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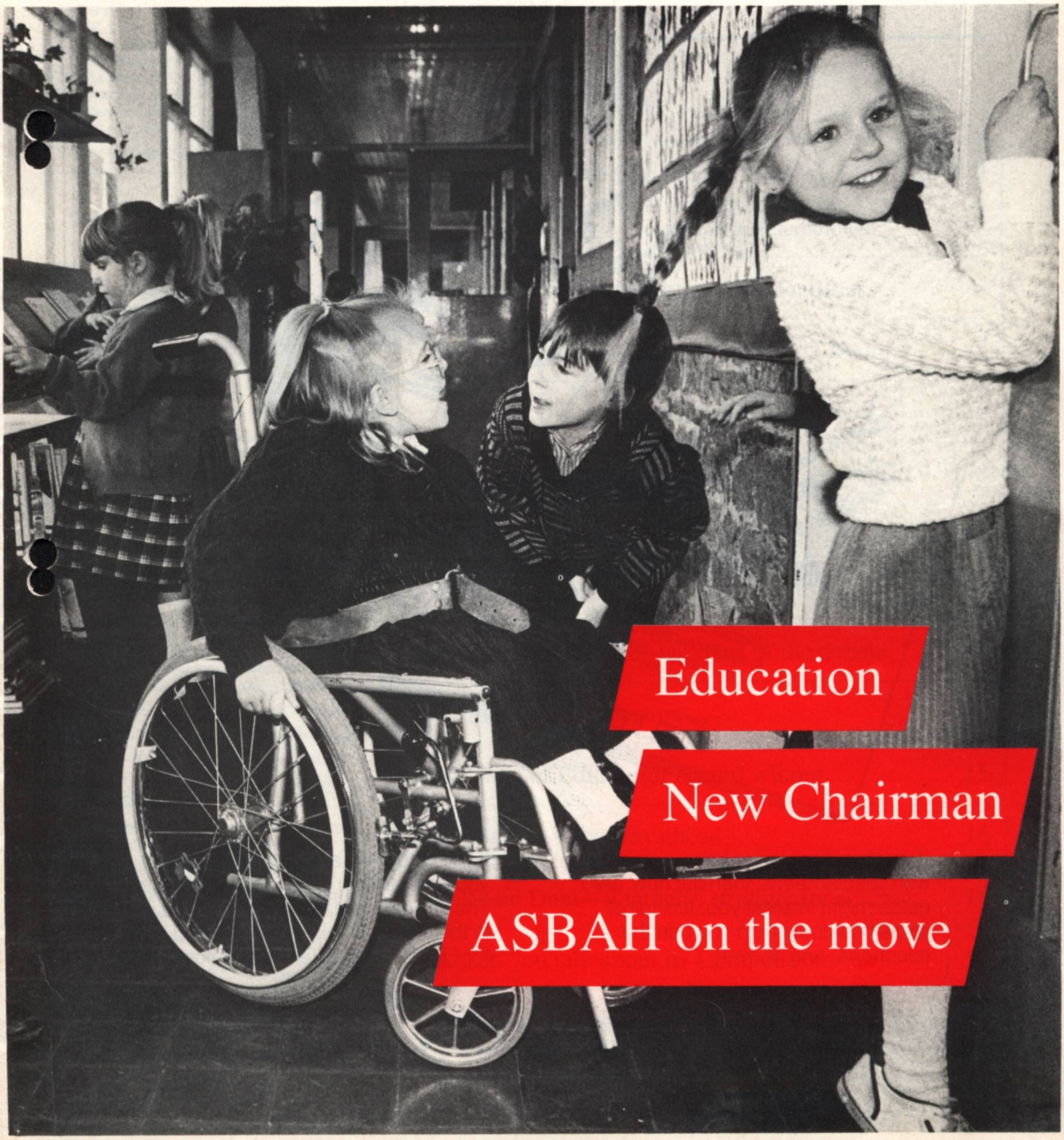
The magazine for people with spina bifida and/or hydrocephalus

# Link



Education

New Chairman

ASBAH on the move

The magazine for people with spina bifida and hydrocephalus

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APRIL 1990 ISSUE NUMBER 127

**Cover Picture:** Integrated education—Gemma Trigg and friends.
Photograph: Chris Goddard.

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# NEW MOVES AT ASBAH

## REGIONALISATION PLANS

For the past twenty years ASBAH has talked about regionalisation and in April 1990 the first regional office is due to be set up. With regionalisation will come further expansion of the services ASBAH is able to offer. ASBAH's ultimate aim will be to develop six to eight regions throughout England, Wales and Northern Ireland. The speed for further development will depend on resources, bearing in mind the financial implications of ASBAH's move to Peterborough which is taking place at the same time.

It is hoped that each region will be led by a Fieldwork Co-ordinator who will be responsible for a group of Fieldworkers and also liaise with head office. Ultimately it is hoped that other support services, like the Disabled Living Advisors will multiply and become more regionalised.

The Co-ordinator will act as an information resource, forging strong links with hospitals, GPs and DHSS departments whilst also creating a bank of facts and figures. It is also hoped that regionalisation will improve the speed with which referrals are made from hospitals and increase contact with local associations.

## NEW HEAD OFFICE

On the 11th June 1990, ASBAH's headquarters will be moving to Peterborough. The relocation is part of an overall commitment to providing better services to people with spina bifida and/or hydrocephalus. The brand new building, which is to be leased by ASBAH, is adapted to make it fully accessible to people with disabilities.

The offices will provide around 50 per cent more accommodation than those in London; all departments will have a little more 'elbow room' but the Telesales department will have the lions share in order to expand the number of salespeople. With greater revenue, expansion of services will remain viable at a time when the government is asking the voluntary sector to play a dominant role in providing services.

As always, ASBAH are committed to increasing their Fieldwork and new Counselling services in order to meet the ever increasing demand. Fieldworkers offer practical help, information on benefits, housing and medical issues as well as emotional support to individuals and their families.

The forthcoming move to Peterborough will be marked by a press campaign to highlight the hidden problems of hydrocephalus. More than 85% of people with spina bifida also have, or develop, hydrocephalus. It is little known that hydrocephalus can cause a variety of 'hidden problems' —difficulties with learning, spatial awareness, and concentration. These can severely hinder a young person's progress at school, at work and their ability to live independently.

However, with support, encouragement and public understanding, many of these problems can be overcome.

*The new head office address will be:*

**Association for Spina Bifida and Hydrocephalus**
**ASBAH House**
**42 Park Road**
**Peterborough PE1 2UQ**
**Telephone 0733 555988**

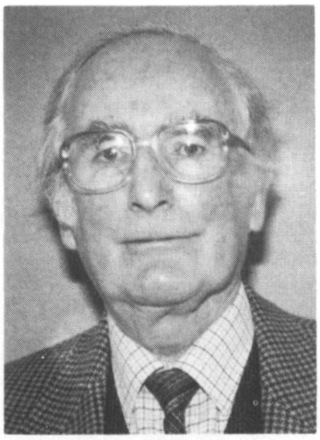
# TOWER HAMLET INSTITUTE

The official opening of two new facilities for disabled students took place at Tower Hamlet Institute Bethnal Green in February.

One of these is a dedicated computer unit specially equipped to meet the needs of visually impaired students and the other a classroom created on the centre's ground floor, incorporating access facilities for people with physical disabilities.

The opening ceremony was attended by ASBAH's President Jeffrey Tate, the Principal Conductor at Covent Garden, and David Blunkett MP both of whom agreed to lend their names to the two specialist rooms. Also present were Miss Moyna Gilbertson, Executive Director of ASBAH and Philip Ridler, the well-known photographer.

# ASBAH ANNOUNCES NEW CHAIRMAN



Patrick Daunt has been appointed Chairman of ASBAH. He is well-known in the educational and charity fields having started his career with Christ's Hospital and later became Headmaster of the Thomas Bennett Community School in Crawley.

He went on to become Principal Administrator of the Educational Department of the European Community and in 1982 was appointed Head of the Bureau for Action in Favour of Disabled People which was run by the European Community in Brussels.

He saw his role as achieving co-operation and exchange between European countries.

His agenda to promote social and economic integration and independence for people with disabilities was enormous and in 1984 he prepared the first recommendations regarding employment for people with disabilities; and he also set up a grant-giving system which enabled voluntary organisations to hold international and European conferences which would not otherwise have been financially possible.

Patrick Daunt now sees his appointment as ASBAH's Chairman as an ideal way of returning to grass roots level. He said "I have great respect for ASBAH's aims and achievements; it is a developing organisation paving the way for the next generation of young people with spina bifida and/or hydrocephalus.

"We have a tough battle ahead to secure an independent future for them, particularly in relation to disability benefits and community charges and I am looking forward to rolling up my sleeves on their behalf."

Miss Moyna P Gilbertson, Executive Director of ASBAH, said "We are delighted that Mr Daunt has agreed to become our Chairman—his expertise will be invaluable in leading us into the new opportunities that lie ahead in Europe".

# CONDUCTIVE EDUCATION

**Following media claims that children with spina bifida with or without hydrocephalus could be cured of incontinence, ASBAH decided to carry out it's own fact-finding mission and comprehensive assessment. Carole Sobkowiak, a Superintendent Physiotherapist, was appointed to visit the Peto Institute on behalf of ASBAH's Medical Advisory Committee.**

Although Conductive Education has been known about in this country for the past 24 years, it was not until a spate of publicity began in 1985 that it became a focus for the media. Such attention, both on television and in the press, has been largely anecdotal in presenting the success stories of children who have returned from Hungary able to walk. Likewise there have been inaccurate interpretations about the Peto Institute in Budapest where Conductive Education originated. At the height of the media exposure, claims were being made that these methods could also be used to achieve continence in children with spina bifida and hydrocephalus.

It was for this reason that ASBAH felt it important for a visit to be made specifically on their behalf in order to see at first hand how children with spina bifida and hydrocephalus were being managed.

It was decided that our representative to undertake this research should be Carole Sobkowiak. Carole also visited other centres in Hungary including children's hospitals, schools for the physically handicapped, psychology and physiotherapy departments, as it was felt important to obtain a broad perspective of the services for young handicapped people within a different cultural framework.

One of the crucial distinctions to make is that in Hungary a child cannot attend a normal school, or school for the physically handicapped, unless he/she is able to walk. Those children not attending school receive six hours home tuition per week or are cared for in other state institutions.

Distinction is also made about the Peto Institute which is an educational establishment under the auspices of the Ministry of Education. Conductive Education is then an educational system where children are given opportunities for overcoming their difficulties—it is not a treatment.

The atmosphere at the Peto Institute was very positive and the conductors worked very hard to motivate the children and to help them find enjoyable ways round their problems. The children were praised when they had done well and were not singled out for chastisement when they had failed, but encouraged to try another way. In contrast to individual therapy, Conductive Education uses group work for its methods of teaching, and the benefits of collective activity could be seen. Tasks could be built up in small stages towards a common goal with the use of speech, chanting, inner language and rhythm to reinforce the learning process.

There were, however, some reservations following observation of the spina bifida groups. It was difficult to ascertain what took place during the assessment period and it has been reported by some British families that this lasted for only half an hour.

The Peto Institute prides itself in limiting the use of aids and appliances as opposed to the procedures here in the West. There was concern that some callipers had been abandoned or reduced and it was observed that many children had hyperextended knees and/or a lordosis of the spine. Some activities were performed in bare feet and again many deformities were seen. Whilst the philosophy was that of managing with a minimum of aids, it was worrying to think what wear and tear the joints wou[illegible] suffer in the long term with th[illegible] possibility of further deformities developing.

Much energy was expended with bowel and bladder training, although little was mentioned about the former. Initially, children spend 20 minutes out of each hour sitting on their potties, tapping their abdomen or lower spines, breathing forcibly in and out in conjunction with pushing activities. Although it was a policy for the children never to wear nappies there were some wet pants which were changed at each conditioning session. Conditioning was carried out at night time if necessary. It was confirmed that the same conditioning methods were used for all children despite the differing bladder states, for example, spastic or flaccid. Catheterization was never used and British parents were advised not to carry on with this method of emptying their child's bladder. Apart from the amount of time spent sitting on potties, there was concern about the build up of abdominal pressure during conditioning, with the possibility of reflux back-up of the ureter to the kidney. The children were tested regularly for urine infections but at the time of the visit the Institute had only recently begun its urinary tract investigations and little was known about vesico uretic reflux (V.U.R) and long term renal damage in their group of children.

The facts and figures about continence [illegible]d daily living activities were given on [illegible] cross-sectional basis for the group as a [illegible]hole over a two year period. In the absence of information about individual children and the lack of hard data correlating bladder conditioning to the level of the lesion, and the state to the bladder, it was difficult to draw any conclusions. It would be helpful if the Peto Institute could provide individual scientific profiles of the children who have undergone conditioning so that further discussion and debate may continue regarding the best methods available to prevent long-term tract damage, which is known to have a high mortality rate commonly due to V.U.R and urinary tract infection.

In conclusion, we have given an honest and considered opinion which has been supported by many professional people who have visited Hungary and who have been in contact with us.

There are many positive aspects of Conductive Education together with the pilgrimage effect for parents and money-raising efforts. The media has highlighted all of these.

We have heard, however, little about the disappointments, the stress to families, the false hopes, the loss of education time or the long term follow-up results of the children who have been to Budapest.

In view of a somewhat biased presentation by the media we feel that we have a duty to point out our concerns. In the light of all the information we have collected ASBAH cannot at this stage recommend this system for children with spina bifida and/or hydrocephalus.

We urge families contemplating undertaking the journey to Budapest to discuss these facts with their medical practitioner and our Association.

We emphasise that we remain committed to supporting families whatever their final decision.

# CONTINENCE—INDEPENDENCE FOR THE DISABLED CHILD

**Managing continence is a crucial issue for many children with spina bifida and/or hydrocephalus. Mary White, SRN Cert (School Nursing), Diploma in Special Needs and Education and an ASBAH Fieldworker describes how the development of localised service can promote independence from an early age.**

Centres of expertise providing care for children with spina bifida and/or hydrocephalus are rare. Children often have to travel long distances from their homes to reach a centre but, once there, they benefit from a wide range of consultant advice, as well as physiotherapy, occupational therapy and an appliance centre. Unfortunately, however, the centre will probably be unaware of local services and may be unable to organise community care.

Child development centres are increasing in number and usually have a large and well qualified staff. The team includes a consultant community paediatrician, a physiotherapist, a speech therapist, an educational psychologist, a teacher/counsellor and a paediatric social worker and has strong links with health visitors and school health workers.

> **"...the answer lies in making a concerted effort from birth to five years or later, with the local child development centre as the clearing centre..."**

Although children with spina bifida and/or hydrocephalus could benefit enormously from such local provision, it is unusual to transfer their management. This is usually owing to the absence of on-the-spot neurological, urological and orthopaedic care.

In practise, services frequently operate in isolation and lines of communication are not always efficient. The care of the child's spina bifida may be entirely separate from the care of his hydrocephalus, especially if he has a valve. It is worrying how little information and advice actually gets passed to the GP/Health visitor and school health department. Indeed, little may be known locally of the child's existence until he arrives in the education system and a multi-professional assessment is requested.

If a child with these problems starts school without an adequate paediatric assessment, the school health service does not have sufficient knowledge of the extent of his disability, renal efficiency, physiotherapy requirements and potential learning difficulty. The service cannot then advise the education authority properly or provide suitable health care. Some children start at mainstream school with a statement and continue to attend a hospital outside the area for specialist care. In such cases, information can be very slow to come through and frequently never arrives.

It is not unheard of for a child to start a new school-term having begun intermittent catheterisation during the holidays. The hospital paediatric department has failed to inform either school health or the education authority so no provision has been made at school. Leaving such important matters to chance makes failure almost unavoidable.

Until fairly recently I worked as school nurse in a special school in West Berkshire. We had 80 profoundly physically handicapped children with another 90 with moderate learning and behavioural problems—most of the latter were severely socially deprived. While recognising the shortcomings of the daily special school system academically, I was impressed by its potential for medical and social management. The medical room was central. For the socially deprived children it was the clearing centre for social problems, while for the physically handicapped children it was the focal point for medical and social care.

Soon after taking up my post I became concerned about the absence of medical records on site. Sixteen of the children had spina bifida and/or hydrocephalus and attended centres in Reading, London and Oxford. Information was rarely made available to us and often had to be formally requested. When received, it tended to be somewhat sparse and parents were the most reliable source of information. If, however, they were unconcerned or did not understand, difficulties resulted. My first priority was, therefore, to convince the school health administrators that we should hold our own files and organise our own medical and immunisation sessions.

The appointment of a new Consultant Paediatrician to our local hospital gave us the opportunity we needed. Part of her job was to run a child development centre for under-fives. Some of those children were in our nursery class, so she began to hold regular sessions at school. These included contributions from teachers, physiotherapists, speech therapist and anyone else involved in the daily care of the child. She rarely, if ever, saw these children in the hospital and blood and urine samples were taken at school and the results returned to us.

> **"These experiences have convinced me that the services we offered in West Berkshire are what are required"**

Drugs were ordered from the hospital pharmacy and dispensed at school. Funding was organised because her school sessions were recognised as an extension of her hospital paediatric clinic.

My second priority was to convince the school health authority that the school nurses should be able to carry out all treatments during the school day and work closely with the hospital, parents and other professionals. In this way we became a bridge between the hospital and the community. Clinics were booked and letters sent home to parents informing them of the time and date that their child would be seen. The letters also stated that in the absence of the parents the child would still be seen unless the parents specifically stated otherwise. Another letter would then be written by the Consultant to parents.

In the event of persistent non-attendance of parents I would make a home visit to try to establish the reason. If there was a genuine problem I would then obtain parental consent to manage the child's care from school. Orthopaedic clinics were held at school once a term, which meant that surgery really was a last resort.

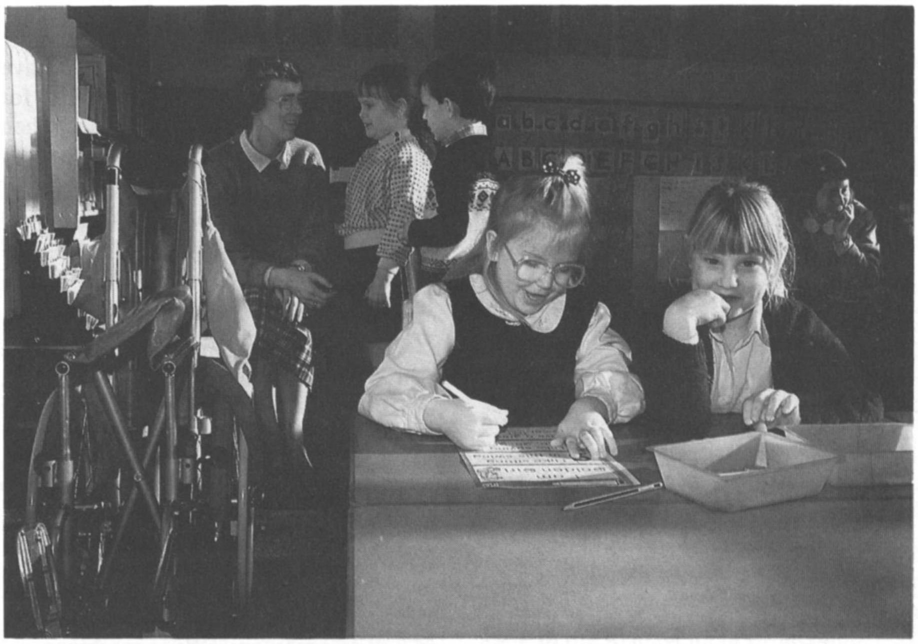
During the first year of the programme it became apparent that independence training was not being given sufficient consideration early enough to be effective and worth-while. Children with spina bifida and/or hydrocephalus are well-motivated as well as being most physically able when they are very young. I could find no published material aimed at these children or their parents so; together with a retired teacher, I produced two books, *Ned and Emma Can be Dry* and *Ned and Emma Eat Good Food.*

We wondered why independence training was being delayed, so started potty training at the usual age, teaching the child to evacuate the lower bowel three times a day by laughing or coughing. Attention was also paid to weight and diet. I made home visits and drew up a plan for each child with copies for home and school. Each child had his own copies of the illustrated books. The nursery class was particularly keen, which was encouraging.

The urologists were informed of our aspirations and were invited to contribute by holding one joint session per term with the paediatrician and school doctor. At the outset they were not sure that it would be a worthwhile exercise for them, but they were convinced when they saw the children at their best on 'home ground' and urodynamics were arranged for each child. Admissions to the ward were arranged as day cases from school with one of the school nurses present and the necessary investigations carried out.

With daily monitoring of intake and output at school and at home, a clear picture of each child soon emerged. At the next joint session the results were discussed and the best method of managing urinary incontinence determined.

Those children who managed to stay dry for fairly long periods of time and were found to have a good bladder volume on catheterisation at school were deemed suitable candidates for intermittent catheterisation. Initially, these children were admitted to the ward for training but this proved unsatisfactory, as the hospital used a sterile procedure which was not the object of the exercise.



**Gemma Trigg with friends. *Photograph:* Chris Goddard**

Training was transferred to school and co-ordinated with each child's home. Again, I made a series of home visits and drew up a plan for clean intermittent catheterisation for the child to be used at home and at school.

The emphasis was firmly on clean, rather than sterile, catheterisation and both parents and children found this procedure far less daunting. GPs were involved from the outset and were asked to order catheters. They were kept fully informed by the consultants and received copies of care plans. Intermittent self-catheterisation was the next step and the younger the children the more easily they seemed to learn and the more pleasure they derived.

Using these methods we were able to bring all our children with spina bifida under local management. They remained patients at their specialist centres, but only attended occasionally for a routine check-up. We sent letters and regular assessment reports to consultants and found few problems with their care.

These encouraging results led us to think about taking on the role of a resource centre. Our school medical officer was also the principal medical officer; he was committed to extending the services that were offered and worked closely with the consultant paediatrician.

We investigated the possibility of giving children toilet and independence training in our nursery, then sending them to mainstream school at the age of five. Physically handicapped children in mainstream nursery school tend to have everything done for them and receive little formal toilet training, for there is no opportunity to train staff.

Results were again very encouraging, for the bodies of very young children with spina bifida and/or hydrocephalus are more supple than they will be later and their back problems have not yet started. The physical demands of intermittent self-catheterisaton and self-urostomy care are met by using mirrors and foam wedges for the more severely handicapped.

The natural progression from couch to toilet is easily made and all their training can be incorporated into the routine of the school day. While very young, these children respond well to a system of rewards, for example, stars, house points or small prizes.

The headmaster formed a link with an outreach mainstream primary school. It was to this school that we sent our most academically able children. They were part-time at first, gradually increasing over a school year to full-time. They remained on our school roll until they, and we, felt quite sure that they could cope with absolute confidence. We trained the staff of the school and acted as their resource centre for a long time.

It was only at this stage that we experienced severe and seemingly insurmountable difficulties. Liaison was excellent and co-operation impressive between those responsible for education, but the school health cover was insufficient.

Under the same health authority, the outreach school came under different school nurse management. All instructions had to be relayed through management and difficulties began to arise. I felt that the long-term answer was to appoint a peripatetic school nurse for the physically handicapped children in mainstream schools, but at the time of my departure this problem had not been solved.

In my present post as a Fieldworker for ASBAH I am again concerned about the absence of independence training in schools. Many of the schoolchildren referred to me for individual training programmes are in mainstream senior schools; they attend centres in Nottingham, Sheffield and Manchester. Referrals are frequently made because of problems at school or the lack of independence skills and poor management or incontinence.

These children tend to have very little self-awareness and have failed to acknowledge and learn about their disability, accept it, or overcome it by developing skills and furthering independence. Incontinence remains their biggest problem.

I attempt to assess bladder function by getting both the school and the family to maintain an accurate record of daily intake and output. This usually provides some idea of bladder stability so that I can draw up a self-care plan. Most schools include this in the GSCE course on life skills.

On occasion, I have managed to instigate intermittent self-catheterisation when the hospital consultant has agreed that the child could be a suitable candidate but results are variable and not very encouraging. These children have no wish to accept any responsibility for their own bodies. They see no need when there is someone at home and very often a welfare assistant at school to do it for them. They are by now, very often physically and mentally slow and the girls may well have to cope with irregular and frequent periods.

The best compromise is to offer an independence course at Five Oaks, ASBAH's Independence Training Centre in Yorkshire, followed up immediately by the introduction of a daily self-care plan. It requires spending a great deal of time with the parents, child and school staff.

Motivating the children and their families at this late stage seems, at times, to be almost impossible. They do not believe in independence and look at the DoH and DSS to make provision for their needs. The pattern is set for the rest of their lives and there can be little hope of these young people ever taking a full place in society. Once they reach the end of their school life, medical management seems to peter out completely.

These experiences have convinced me that the services we offered in West Berkshire are what are required to enable these children to reach their full potential. However, we ran our service from a special school—these are now rare. The problems we encountered when attempting to integrate our children into mainstream education proved that there was still room for improvement. I believe that the answer lies in making a concerted effort from birth to five years or later, with the local child development centre as the clearing centre for information.

The children could then be regularly and fully assessed with equal attention paid to their medical, social and educational needs. The professionals dealing with the children would be fully conversant with local services and would be able to plan ahead. Access to physiotherapy and occupational therapy would be assured, and the provision of aids and home adaptation would be much easier to arrange on a local level. The paediatric social worker would be well placed to monitor the family's situation and arrange for relief, including respite, before crisis situations arise. Case conferences could be held in the unit when necessary.

Full urology assessment would have to be done in the hospital, but with such a high level of support a suitable method of continence management could be decided upon early enough to be of maximum benefit. Orthopaedic assessment could be similarly managed, with major surgery being undertaken only after full consultation with the rest of the team. The parents would then be in a much better position to make informed decisions for their children.

Regular CT scans could be arranged through the hospital and the effects of hydrocephalus on the child's performance noted. The resident educational psychologist and teacher counsellor could advise on suitable educational placement.

With the consultant community paediatrician at its head, such a unit could offer a wide range of services. A child should be able to start school at the age of five years with a level of independence equal to his able-bodied peers. Excessive and unsuitable adaptations would be avoided as the child would be learning to adapt well to his surroundings.

From five years onwards, a named worker who fully understands the medical social and educational implications of spina bifida and/or hydrocephalus could be assigned to monitor the child's development and co-ordinate local services. Health and education professionals would then be able to help the child take his place as a fully independent, though physically handicapped, young adult.

The total commitment of both Peter Godfrey, the Deputy Director of Education in Derbyshire, and the Support and Advisor Teacher Services to meet special needs has made it possible for children to take their place in mainstream education. This authority shows itself to be ready to listen and to provide services where possible which will improve the quality of life at school for children with spina bifida and/or hydrocephalus.

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# CONTINENCE—UPDATE

## INCONTINENCE PADS AND THE CONTINENCE ADVISORY SERVICE

ASBAH and a number of other voluntary organisations including The Spastics Society, Age Concern England, Spinal Injuries Association, MS Society and the Disabled Living Foundation Incontinence Advisory Service recently met with Baroness Masham of Ilton to discuss continuing problems of the Continence Advisory Service and the provision of incontinence pads.

Concern was expressed that the health districts are financially squeezing the Service to such an extent that people are being rationed in the number of incontinence pads provided to them and are unable to be provided with the pad most appropriate to their needs. People are also increasingly having to wait for access to a continence adviser which can be very damaging as good continence advice is sometimes critical to the individual's ability to remain living in the community.

A further area of concern is that people in nursing homes are frequently being charged extra for continence aids despite the fact that Government advice clearly states that such aids should be covered by the fees. There is also increasing evidence that people in residential care homes are either being rationed or offered only one type of pad which is not necessarily suitable to their particular needs.

It was felt that the anomaly whereby GPs can currently prescribe aids such as sheaths and catheters but not incontinence pads should be removed, and that the proposed P S nurses prescription lists should include the range of incontinence aids, including pads. The exclusion of these pads means there is added pressure on people to use catheters rather than pads and catheters can often lead to complication requiring hospital care and therefore considerable cost.

Lady Masham has written to Baroness Hooper, the Minister of State for Health, putting these points to her. There have also been parliamentary questions tabled on the issue and it is hoped that continuing action will ensure that improvements are made to the present situation.

## NORTH WEST REGIONAL STUDY DAY ON CONTINENCE MANAGEMENT

**Saturday 9th June 1990 in Liverpool**

This study day is designed for people with spina bifida and their families to bring themselves up to date in the management of incontinence. Interested professionals are also welcome.

Mr A M K Rickwood FRCS, Consultant Urologist at the Royal Liverpool Hospital, Alder Hey will be the key Speaker.

The cost for the day is £3.50 including lunch. For further details and a booking form contact your local Fieldworker or telephone 051 733 4495 or 051 427 8500.

# CHURCH ACTION ON DISABILITY

A three year campaign was launched by CHAD (Church Action on Disability) in July 1987 at the Westminster Cathedral Conference Centre with the following three objectives:-

1) That all people should have access to the Church, its premises and activities.
2) That all people should be able to participate in the life, work and ministry of the Church without barriers of disability.
3) That all people in the Church, whether disabled or not, have much to learn from the experience of disability among their members.

Clergy of all denominations were mailed and information packs were sent to over 1,000 people who responded. Over forty volunteers joined CHAD to act as a network of local contacts and the organisation took over responsibility for the publication of a magazine appropriately called *All People*, increasing its circulation to 1,000 per issue.

In view of the interest that has been shown it has therefore been decided to extend the campaign until the end of March 1991. The introductory leaflet has been republished and is available free and a new Information Pack is available price £1. Other printed material can also be obtained from:

The Secretary
CHAD
Charisma Cottage
Drewsteignton
Exeter EX6 6QR.

# COMMUNITY CARE

**In the second of a series of articles on the Government's proposals for community care, Fidelity Simpson outlines the most significant responses and commitments given by the Government. There were a great many amendments tabled for debate and the following resume picks out the salient points arising from these.**

## Community Care Plans

There were a series of amendments which sought to place duties on Local Authorities' drawing plans for community care to consult with service users, service providers and representatives from voluntary organisations. In response to these, Virginia Bottomley, MP, Minister for State, said:

*"We are reluctant to write on the face of the Bill the precise mechanisms for consultation and to state precisely which group should be considered....*

*"Instead of being a framework for making community care plans, the Bill would become a straight-jacket. We want people to think broadly about their communities and to understand their task in a creative fashion."*

She intended to issue a consultation document on community care plans and the guidance to Local Authorities would reiterate the White Paper's emphasis on the importance of consultation on plans. Speaking directly to an amendment that would establish a Community Care Advisory Committee composed of 50% of service users and 25% of service providers, she said:

*"The importance of consultation and working with groups in the community is endorsed throughout our discussions of community care plans.... It would be inappropriate to include in the Bill an organisation such as a Community Care Advisory Committee or an elected body, or to specify formally the groups that should be consulted.... Guidance is important because of the flexibility that it offers and because it allows local innovation and diversity.... The SSI, too, has a major part to play in monitoring community care plans and the development of the service after 1991.*

*"There is a strong, overwhelming commitment to make the community care plans an effective tool, and consultation is a fundamental first step in the provision of plans. In view of the strong views expressed by my honourable friends, I shall reconsider the amendment and come back at a later stage when I have thought through an appropriate way forward."*

On the issue of requiring Local Authorities to draw up plans for three years, Virginia Bottomley said:

*"We are reluctant again to set down in statute the precise timing arrangements for the plans. The guidance will outline what that planning should be. We envisage a three year planning overview, and we want to give the Secretary of State enough flexibility to call for plans between certain times. The guidance will deal with the matter. It is important that the plans of local authorities coincide with the financial year.*

*"In that way, they can be used as a useful tool in the planning of services and their relationship with resources, and the implications that may arise from that."*

In a debate on joint planning agreement Virginia Bottomley said:

*"The Government intend to concentrate on outcome rathe than machinery...social care plans should be prepared an published by social services authorities. They will be expecte to produce the plans jointly with health authorities and family health service authorities and in consultation with representatives of the voluntary and private sectors, housing authorities and housing associations.... if the need arises, the Secretary of State will be able to direct district health authorities and social services departments to collaborate or to make planning agreements if there is any failure to comply with guidance".*

## Assessment

Virginia Bottomley said:

*"The Government will not prescribe how local authorities should make the essential assessments. The challenge to local authorities will be to tackle that task within their resources."*

Speaking about carers, Virginia Bottomley said:

*"Often their predicament is not recognised until they reac breaking point. For humanitarian reasons and to make the mos effective use of resources, it makes sense to meet carers half way. The White Paper states: 'Assessment should take account of the wishes of the individual and his or her carer and of the carer's ability to continue to provide care, and where possible should include the active participation. Efforts should be made to offer flexible services which enable individuals and carers to make choices.' The words could not be more unequivocal and they will be translated into the guidance.*

*"The position of carers, which is strongly recognised in the White Paper, will be carried through in the guidance.... The local authority must safeguard itself in a case where an individual might have an unreasonable wish for assessment. Once an individual becomes a disabled person—that right is ensured (under Section 4 of the Disabled Persons Act 1986).... I can conceive of no circumstances in which a local authority that may provide an assessment would reasonably refuse such a request from an individual or a carer.*

*"In a case where a request was refused, the Secretary of State would have powers to act when local authorities failed to comply with their duties."*

Later on in the debate, Virginia Bottomley says:

*"Assessment is a crucial tool in our community care plan. I do not think that we shall have a definitive model for assessment by 1st April 1991, but those who need community care will be receiving, by that date, a more comprehensive assessment of their needs than they have had before. Over the next decade we shall learn from our experience, we shall update our guidance, and many examples of good practice among local authorities will emerge which other authorities will be able to copy. It would be wrong while we are embarking on a new model to be overly prescriptive in legislating about the most effective model."*

## Appeal Procedures

*"Complex, bureaucratic, time consuming and costly.... and would not be remotely helpful to Local Authorities or to those who require services to build such a process into the Bill. We require Local Authorities to ensure, however, that their complaints procedures are properly advertised and promoted. People should be aware of how to complain."*

## Quality

In response to an amendment that would extend registration and inspection and put a duty on Local Authorities to ensure that service providers are inspected, Virginia Bottomley said:

*"We do not think it realistic in the time available (for local authorities) to take on yet another responsibility, but there are a number of ways in which quality can be safeguarded. The first method will be in the placing of contracts, which will contain mechanisms for monitoring and ensuring that quality is being secured.*

*"Secondly, the process of case management will ensure that those who receive community care will continue to have their cases reviewed. We are aware of the importance of local authorities establishing and promoting their complaints procedures to ensure that difficulties are dealt with satisfactorily. The clause gives the Secretary of State powers to inspect premises where community care is being undertaken, particularly those premises that are not safeguarded by existing legislation."*

In response to a further amendment to establish a quality Commission Roger Freeman MP replying for the Government said:

*"We are not persuaded that a National Agency is called for, because we think it would be a duplication of what is in place and what we propose to augment. There is a danger that it could become rather costly and bureaucratic. There are three ways in which quality can be monitored. First, all Local Authorities will have a duty to inspect and, through guidance we shall set out how Local Authorities could inspect. That inspection must be at arms length, of course. Nationally, there is the Social Services Inspectorate and the Health Advisory Service to help advise and monitor on national quality standards and draw attention to ministers in the Local Authorities where those standards fall short."*

## Funding and Ring Fencing

For the Government, Roger Freeman said the Ring Fencing of funds for a particular part of Local Authority expenditure would be a *"complete abrogation of what Local Government should be."*

Asked about new money for Community Care he replied:

*"Of course, it will be a relatively modest sum, because it will be only the amount of money necessary to care for those who come into assessment after 1st April. Therefore, in the first year, the old sum of money spent by Local Authorities on domiciliary care and other such Local Authority expenditure will continue. The new figure, as a national aggregate, will be in the public domain".*

Asked whether new money will be made available over and above that which would otherwise have been spent through the DHSS on the support of those in residential care he said;

*"The money will be separate and additional.... additional resources will be required over and above the public expenditure survey transfer which is the amount that would have been spent on the social care element of income support by the department of social security in the year 1991/92.*

*"Community care would have to be funded adequately, and clearly, therefore new money will have to be found for the introduction of the system and for new assessment mechanisms. That is a matter for detailed discussions in Government. Additional investment will have to be made in facilities that provided domiciliary care. We are under no illusions about the fact that the new system will have to be financed.*

*"Assessment of the additional cost has not yet taken place and it would be included in the public expenditure procedure that has just started and runs for several months"*

On the issue of training, Roger Freeman said,

*"We already have the power to make special grants for Social Service Training.... when the budget is set for 1991-1992 it will take into account the need for training and research in community care."*

## Joint Finance

On Joint Finance, Roger Freeman said that the Government was conducting a review of Joint Finance. He said;

*"Joint Finance resources will be £125 million for 1990/91. Options include; giving the money to the Local Authorities; giving it to the Regional Authorities; making no change in the procedure, (which means allowing the DHS's to spend the money by making grants to Local Authorities) or something like the proposal in New Clause 20. That would involve a centrally organised pump priming initiative aimed at developing innovative projects by Local Authorities, Housing Authorities and so on. When we have reached a conclusion later this year, we should bring proposals back to the House, including any necessary legislative changes."*

# INTEGRATED EDUCATION

**In this article Dorothy Dearing gives her own personal account of her fight to achieve appropriate schooling for her daughter.**

Our daughter Kristen was born in December 1974. She was diagnosed as having spina bifida and hydrocephalus. The medical profession, although sympathetic, did not give us much hope for the future.

When Kristen was three, she was accepted into the local pre-school playgroup, where she settled well and soon made friends with the other children. The other children were very interested in why Kristen was 'different', and the playgroup leader answered their questions as honestly and simply as possible.

At about the same time, an educational psychologist visited us, with a view to arranging Kristen's attendance at a special school. He seemed put out when we informed him that she was not going to a special school and that we wanted her to attend the local First school, and was adamant that no mainstream school would accept a child with such severe physical disabilities.

**The way in which the LEA treated Kristen is appalling...**

We were not prepared to accept this; fortunately the headmistress of the local First school was very supportive and encouraging and accepted Kristen into school. Everything progressed smoothly from First to Middle school, and Kristen expected to transfer to Cramlington High School with her friends in September 1988. However, Kristen was due for re-assessment under the Education Act 1981 at this time, and when her new statement arrived in June 1988 this stated she should attend a designated school seven miles away. This was against the advice of LEA's own Educational psychologist, who had strongly recommended Cramlington High School in his original report, but had been instructed to re-submit his advice, omitting this recommendation.

We immediately put an Appeal in motion. We were led to believe this would be fair, unbiased and informal but it seemed that we as parents were on trial. The Deputy Director of Education, representing the LEA, was dismissive of us, and on occasions would not even answer our questions. Reports which we had never seen before were produced at the Appeal to support the LEA's case. These reports were all inaccurate and one in particular, not on headed notepaper, was not even signed. The person who had supplied this information had not even met Kristen or us, and yet her information implied that we did not have Kristen's best interests at heart.

The Appeal Panel was made up of three Council representatives and two independent educationalists. We lost on a vote of three to two. The Council representatives all voted against us.

Nevertheless, we were not daunted by this. British justice being what it is we made an Appeal to the Secretary of State for Education, surely he would see some sense. The LEA's comments to the DES were misleading and inaccurate. On a number of occasions we requested a personal meeting with a representative of the DES, but this was refused out of hand. We sent numerous letters to them, but these seemed to be disregarded. On one occasion, important documents, sent Recorded Delivery, were lost in the post despite delivery having been confirmed by the Post Office.

After a whole year, a decision supporting the LEA appears to have been made by a civil servant, who signs herself in a letter to the LEA, 'I am Sir your obedient Servant'. How can parents be expected to have any confidence in such a system? By this time it appeared to us that the LEA were a law unto themselves, and the LEA appeared to believe this too.

Although the decision went against us, we could not back down, as despite the LEA's claims to the contrary, we knew they could not cope with Kristen's needs at the designated school. The LEA did not even know what her needs were, as her Statement of Special Educational Needs had been tailored to fit the designated school. We were very concerned about Kristen's education—or the lack of it as she was now into her fourth term out of school. In desperation we enroled her in the evening classes at Cramlington High School, the very same school she was not allowed to attend during the day.

On 1 December 1989, two Recorded Delivery letters were delivered to our home. One for Kristen's mother, the other for her father, containing a Notice of Attendance Order. We would have expected the LEA to know the Education Law but this notice had been issued under the wrong Act. In effect the LEA were depriving us, as parents, of the right to name the school on the Attendance Order.

During the preceding months our MP had been supporting us. On 17 December 1989 his agent brought the Chairman of the Education Committee to our house to meet us. It did not take him long to realise that the situation was not as he had been led to believe. He subsequently discussed this with the Leader of the Council, and then the councillors instructed the Officers of the LEA that Kristen was to attend Cramlington High School from January 1990. The Attendance Order was dropped.

Kristen is now attending Cramlington High School where she is coping well and is happy to be back with her friends. What a pity this did not happen eighteen months ago.

During this dispute our family has suffered great distress and injustice at the hands of the Officers of the LEA. We would hesitate to count the cost financially, except to say that it must be a sizeable amount. It must have cost the LEA considerably more.

The way in which the LEA treated Kristen is appalling. For no reason other than her disability, they acted as though they had a divine right to separate her from her friends and 'bus' her to a distant school. This appears to be discrimination against a disabled person in exactly the same way as we get Racial or Sexual discrimination. It should be dealt with in the same way—by Statute and as soon as possible.

Our thanks must go to ASBAH who supported us during this dispute, and special thanks to the Independent Panel of Special Education Experts who gave us invaluable advice and support when the going was tough.

# AWARD SUCCESS FOR SANDRA

After eight and a half years hard work, 25 year old Sandra Cole from Lymington in Hampshire has achieved her Bronze, Silver and Gold Duke of Edinburgh Award. Today, she awaits an invitation to London to receive the medal personally from HRH The Duke of Edinburgh.

During the last few years Sandra has been assessed on subjects ranging from soft toy making and the care of animals to archery and yoga. A First Aid Course under the umbrella of the St John's Ambulance Brigade was followed by lectures on 'Caring for the Sick'.

For the expedition Sandra began in Hampshire and took a two month tour of New Zealand. Although not able to rock climb or cycle, Sandra found a skill in ordnance survey map reading. "In England I carried out a number of surveys into methods of transport and used to sit at the road side for hours counting cars, lorries and bikes".

The most exciting and personally satisfying research project Sandra undertook was an in-depth study of David Essex and the music industry. "I never realised that it could take months to produce a 3 minute record" she explained. "I have met some wonderful and friendly people on the way. I have been allowed in recording studios, given opportunities to tour factories and have learnt a great deal about the marketing and promotion of records."

Sandra is convinced that the Award has given her a great deal of confidence as well as knowledge. "I still believe my dream to be employed as a clerical assistant in the music industry will have to remain a fantasy. Music will always remain my first love. I have followed David Essex on all his tours and been able to meet him. He is a very charming down-to-earth man. I have read all the books ever written on him".

The production of a video was another area in which Sandra became involved. "I was on a PHAB residential course when I took part in a video that looked at the attitudes of able-bodied people to those with disabilities. I feel very bitter that disabled people who are reliant on a wheelchair are barred from cinemas because of local authority fire regulations. There is still inequality about. I have given up a great deal of my spare time to volunteer for the St John's Ambulance Brigade—they are crying out for volunteers—but they will not let me wear their uniform, as they say that I am not fit enough. With the Duke of Edinburgh Award I was competing equally. I can't walk long distances because of my spina bifida, but that does not mean that I am incapable of doing what I want to do. Results at the end of the day are what matter. I can't stand unsupported, but in yoga my movements from the waist upwards were far stronger than those of my able-bodied counterparts."

Sandra has always made a point of spending her time with able-bodied people and works part-time in an office. She would like to encourage other people with a disability to enter for an award. To this end she is now taking part in a training programme organised by the Duke of Edinburgh Award Scheme for Leaders. "My aim is to acquire the skills to teach other people whilst also learning to assess them to qualify for the scheme. These residential courses are very intensive, but having a disability should not stop anyone from getting what they want out of life" Sandra concluded.

**Sandra with songwriter Guy Fletcher**

# THE WAY AHEAD: BENEFITS FOR DISABLED PEOPLE

**by Fidelity Simpson**

**On 10th January 1990 the Government brought forward its response to the OPCS surveys into disability in a document 'The Way Ahead: Benefits for Disabled People'. In the foreword to the document the Secretary of State for Social Security, Tony Newton, says:**

"The main needs are clear, better coverage of assistance with the extra costs of being disabled; better help for those disabled people who wish to increase their independence by working; and a better balanced structure of benefits to support those who cannot work, giving greater emphasis than now to those who are disabled from birth or in their early years.

When completed, this programme will build on the many other improvements already made in recent years to give us a more comprehensive and coherent system of disability benefits than ever before."

**The Government has said it will implement its proposals in a three-stage programme as follows:**

**Stage One** will be implemented by Autumn 1990 and involves the package of improvements worth £100 million announced in the upratings statement on 25th October 1989 and detailed in LINK December 1989.

**Stage Two** will be implemented by the 1990 Social Security Bill. The Bill introduces a small age-related addition to recipients of Severe Disablement Allowance under the age of 60. It deletes the six months qualifying period for eligibility for Attendance Allowance for terminally ill people. It also introduces measures so that from April 1991 there will be no new rights to additional pension with Invalidity Benefit and no new awards of Reduced Earnings Allowance in the Industrial Injuries Scheme.

**Stage Three** is expected to be in place in April 1992. The Government proposes to merge and slightly extend entitlement to Attendance Allowance and Mobility Allowance and will call this a Disability Allowance. A Disability Employment Credit will be introduced to top-up low earnings.

The Government has said that more detailed work will be required, especially for the third stage, and in the course of this they will take account of comments made by disability organisations and others.

Some of the modest improvements have been welcomed by disability organisations but the phasing out of the two disability benefits in stage two and the introduction of a so-called 'new' disability allowance have been widely condemned.

By the year 2000 the initial cost of the changes will be off-set by savings and by early next century the savings on Invalidity Benefit will be more than £1.5 billion.

**The Disability Benefits Consortium has said:**

"The Government's Paper fails to take up the challenge presented by the OPCS findings and overlooks the views of disabled people themselves. Despite saying it will be taking account of disabled peoples' organisations in working up its proposals for a Disability Allowance and an Employment Credit, it already has clear ideas about how many people will benefit.

The proposals are inadequate against the scale of need and complicate further an already complex and anomalous system. More resources, genuine consultation and more imaginative thinking are needed if disabled people are to overcome the low incomes that hinder their independence."

In a briefing paper on the Government's proposals, the Disability Benefits Consortium makes the following points:-

## Stage One

The package of measures announced will only benefit 500,000 disabled people and their carers, out of the 6.5 million disabled people identified by OCPS and 6 million carers identified by the General Household Survey 1985.

## Stage Two

The additions to SDA are very small, only £3.10 for those becoming disabled between the ages of 50 and 60 with a maximum of £10.00 for those disabled under 40 and no addition for those over 60.

It is disappointing the Government has not followed the advice of the Social Security Advisory Committee which recommends that rates of SDA be progressively raised to the level of Invalidity Benefit. The increases are little more than a recognition of the inadequacy of the existing benefit.

Recipients of both SDA and Income Support will have their Income Support cut as their SDA rises—thus out of the 263,000 claimants on SDA, the 143,000 on Income Support and a further unspecified number on other means-tested benefits will not get the full increase.

### Phasing out Additional Pension with Invalidity Benefit

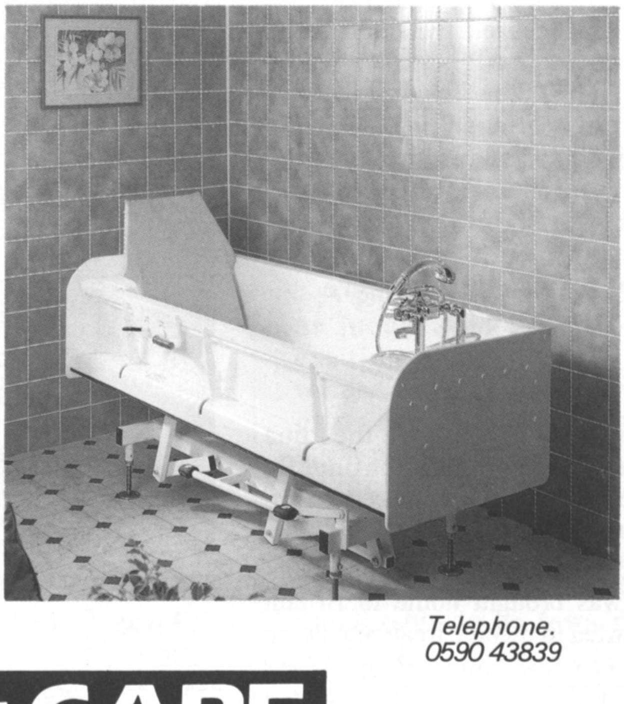
This is a straightforward cut in benefits to disabled people. The Government expects to save £350 million by the end of the century. The Government however also states that by 1998 the cost of Additional Pension will be £1.6 billion a year (para 6.9 of 'The Way Ahead'). The Government has justified the measure on the grounds that it redresses imbalances in the current system and will help stimulate occupational schemes.The Government should indeed be addressing the structure of the system but by improving not by levelling down benefits.

The OPCS data reveal 70% of disabled adults are on incomes 75% or less of average income. The DBC is also concerned that the Government is suggesting state benefits be replaced by private sector insurance particularly as many occupational schemes have proved inadequate.

## Stage Three

The proposed so-called Disability Allowance is simply a merged and slightly extended version of the existing Mobility and Attendance Allowances. It falls far short of the much needed comprehensive costs allowance that disability organisations are united in calling for. The disability allowance is intended to cover only mobility and care costs. It does not take into account extra costs that disabled people may incur on diet, laundry, heating and clothing or communication. Neither does the allowance recognise that severely disabled people have even higher costs.

The Disability Employment Credit will top up low earnings. There is however too little detail on the proposed Employment Credit to assess its value at this stage. More detail and genuine consultation is needed to ensure this benefit is of real value to disabled people.



# ROALD DAHL
# A FATHER'S STRUGGLE FOR SCIENCE

**Roald Dahl, the world's best-selling children's author was recently interviewed by Paul Rowinski, a reporter with the Bucks Free Press. In this article Roald Dahl explains how his son developed hydrocephalus following a road traffic accident as a child.**

In 1959 Theo, Roald Dahl's three-month-old son by former wife Patricia Neal, was tragically hit by a taxi in New York. "Immediately Theo went blind. Nobody knew if he would see again," said his father.

Theo underwent an emergency operation almost straight away at New York's Presbyterian Hospital. Surgeons implanted a shunt into his head to relieve the pressure on the brain caused by fluid build-up. It was the first of six major brain operations without which Theo might well have died. It also helped to bring down the initial pressure on the optic nerve which had caused the child to go blind.

> **"It has saved many lives across the world; especially in the underdeveloped countries.... thousands of young children were saved...."**

The shunts in use at the time worked badly. They continually blocked and had to be replaced to give Theo a chance of survival.

Three months after the accident Theo was brought home to Britain and started to receive treatment at the Great Ormond Street Hospital for Sick Children. There he was treated by the then head of neurosurgery Kenneth Till.

Mr Dahl reflected on the true-life problems they faced, "Till said to me, I wish these shunts didn't block all the time." "I said I was going to try to get a better shunt made."

Away from his writing in an unlikely but nevertheless believable friendship Roald Dahl once an operational pilot, met a man named Stan Wade just after the war, through their common passion for flying model aeroplanes. It was to him he now turned many years later, in his drive to find a solution to his son's problem.

"He was a great model plane enthusiast. He built these minute engines, thimble-size some of them. I knew he was a master engineer and a brilliant metal turner. His field was water pumps." He had made commercial hydraulic pumps used all over the world. He was soon to embark on a project of equal importance in 1962, that would again be of use across the globe.

Roald Dahl said "I went to Stan Wade, son of one of the founders of Broom and Wade Ltd, who had gone on to become a director of J T Wade and Sons Ltd. I said; 'Look here do you think you can make us a better shunt than the present one?' He was such a generous kind man. He immediately agreed to devote his time to it."

From then the two men were to work closely together, watching brain operations taking place, planning their next moves. It was to be the beginning of four years relentless work to find a solution. In a very different role from his creative prose, Roald explained the intricate medical problems while Stan perfected the valve in the shunt which had to open and close at an exact pressure if disaster was to be avoided.

The author said, "The actual making was done by Stanley in a little shed at the back of his house in the West Wycombe Road, where he had magnificent machinery. He could work a small piece of metal to the nearest 5,000th of an inch, not many people can do that. He was beavering away in that little shed. I was the courier between Stan and the hospital. He was the inventor."

Stan was to spend a long time working on the shunt, perfecting it and making it work properly. Eventually the finished product was delivered to Great Ormond Street Hospital. Prior to that an American model, costing approximately £100, was available. Now Stan Wade's version could be distributed, which cost a fraction of the price to produce and was marketed as a non-profit making product.

"It has saved many lives across the world; especially in the under-developed countries. They simply could not afford to get them before. Thousands of young children were saved," Mr Dahl added with total conviction.

The invention became known as the Dahl-Wade-Till valve, as a tribute to the man whose idea it originally was, the man who made the dream reality and the man who worked on the delicate surgery itself.

More than a quarter of a century later, neurosurgeon Kenneth Till (now living near Taunton, Somerset) looked back on what they achieved. The problems they had to overcome were many. The shunts at the time blocked. They needed a valve which could be inserted into the human body, could be sterilised and not cause infection, and flow one-way, away from the brain."It took Stan very little time to produce the first model. He made the prototype in a few weeks," said Mr Till. "He had considerable ingenuity. Unlike the ones before, the new mechanical movement of the shunt cleaned itself and did not get gummed up. That was the clever bit. In that sense it was pioneering work."

Mr Wade's invention needed less frequent replacement. "These operations were quite a serious upset to the brain and could leave a mark on the brain of a child," he said. Great Ormond Street Hospital set about using the valves—Stan Wade, in typical style, having given the patent to the hospital as a gift.

Roald Dahl reflected on their achievement with pride tinged with sadness, "Theo had already suffered mild brain damage by then. It was too late for him but benefited many others. My son eventually recovered by himself which is very rare". He went on to say that his son, now 29, can drive and works in Beaconsfield as a storekeeper. He thinks that all considered he has made a great recovery living a normal life.

Stan Wade continued with his work, "There was no question of him stopping. He was in too deep then with the hospital and the neurosurgeons."

Stan Wade died on 18 June 1986, aged 86. Roald Dahl attended the funeral to pay his respects to the man who had fought to help his son.

# CAN YOU TALK ABOUT IT?

**If you are articulate, enjoy a friendly chat, an interesting conversation, putting over your views on anything from world peace to the price of potatoes, now is your chance to test your skills—and help ASBAH at the same time.**

**Why not enter the Conversationalist of the Year Contest which takes place on Sunday 13th May at the Glaziers Hall in London. This year's event is being sponsored for ASBAH by *Whitaker's Almanack*, Britain's best known book of reference.**

**All you have to do to take part in this marathon chatathon is to talk eloquently with various given partners, for 12 rounds of words and wit; you do not have to have great knowledge of the stated subjects—just be able to converse reasonably intelligently about them and out-talk your partner.**

**A panel of celebrities will act as judges and there will be exciting prizes for the Title winner. In addition, there will be prizes for those who raise the most sponsorship money and the chance to enter a free champagne draw.**

**To enter, contestants are asked to raise £100 in sponsorship to go towards the work of ASBAH. For more details and an entry form please contact:**

**Conversationalist of the Year,**
**ASBAH, 22 Upper Woburn**
**Place, London WC1H.**

## KAMP FOR KIDS

Kamp for Kids is a unique summer camp in the USA. This article is an extract from *The Exceptional Parent* and was prepared with the assistance of Judy Hoyt, Mark D Havens and Chris Roland. It presents a recreation programme that involves parents of children with disabilities in a variety of ways. The programme described began because parents wanted to create a positive summer camp experience for their children, and continues to be maintained through their efforts.

Every summer in Western, Massachusetts, 120 campers, some of them able-bodied, some of them in wheelchairs or on crutches, can be seen playing volleyball, doing arts and crafts projects, or going through an obstacle course that can be adapted for different levels of ability. Kamp for Kids, an innovative summer recreation programme, stresses parent involvement, as well as the belief that the only failure any one of us can have is not to try.

In the history of Kamp for Kids, parents of children with disabilities have persevered to find summer recreation for their children. The camp is a model for parents' involvement— from its fund-raising activities to the family weekends held four times a year, attended by parents and their disabled and able-bodied children.

Kamp for Kids began through the work of a small number of parents. They wanted to create a programme that would enable disabled children to enjoy a positive camp experience, as well as to provide able-bodied children with the opportunity to relate to a child with disabilities as a peer. They felt it was important to show children that even though they had some differences among them, they could all have fun together.

Judy Hoyt, one of the principal founders of Kamp for Kids, and her husband felt strongly that they wanted their son, Rick, to experience all the things that other children experience.

In order for Rick to be able to go to camp, she had to volunteer to go with him, and care for any special needs he had. The experience of many parents of children with disabilities has been that they have to give something to the community in order to get something in return. This has become one of the basic principles of Kamp for Kids.

When parents of children with disabilities got together and started talking about the summer, they realised they all had a similar problem. With no school to go to and few recreational opportunities, their disabled children had nothing to do during the summer.

While their able-bodied siblings could go off and play with other children, they required their parents' assistance. The children were not accepted by most summer recreation programmes, and the only way they could go was if they were accompanied by their parents.

As a result, parents did not have the opportunity to spend some time alone during the summer like parents whose children are away at camp are able to do. Respite care was not an entirely satisfactory option, since it did not adequately provide for the children's eeds, so a small group of parents ecided to start a day camp programme hat would integrate disabled and able-bodied children.

Kamp for Kids developed out of that small day camp. It opened in 1976, and was funded initially by a federal grant from the Westfield Community Development Office. The camp stressed the right of every child to be free to learn and participate with everyone else, within the limits of safety, ability and personal satisfaction.

One of the goals of those who began Kamp for Kids was to encourage disabled and able-bodied children to play together, and learn to accept one another. After the camp's grant ran out, the board of directors decided that the camp would have to close unless they found some way o pay its bills.

They worked hard to come up with a udget. They started with trade-offs. If a parent helped with fund-raising, his or her child could go to camp. If a parent directed or taught a swimming class at camp, her child could come. The problem with this system was that some families felt they were being excluded. They said they did not feel they had the time to fund-raise, or take time off during the day to teach a class at camp.

**Support is a key factor for many—if the other parents can do it, so can I. And we can do it together.**

A point system was devised. Parents pay for as much of the camp costs as they want to. Almost anything a parent does that contributes to funding the camp gets translated into points. In the past, the camp has run bake sales, clothing sales, etc. The hours it takes to bake a cake, drive it over to the sale, and sit and staff the bake sale table all count as time for camp. Even someone who has to stay at home can earn points by licking envelopes or making phone calls. Points are translated into dollar amounts which help to pay the cost of a child's time at camp.

Other aspects of parent involvement in Kamp for Kids are the parent weekends run by the camp approximately four times a year—twice in the spring and twice in the autumn. The purpose of the weekends is to have the entire family unit enjoy time together and learn how to play together. In addition to the camp staff stressing integration of able-bodied and disabled kids at camp, they also attempt to teach parents the skills to integrate their child with disabilities into the family unit. There is a full programme of activities and discussions involving parents, children and staff throughout the weekend.

The staff believe that the weekends work because parents feel more comfortable when there are other people who have the same difficulties participating and learning to play together. Support is a key factor for many—if the other parents can do it, so can I. And we can do it together.

Kamp for Kids was created and continues to thrive through parent involvement. Its structure makes participation possible on several different levels. The point system is one way in which parents remain active in their children's recreational experiences.

Parents work throughout the year to ensure that their children will be able to enjoy a quality camp programme in the summer. By offering an integrated recreation programme and parent weekends, Kamp for Kids gives families that include a child with disabilities the opportunity to learn how to play and live together.

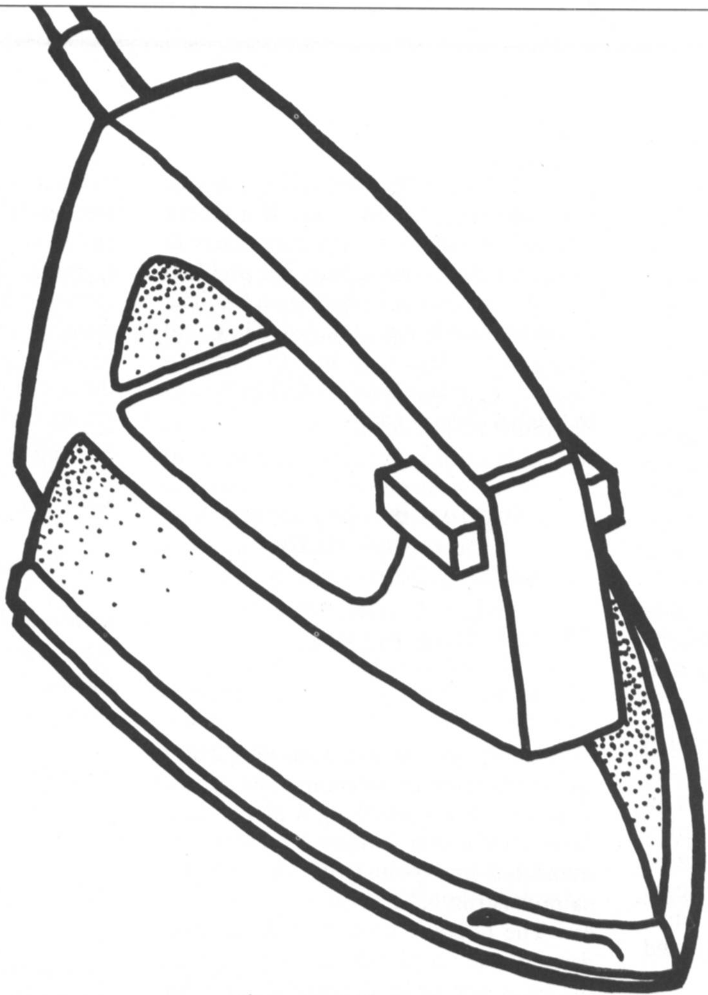
## BOURNEMOUTH ROADSHOW

The ASBAH Roadshow visited Bournemouth at the beginning of April to share information about our work and offer support to people with spina bifida and/or hydrocephalus, their families and those who work with them. The Roadshow was very kindly sponsored by BP who also fund Jill Slade, the ASBAH Fieldworker for the area.

Many events were crowded into three days, all of which were very well attended. On Thursday 5th April a Reception to launch the Roadshow was held at the Durley Hall Hotel hosted by ASBAH's immediate past Chairman Mr R R Mackenzie. Unfortunately, the Mayor was unable to attend, but a past Mayor Councillor Dan Crone and Mrs Crone were able to extend a Civic welcome. Guests heard about ASBAH's work at national and local levels and meet the staff.

The Reception was followed by special interest sessions for parents, social workers, teachers, medical workers and other professionals. This occasion provided an opportunity for sharing views and experiences with the overall aim of better services for people with spina bifida and hydrocephalus and their families.

A similar day was also organised for parents and others involved with the Hydrocephalus Support Group. A young people's disco on the Friday night was a great attraction and well attended.



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**Rates: £3 for 30 words max; £4.25 for 30-45 words; £5.50 for 45-60 words.**
**Cheque or postal order payable to 'ASBAH'**

**Adverts for the next issue of LINK (June) should be in by the 6th May. Send to: The Editor, *Link*, ASBAH, 22 Upper Woburn Place, London WC1.**

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