

JILL VERNON

Health matters

Watch that weight!

Being overweight is the commonest nutritional disorder in the western countries of the world and maybe as many as 5% of all school-age children are far too fat.

Overweight is always the result of the child eating more than he needs and taking less exercise than he should. The amount of food a child needs depends very much on the amount [illegible] activity he undertakes. It is not surprising that spina bifida children who are inactive because of weakness of their legs, are much more likely to get fat than others. This risk particularly applies to those who are in good health and whose parents are fat. It is striking, at a clinic, that most really fat spina bifida children have overweight mothers or fathers.

It is not that most spina bifida children are gluttonous and eat more than other children. It is merely that because of their inactivity they cannot use up all the calories.

Obesity is a very gross disadvantage. It further limits mobility so a vicious circle is established. It will be more and more difficult for ageing parents to lift their bigger, heavier children so obesity may often lead to being bedridden.

There are also all the other complications of being overweight—like greater problems if operations are needed, the increased chance of heart attacks or strokes later in life or of getting diabetes or gall stones. These children have enough problems without these added fears in the future.

It is very difficult to treat fully established obesity, even in normal children. It is, therefore, essential to keep a very close eye on the children's weight which *must be related to their length*. Most spina bifida severely handicapped children are short and just weighing them and seeing that their weight is 'average' or less does not mean that they are not fat. Their weight and height must be proportionate to each other. Appropriate charts are available (from hospitals) to show this.

It must be realised that after a child begins to show a tendency to overweight his diet should be strictly looked at and the fattening foods, in particular, must be cut out. These are sugar, jam, marmalade, potatoes, biscuits, cakes, sweetened drinks—just the kind of things that children like.

Sometimes obese children are put on a diet containing about 1,000 calories which is a slimming diet for a fully active child but it is a fattening one for a child who is not mobile. The best indication, therefore, is a close check on weight and avoidance of all unnecessary snacks.

GIVE CHILDREN RIGHT FOOD FROM START

Do not worry if your spina bifida child eats much less than his brothers or sisters because he needs much less if he is inactive.

Apart from weighing him an easy way to see whether he is getting too fat is just looking at him. Look at yourself in the mirror and if you are fat you will realise that the chance of your child becoming obese is much greater.

Because the fattening foods are just those that many children like to eat and are used to, it is best to start on the right lines and get your children used to eating green vegetables, tomatoes, fresh food, meat and fish, eggs and milk and to use saccharine in tea or coffee. Otherwise if you try to introduce salads and so on into their diet later they often do not like them and refuse them.

Keep your child slim. It will be easier for him, for you and for the doctors who deal with him.

Dr J. LORBER, MD, FRCP,

SPINA BIFIDA

The two articles published on these pages and continued on page 10 must be taken together. The first is a personal and frightening view of the impact a spina bifida child can have on the family and on brothers and sisters. It is presented in such stark terms in response to the accusation that parents are not made sufficiently aware of the problems until they are overtaken by them. The second article admits to the problems, but is more optimistic, pointing to commonsense measures which are, or might be, available to most families.

It must be remembered that the support and help available to families varies enormously from one part of the country to another. Many Local Associations and their social workers do a tremendous job in helping to share and relieve the problems of individual families. National Association, too, is always willing to advise and assist wherever possible.

Both the writers are parents of spina bifida children as well as being active members of ASBAH at local and national level. They are John Saunders of Braintree, Essex and John Roddom of East Horley in Surrey.

Pressure on space made it necessary to edit both articles, however full copies are available from Mrs S. Gearing, 'Link', ASBAH, 30 Devonshire Street, London W1N 2EB.

Perhaps this will help families consider the problems before they are overtaken by them unawares

In considering the problems of the sibli[illegible]s (brothers and sisters) in a family that has a child with spina bifida it soon becomes apparent that a handicapped child means a handicapped family. The range of activities undertaken by a normal family is not available to the handicapped family. Activities such as pony riding, swimming, etc., soon become modified or curtailed altogether, writer John Saunders.

'This', he suggests 'constitutes a form of deprivation for the siblings of the handicapped child and is in most cases directly proportional to the severity of the handicap of the spina bifida child . . .

'Surgeons are able to tell us of the pending problems for the new spina bifida child but no-one—hospital medical social welfare worker, health visitor, social worker or anyone—tells us (or dares to!) of the poignant dramas to follow, of the pressures and tensions . . .'

Mr Saunders gives as examples the stresses which accompany the many stays in hospita[illegible] and the distressing disruption of normal fam[illegible] life that these can cause. Some brothers and sisters, he says, experience such a sense of loss that they too need medical care.

Mr Saunders believes that the family which faces the greatest problems is the one in which the spina bifida child is the oldest. The mother, he points out, may also have to cope with a baby.

'The strain on the mother trying to get across a city like London, in the rain, for a hospital appointment with a wet and tired baby in her arms as well as a calipered offspring produces

IN THE FAMILY

[illegible]in that reverberates through every family member.

'Over a period of years these pressures inevitably modify the family unit. It moulds itself to the prevailing conditions to the detriment of the siblings of the handicapped child . . .'

Mother inevitably has less time than she would like to spend with the younger children, who in turn have to learn to show an independence which is beyond their years.

They may have to be left repeatedly in the care of friends; an exhausted mother may just not have the energy to trail back upstairs at bedtime for that extra cuddle. When the other children go to school parents may find it impossible to give them the active support and encouragement they need.

The family in which the spina bifida child is the youngest is in a better position to cope, believes Mr Saunders. Older children can be an 'absolute blessing' but he warns that too much [illegible]ponsibility for their younger brother or sister [illegible]y cause anxiety.

He concludes: 'The considerations given here are drawn from several sources. Obviously many families cope very well but the big majority, I maintain, find themselves at their wits end. Not only must they come to terms with the physical and medical considerations of spina bifida but they have economic problems thrust upon them as well'.

Perhaps this will help families consider the problems before they are overtaken by them—unawares.

Positive solutions are what we need; specific, practical proposals leading to positive action

'The effects of spina bifida on family life are obviously considerable, but they are difficult to measure and by no means well understood' writes Mr John Roddom.

'It is clear', he warns 'that it is dangerous to generalise. People are very different in the way they react to circumstances; families are highly individual'.

He believes, however, that recognising the problems faced by the 'average' spina bifida family and voicing some of the worries and anxieties are the first steps towards providing positive help.

He adds, 'That the whole family is somewhat "physically handicapped" by the pressure of disability is a truism; that it causes many normal activities and family pursuits to be curtailed is obvious, but much can be achieved in the face of adversity and much more could be achieved with the imaginative provision of transport and other aids to mobility'.

He believes that the extra work and worry of constant caring which impose additional strains on many parents, can sap their physical and emotional energies so that the other children

SPINA BIFIDA IN THE FAMILY

may miss the full degree of parental attention that they would 'normally' expect.

But again Mr Roddom warns we must be careful. He asks, 'What is normal? Are not many families—ostensibly normal—similarly prone?'

He continues: 'Of course some families cope better than others; this is not necessarily a criticism of those whose resources and stamina are inadequate or falter. They obviously need and deserve help. Perhaps it is also a fact that adversity will make a strong family stronger, and one which, from the beginning, is inherently weak, weaker'.

Mr Roddom considers that there is satisfaction in overcoming a challenge and it is here that ASBAH can play a role. He lists the following areas where he believes ASBAH involvement to be important.

- The spina bifida family, willy nilly, must learn to live with handicap. Society in general must do the same and be made more aware of the facts and the needs.
- The family fears or suffers from isolation. Greater public awareness would alleviate this as would various aids to mobility.
- The family suffers from the disruption which frequent hospitalisation brings. But again greater assistance with common problems of transport and more understanding by hospital authorities and specialists in arranging convenient appointments would help.
- The family needs, more than most, a break from routine and every member is entitled to some opportunity to show their independence. Wider holiday opportunities and facilities will help.
- The family, and in particular, the mother needs help in the form of domestic help, mobility aids, home conversions, baby sitters.
- The family needs to keep a careful balance between the legitimate needs and interests of all members. Counselling and advice will help relieve some of the stress and anxiety.
- The family must also be confident that there will be opportunities for further education, training for adult life and suitable job opportunities.

Mr Roddom adds the above is no more than an indication of the things which ASBAH has achieved or is working for—things which will provide the kind of support which will help make the life of the spina bifida family worthwhile.

And he concludes, real and genuine anxiety exists and it would be wrong to gloss over it. It would be equally wrong, however, to be too negative and give an impression of unrelieved gloom.

'Positive solutions are what we need; specific, practical proposals leading to positive action'.

Appeals and publicity

Some Advice on Spending Money

This time, for a change, it seemed to me that my ideas on how to spend money might be of interest.

If anyone in your Association has some spare space, what about bulk buying items in everyday use, like paper kitchen towels, soap, detergent, etc, etc? One firm which gives very good value is John Dron Limited, Devonshire House, 4 The Broadway, Crouch End, London N8 9SN. You will know people in your own locality who operate similar schemes. I am sure bulk buying could make a great difference to household budgets.

In the same vein, we at the National Association could bulk buy the kind of stationery that local Associations now buy in small lots and so pass on the savings. Unfortunately the saving is lost where postage is involved, but if your Council member could carry back your orders, I would willingly arrange to have your parcels at the meeting, to be collected. Would you let me know what you think about this? I am thinking of envelopes particularly, and as ASBAH is registered for VAT we could save you having to pay this tax.

KATE WHITE

Appeals Secretary

Mr H. D. Macfarlane, 'Mac', ASBAH's Liaison Officer is presented to HRH The Duke of Gloucester, standing in for our Patron at the Gala Preview of FIRE ANGEL at Her Majesty's Theatre.

It was very gratifying to be asked to the annual Charity Ball of the Institute of Travel Managers, who organised the tombola at the ball, in aid of ASBAH. The organiser's daughter had spent her holiday looking after spina bifida children and he was so impressed by what she told him of the children's courage and determination that he felt he must lend a hand.

That money is getting really tight now was borne out at the United Charities May Fair, where we had a stall. We concentrated on home-made cakes, home-made marmalade, etc, and it went like snow in the sun. Other stalls with fancy goods and luxury items had to take most of their wares home. The moral is that we should concentrate on selling the everyday things that people need.

ASBAH's planned development for this financial year requires an additional £75,000. As you know, the Lotteries and Amusements Act 1976 now allows for large-scale lotteries and I would like to know from *LINK* readers whether they would be interested in taking part in a national ASBAH lottery timed to be drawn just before Christmas. Registration with the Gaming Board is necessary, but, for the purposes of the Act, I think that it would be accepted that Associations selling the national ticket would not require to register also. If we thought we could sell £40,000 worth of tickets, we could give generous prizes, perhaps a first prize of £5,000.

Letters

In the March/April issue of *Link*, Vera Stevenson expressed her personal preference for a special school for her child. On the same personal basis other parents have written to explain why they opted for ordinary schools and why they believe they have been proved right. Pressure on space has made it necessary to edit the letters but we are confident the essential points have been retained.

'Mobility risks justified'

Mrs Susan Foster of Stoke-on-Trent: Simon has steadily improved since taking his first few steps and although he has hydrocephalus, for the last 4½ years it has been successfully controlled with the aid of a valve. Before Simon went to school we built up an excellent understanding with the staff. We drew diagrams of where the valve was situated, explained what to do if he became ill, who to contact and where. The headmistress has the diagram and list in her office and the same information is posted by the teacher's desk in Simon's class.

The school allowed children aged 4-4½ years to attend mornings only to start with and this benefited our little boy—he was going to school with the other children, but it was not too tiring for him.

Simon has settled so well; he loves his new friends who have shown him great kindness. His physical immaturity, due to his condition, has lessened as he tries to keep up with his friends.

With mobility comes more risk of head injury but as parents who want to give their little boy as much experience of life as possible, we feel the risk is justified.

We need to consider what is best at every stage

Mrs Sheila Gompertz of Potters Bar: My daughter is now seven years old; she started to walk, without calipers at three; she is incontinent (she wears a 'bag'); and she has hydrocephalus controlled by a valve. We realised that as far as IQ was concerned (95) she would be acceptable at normal school.

Our two boys, now 11 and 9½, attended a local infant and junior school. Before she started there she knew her brothers' friends and she has since made more of her own. If she had attended a special school far from home she would have missed this opportunity of making friends in her home district.

Are children cruel? We have had little trouble. A quiet word from the teacher will usually solve the problem. As far as running in the playground is concerned, my daughter loves this. Obviously she cannot always keep up, but this is a problem she will have to come to terms with sometime. I am not sure being 'top dog' in a special school will do much to help this. As for toilet arrangements, the welfare assistant goes with her and watches while she empties her 'bag'. Soon she will take responsibility for herself. She is a lively, sociable little girl and enjoys school.

I am not sure that Mrs Stevenson was fair to compare the problems of an ESN child at normal school and a spina bifida child, with a reasonable IQ. I am aware that children with shunted hydrocephalus may have specific learning problems. My daughter's reading is adequate, but her ability to deal with numbers is still very limited. We have recently been discussing with her own teacher and headmaster, the advisory teacher for physically handicapped children, and the educational psychologist what additional help she might be given. However all these people say normal school is definitely right for her at the present time—a feeling which I share.

The important thing is that we need to consider what is best for each child at every stage of school life—emotionally, socially and educationally: the answer may be special school or normal school, or perhaps a mixture of the two.

Local friendships made for him and for us

John and Margaret Costello of Keyworth, Notts: Every child, handicapped or not, is an individual and to some extent has special educational needs which, we feel, we should try to meet in a normal school.

Our son, Timothy, is 5½ years old. He wears full-leg calipers and can walk with the aid of a rollator; he is incontinent, and has a valve to cope with hydrocephalus. For the past two terms he has attended the ordinary infants' school in the village, and we have been surprised and delighted by the successful way he has fitted into the school.

Six months before Timothy's fifth birthday we visited the school without him and talked to the headmistress. We looked at the classroom he would be in and spoke to the class teacher. We walked around the school, pointing out where Timothy would need help and the kind of attention he would need.

In the school there are two 'infant helpers', one of whom is NNEB trained and they share the responsibility of looking after Timothy.

When Timothy first started school he was something of an attraction. Now other children are neither cruel nor protective towards him. We meet his school friends in the village, in the shops, and in the park; he is invited to their birthday parties, and their parents are our neighbours and friends. It has been of great value to him, *and to us,* **to establish social relationships of this kind within the local community.**

A persistent problem has been that Timothy cannot sit down wearing his calipers and the staff have, until now, taken them off and let him sit on an ordinary chair for part of the time. However he is heavy to carry around and a wheelchair will be available in future when the teacher feels that it is needed.

We expect Timothy to have an orthopaedic operation in the near future and to have a spell in hospital. It may be that he will need more individual attention for a short time after this. Like all other arrangements it will depend on cooperation and discussion between us and the school.

In two terms Timothy has learned to read quite a lot and to write very untidily. His knowledge of numbers and number relationships is well developed. He is able to compete quite well with other children of his age in this respect.

Timothy's assessment is not a once-and-for-all decision: every year, perhaps even every term, we shall have to consider what kind of education is right for him. Whatever school he goes to, if his needs can be met as effectively as they are now, we shall be entirely satisfied.

'By no means an underdog'

Mrs Kathleen Lake of Lancing, Sussex: My husband and I thought long and hard on the subject of school and decided to try for normal school. When she was four I was more than lucky to get Melanie into a state nursery, part-time. I can only say that Melanie blossomed and after a year I got her into the local school.

I have found no ill feeling or cruelty—in fact the reverse. Melanie had to stay in hospital with a broken leg; she has a scrapbook filled with letters and drawings and cards from her classmates. Even though she was in Surrey three parents took their children to visit her.

Melanie is by no means 'underdog' in a normal school. We all have to accept handicapped adults living, working and enjoying life alongside us so is it too much, where possible, to start at this age?

On more than one occasion she has taught us she is a normal, bright, happy little girl who enjoys life to the full, first, and a handicapped child, second.

Academically she is well up to her age and beyond.

A further letter appears on page 14.

It was good to have such a response to the article by Vera Stevenson, and we hope that readers will follow up other *Link* **articles with similar energy—Editor.**

Letters

(Continued from page 13)

'He didn't need pampering'

Mrs P. Stott of Rotherham: My son Shaun suffers from spina bifida, is paralysed from the waist down and is incontinent of bladder and bowel. He is now 14 and has attended normal school from the age of five.

Being with normal children he has tried to do as they do and has stuck fast at hardly anything. When he was 11 he went to the comprehensive school. At first he was most unhappy when he was not allowed to play as he might get hurt.

I saw the headmaster and said that he must be treated as normal and be allowed to take these risks. Shaun didn't need pampering as he had always been treated as a normal child.

Shaun has lived his life to the full and misses out on nothing except football and 'gym'. He will always have someone to take him out as he gets older because the kids at the school will never forget him. When young people leave special schools they tend to be cut off from the normal children who don't know them.

Shaun was outside one day with a friend of his and was laughing about somebody having 'cross-eyes'. Karen, the friend, turned and said, 'Shaun Stott you ought to be ashamed of yourself and be thankful you are not like that'. I think this sums up the normal way in which Shaun is thought of and why I am glad he goes to normal school.

ASBAH booklets . . . leaflets . . . posters

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	20p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	15p
The Nursery Years, by S. Haskell, MA, Ph.D, and M. E. Paull, Dip.Ph.H	15p
Children with Spina Bifida at School. Ed. P. Henderson, CB, MD, DPH	30p
The Care of an Ileal Conduit and Urinary Appliances, by E. Durham Smith, MD, MS, FRACS, FACS, and others	15p
Clothing for the Spina Bifida Child, by Barbara Webster, SRN, RSCN	15p
Aids and Equipment.	60p
Information leaflets	100 for £1.30

All available from ASBAH, 30 Devonshire Street, London W1N 2EB. (Special rates available to Local Associations.) Please note that postage is extra. Allow a minimum of 9p per booklet.

Scottish Spina Bifida Association booklets.

Growing Up with Spina Bifida, by O. R. Nettles, MCSP, ONC	20p

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

FUND RAISING AND PUBLICITY MATERIAL

Posters

Best Foot Forward 20 × 30in. — 10p each.
Best Foot Forward 15 × 10in. — 10 for 40p.
For local publicity 15 × 10in. — 10 for 40p.

Car Stickers — 5p each.
Cards for Notice Boards — 10 for 10p.
Plastic Lapel Badges — £2.10 for 100.

All available from Appeals Dept. — postage extra. Full list on request.

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

Spina bifida badges. 25p each, postage extra (for one badge enclose SAE). Bulk orders particularly welcome. Available from: Mr K. McKenzie, Salisbury & District ASBAH, 111 East Gomeldon Road, Gomeldon, Salisbury SP4 6LZ.

Holiday accommodation for spina bifida families

Camber Sands, nr Rye, Sussex. New well-equipped 6-berth chalet near the sea. Details: Mrs Evans, 1 Coniston Gardens, Wembley, Middx. 01-904 7840.

Christchurch, Dorset, Hoburn Farm. 6/8-berth caravan, 1 mile from sea, near New Forest club house. Details: Mrs D. Collier, 359 Cricklade Road, Swindon, Wilts.

Easington, Withernsea. 7-berth caravan on well-equipped site by sandy beach. Details: Mr A. Clark, 3 Leys Close, Carleton, Skipton, N. Yorks, BD23 3EW.

Golden Sands, Voryd, Rhyl, N. Wales. 8-berth caravan, mains water, electricity, gas, shower and TV: Every facility on site, right by the sea. Details: Mr Adams, 58 Strathedan Road, [illegible]deley, Stoke-on-Trent.

Great Yarmouth, Caister Beach Caravan Camp — 6-berth caravan. Details: Mrs E. N. Barefoot, 23 Marlborough Road, Southall, Middx. Tel. 01-574 5067.

Haggerston Castle (5 miles south of Berwick-on-Tweed). 8-berth caravan. Details: Mrs Shepherd, 115 Holborn Road, Sunderland. Tel. Sunderland 283568.

Isle of Wight. Brambles Chine, Yarmouth. 6-berth luxury chalet-bungalow, adjoining beach. Available all year. Car an advantage. Details: Mrs S. Gully, Little Orchard, Eddington Road, St Helens, IoW. Tel. Bembridge 2141.

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Mablethorpe. Two well-equipped self-contained chalets, 6-berth, at Golden Sands Estates. Details: Mr B. Guest, 57 Bloxwich Lane, Leamore, Walsall, Staffs.

New Forest. Well-equipped 6-berth chalet. Easy reach of Bournemouth, Beaulieu etc. Swimming pool, paddling pool, restaurant, playground on site. Details: Mrs A. Rae, 16 Clifton Road, Lee-on-Solent, Hants. Tel. Lee-on-Solent 550242.

Prestatyn. 2 luxury 6-berth caravans at Bourne Leisure Site. £22 per week. Due to demand one week bookings only. Vacancies for Sept., Oct. only. Bookings to: E. Taplin, Colonial House, 63 Corporation Street, Manchester M4 3DT.

Selsey. Well-equipped, self-contained 16ft × 30ft 6-berth mobile home. For details send sae to: Mr R. V. Taylor, 3 Dickins Way, Horsham, Sussex, RH13 6BQ.

Well-equipped specially designed, mobile home. 7-berth plus cot. Details (please send sae to): Mrs L. Thomson, 154 Stafford Road, Caterham, Surrey.

Skegness. Specially designed, well-equipped bungalow, sleeping 8, at Chapel St Leonard's, nr Skegness. Pleasant site near safe beach. Details: Mrs J. Brook, 11 Standiforth Road, Dalton, Huddersfield HD5 9HD. Tel. Huddersfield 21776.

Winterton-on-Sea, nr Great Yarmouth. New well-equipped 6-berth chalet. Indoor swimming pool, shop, and play areas. Details: Mr R. Morris. Tel. High Wycombe 32184.

Withernsea. Well-equipped 6-berth chalet at Golden Sands Chalet Park. Shop, licensed club, play areas, amusements on site. Details: Mr F. D. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax. Tel. 0422 56402.

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