

asbah

Association for Spina Bifida and Hydrocephalus

Tavistock House North

Tavistock Square

London WC1H 9HJ

Telephone 01-388 1382

LIFT

Towards Independence

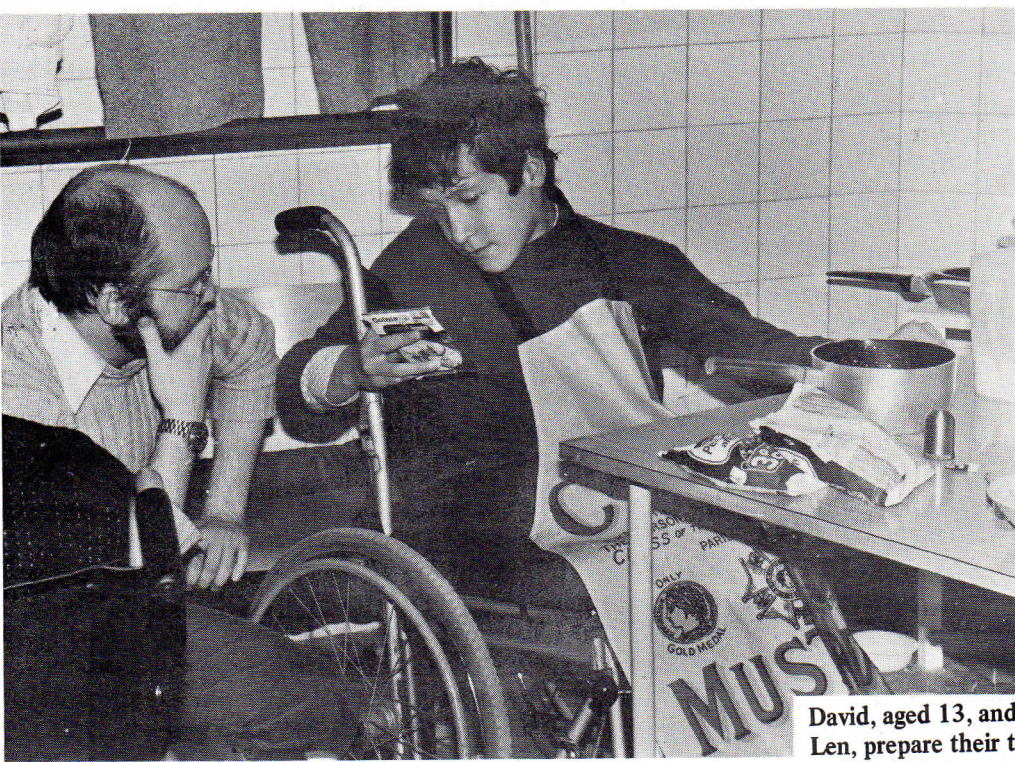
A training programme for young people
run by LIFT - Young ASBAH

This Association is particularly concerned about the problems of the large number of adolescents and young adults with spina bifida and hydrocephalus. Improvements in the surgical treatment of babies in the early 1960s have resulted in a dramatic increase in numbers of teenagers with these conditions. These young people, and their families, face numerous problems, including social barriers of incontinence and restricted mobility, and inadequate preparation for further education, training, employment and leisure. In an effort to help young people overcome some of these problems, National Young ASBAH - LIFT - along with several of our Local Associations and other centres such as hospitals are taking positive action in the form of Independence Training Weeks.

Photo: Len Hooper



Michelle and Graham tackle the everyday problem of what to buy for the meals ahead. They learn how to keep to a budget and at the same time provide a balanced diet.



David, aged 13, and helper Len, prepare their tea.

WHY DO THESE YOUNG PEOPLE HAVE SPECIAL PROBLEMS...?

The many physical difficulties resulting from **spina bifida** itself, such as incontinence and lack of mobility, may well have limited a young person's experience of everyday activities. However, research has shown that **hydrocephalus** may also cause additional problems affecting the learning of new skills. As this generation of young people has grown up, we have a much greater awareness of how hydrocephalus can adversely affect perceptual abilities, motor co-ordination, and problem solving, and also general motivation and speed of performance.

In the classroom, systematic teaching of basic skills has shown encouraging results and the same approach is necessary with practical tasks. We take it for granted that children will easily learn to wash and dress themselves and help with household activities, by watching and working with other members of the family. However, those who have physical disabilities and also learning problems needs structured, step-by-step teaching and considerable time to practice such apparently simple things as fastening straps on calipers, tying shoelaces, handling knives and scissors etc. Many young people may also find it difficult to plan ahead or to know how to set about organising their personal routine, and, here again, a structured approach is helpful.

TRAINING MUST BEGIN AT HOME, BUT

Independence is as much an attitude of mind as a competence in a series of skills. Any training in independence should begin in the home and from a very early age, but parents are not always sure of the best ways of teaching their own children, and are often not given enough help or advice.

Domestic routines may not allow for a mother to encourage her child to dress himself if this takes a long time, and the wish to help a disabled child is understandably very strong. Within a day special school there may be little time allocated to personal care, such as learning to manage urinary and bowel incontinence, and within the ordinary school the right kind of specialist help may not be available.

Children and young people with spina bifida and hydrocephalus may have little confidence in their own abilities and may need encouragement to make decisions and gain experience in an environment where it is possible to make mistakes and learn from them.

We believe that residential training courses away from home can help young people to acquire greater personal and social independence. To be effective these must be combined with detailed liaison with families and schools, so that newly acquired skills can be consolidated, and so that the young person's changing perception of his own abilities is matched by a recognition of his increasing independence in those with whom he lives.

ASBAH hopes that independence training will soon become fully integrated into the curriculum in all schools, with teachers, therapists, and care staff working together to organise training programmes. However, while there is still a need, we will continue to run National courses, and we are also happy to give advice to local projects and assistance to schools so that they may benefit from our experiences.

Just what goes into a week of independence training

Venues and Funding of Courses

National ASBAH is currently running seven residential courses year year. Each course lasts for one week and they are held at different venues throughout the country. Courses are subsidised, but a fee is charged for each student, and this is usually paid by the local education authority or social services department.

Students

Usually ten students are taken on each course, with ages ranging from thirteen years upwards. Many young people are nominated by their special school as part of their leavers' programme, and we are also particularly keen to give places to students in ordinary schools. Before a student is accepted on a course, a home visit is arranged to give a young person and their parents an opportunity to discuss the programme, and to decide if that particular course will suit the individual's needs.

Staff

The courses are staffed by volunteers who come from all walks of life – many are professionals such as therapists, health visitors, care staff, teachers etc. who are seconded by their employers to work with us for the duration of the course. Staff are matched with students on a one-to-one basis, with back-up provided by National ASBAH officers, and visiting professionals such as stoma care nurses. This means that staff as well as students may be learning new skills!

The Course Programme

Morning and evening sessions are devoted to developing individual personal care routines including the management of urinary and bowel incontinence, bathing, dressing, coping with calipers and wheelchair transfers. There are also group sessions on wheelchair proficiency, wheelchair maintenance and road safety, and opportunities to try new sporting and leisure activities. The students discuss the importance of a balanced diet, and plan some of their own meals, and are responsible for budgeting, shopping and cooking.

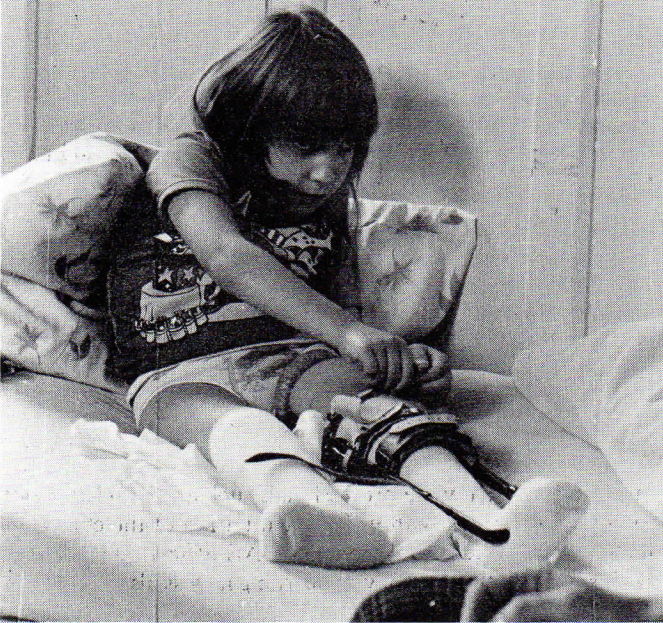
Students have a chance to discuss their own disabilities, and their implications. Visits to local workshops or day centres may be arranged, followed by discussion about the opportunities available on leaving school.

Parents are invited to attend on the last day to discuss achievements made during the week, and ASBAH liaises with school staff, social workers, careers officers, medical consultants etc. before and after the course. In some areas ASBAH Field Workers are also able to keep in touch with the family afterwards.

The programme is intensive and may be exhausting, but is also enjoyable!

A typical independence week for the 15+ age group

SATURDAY	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
BREAKFAST	BREAKFAST	BREAKFAST	GROUP 3 COOKING OWN BREAKFAST	GROUP 1 COOKING OWN BREAKFAST	GROUP 2 COOKING OWN BREAKFAST	BREAKFAST	BREAKFAST
Arrival of staff and briefing	Planning individual personal care programmes	INDIVIDUAL PERSONAL CARE PROGRAMME					
		Diet and menu planning discussion	GROUP 1 washing and ironing GROUPS 2/3 Baking	GROUPS 2/3 washing and ironing GROUP 1 Baking	Visit to Remploy factory	Shopping	Packing Preparation of buffet
LUNCH	LUNCH	LUNCH at local technical college	LUNCH	LUNCH	LUNCH	LUNCH – in town	BUFFET LUNCH for staff, students and parents
Arrival of students	Wheelchair mobility	Shopping for groceries	What are spina bifida & hydrocephalus? – discussion	Community work - discussion led by speaker from CSV	Education, training & employment – film & discussion	Personal relationships – discussion	Individual discussion with parents
HIGH TEA	HIGH TEA	GROUP 1 COOKING OWN HIGH TEA	GROUP 2 COOKING OWN HIGH TEA	GROUP 3 COOKING OWN HIGH TEA		HIGH TEA	DEPARTURES
Introduction to course	Ideas for leisure activities	Personal hygiene – discussion	Folk evening	Free evening	Visit to restaurant	Discussion on course	
INDIVIDUAL PERSONAL CARE PROGRAMME							



Joanne, 7½ years, learns to master putting on her own calipers, as well as dressing and washing herself. It's all part of her own personal care routine.

SHORT INDEPENDENCE TRAINING COURSES

Many of the activities included in courses for the 14+ age group can be tackled by younger students. It is important that children begin to understand their disabilities and learn how to cope with practical tasks as early as possible and for this reason short courses for children in the 9-13 age group are included in ASBAH's annual programme.

As this may be the first time a child has been away from home, other than in hospital, these short courses last only 5 days, and take a small group of four students, either boys or girls.

The programme is based on that used for older groups, but emphasis is placed on the more practical aspects of independence. Students are also introduced to topics such as the importance of a balanced diet, simple homecraft and spina bifida and hydrocephalus through talks and practical sessions, which are specially planned with the younger student in mind.

The short courses take place at Five Oaks, ASBAH's residential home in Ilkley, Yorkshire, which is an adapted family house, run by our experienced staff. A fully equipped centre, completed in 1980, is used as the base for the programme of activities.

Murray Campbell, aged 10, has attended a course at Five Oaks

"When we arrived at Five Oaks we had a "getting to know you" session and were told what was going to happen during the course. The next day we started a personal care programme in which we were taught how to take care of our bodies, and in the afternoon we learned how to manage our wheelchairs: I enjoyed this because I like to do wheelies.

One day we went shopping in Ilkley. We bought sausages, beans and brown bread which we had to cook for tea ourselves. We went to a restaurant for tea on another evening.

At the end of the course we talked about our achievements during the week. I learned a lot on the course and, although it was tiring, I enjoyed it".

IF YOU WOULD LIKE:

- * details of courses being run in the coming year
- * to nominate a student
- * to volunteer to help on a course
- * to second any of your staff to work with us on a course

Please contact: The Assistant Organiser – LIFT, Young ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. Tel: 01-388 1382