



Disability Living Allowance Advisory Board

NEWS & UPDATE

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Topics for Future Issues

- ◆ Aphasia
- ◆ Epilepsy
- ◆ Extended stress after amputation
- ◆ Falls in older people
- ◆ Chest pain/chest conditions
- ◆ Stereotypes

DM's suggestions for topics welcome. Please contact us.

INTRODUCTION BY THE CHAIR

Hello and welcome to this edition of DLAAB UPDATE AND NEWS. There are 2 articles that I hope you will find both interesting and informative. Spina Bifida can be complex and cause many problems throughout a lifetime. This article, however, explains the different aspects of the condition and the effects that can occur to both care and, through pain and weakness, to mobility. It is a thoughtful and informative piece that I hope you will enjoy.

We are often asked for more information in the assessment of children and what might be considered over and above what is expected of children at different ages. This article explains the different terminologies for assessment and, together with other previous articles, I hope, will help to build a picture of the different aspects of childhood development.

As usual, we are always interested in what might be causing difficulties for you and are very willing to help by these short articles so please let us know.

With best wishes

Anne Spaight
Chair DLAAB

Spina Bifida Doug Ross

What is Spina Bifida?

Spina bifida is a neural tube defect that literally means 'split spine'. It results from the failure of an embryo's neural tube to develop properly. The central nervous system and spine develop between the 14th and 28th day after the start of pregnancy, with the neural tube normally having fully closed between the 26th and 28th day. In cases of spina bifida, the vertebrae fail to form properly, leaving a gap or a split, exposing the spinal cord to possible damage.

Types of Spina Bifida

There are three main types of Spina Bifida.

1. Spina Bifida Occulta. Sometimes referred to as a hidden form of spina bifida, and the least serious form. Many people are unaware they have the condition, or only become aware after they have an X ray or a scan. Estimates vary widely, but it is suggested that anything from 5% to 30% of the population may be affected.

2. Meningocele. In this type, the covering of the spinal cord, the meninges, pass through the opening to form a sac or cyst-like swelling called a meningocele. The sac contains tissue and cerebro-spinal fluid. Nerves may not be damaged and there may be little disability present. This is the least common form.

3. Myelomeningocele (or Spina Bifida Aperta). In this, the most serious type, the sac not only contains tissue and cerebro-spinal fluid, but nerves and part of the spinal cord as well. The spinal cord will be damaged, or not properly developed. The level of disability will depend on the amount of nerve damage.

Hydrocephalus

Many people born with spina bifida will also have hydrocephalus (from the Greek - 'water on the brain'). Rather than actual water, this is an accumulation of cerebro-spinal fluid within the brain that can lead to a build up of pressure. The insertion of a shunt valve by surgery may relieve this pressure.

What Causes Spina Bifida?

The exact causation is still unknown. However, research indicates there may be both genetic and environmental factors. Diet is one factor that has been linked to spina bifida. There is no 'cure' for spina bifida. However, it is possible to reduce the likelihood of spina bifida occurring. Women contemplating pregnancy and those in the early stages of pregnancy are recommended to take folic acid as a precaution. Where there is a family history of neural tube defects, a higher dosage is recommended. Pre-natal screening techniques can be used to identify if a developing foetus has spina bifida. In such cases, specialist counselling may be offered to the parents.

Effects of Spina Bifida

The level of disability will vary with the individual and will depend on the site of the spina bifida, and the amount of damage caused to the nerves.

Physical effects can include paralysis and loss of sensation below the damaged area, back pain, lower limb weakness, unsteady walking gait, balance problems, sexual problems, and bowel and bladder problems. In more severe cases, individuals may need the use of wheelchairs, or walking aids.

Aside from the physical effects, there may also be psychological issues around coming to terms with having a disability, particularly in the transition to young adulthood.

Treatment and Support

Advances in surgical and medical treatment have impacted dramatically on both life expectancy, and the quality of life for people born with spina bifida and/or hydrocephalus in the last 20 – 30 years. A decision will be made shortly after a baby's birth whether to operate to try and repair the defect in the back. The surgeon may operate to 'close' the opening in the spine.

The child as it grows may go on to have further assessment and undertake a programme of rehabilitation and physiotherapy. The physiotherapy may include swimming and other exercises designed to mobilise and strengthen the back and legs.

Help may be required with everyday tasks such as bathing, toileting, and dressing.

Pain killing medication and/or pain management techniques may help to alleviate to some extent the discomfort that can arise from the condition.

Further information and support for people with spina bifida, or families affected by spina bifida is available from a number of organisations including the Association for Spina Bifida and Hydrocephalus (www.asbah.org) and the Scottish Association for Spina Bifida and Hydrocephalus. In some cases these organisations may be able to help with individual or family counselling.

Living with the condition

In the past, it was often the norm that children with spina bifida were expected to attend special schools. Nowadays, with the move towards integration, many children and young people with spina bifida can and do access mainstream educational provision, with appropriate support where required.

It is easy to subscribe to the often seen stereotype of a person with spina bifida as a wheelchair user with limited mobility below the waist. However, many people with the condition live full and independent lives, in spite of the physical restrictions placed upon them. Spina bifida need not prevent someone from playing an active part in many of the activities that we may take for granted, such as playing sports, driving a car, working, or raising a family. You only have to look at Britain's most successful wheelchair athlete Dame Tanni Grey-Thompson for inspiration. Born with spina bifida, she has gone on to become Paralympic champion, London Marathon winner, and mother.

Terminologies used by Education professionals in children with special educational needs

Dr Ben Ko

The following are the main stages that a child with special educational needs may go through, depending on the degree of needs and how well the child progresses after special interventions. Some may remain in the early stages if satisfactory progress has been made while others may progress to a full statement. Children with obvious and significant needs may go straight to statutory assessment and statement, bypassing the earlier stages e.g. children with four limb cerebral palsy and severe learning difficulties.

Stage 1: School Action

When a class teacher or the Special Educational Needs Co-ordinator (SENCO) of the school identifies a child with special educational needs, the class teacher should provide interventions that are additional to, or different from, those provided as part of the school's usual differentiated curriculum offer and strategies.

This stage is triggered if a child is not making satisfactory progress despite targeted teaching approaches. The cause of concern could be any significant cognitive need e.g. literacy or numeracy skills, behavioural difficulties, sensory or physical problems, or communication and interaction difficulties.

As a result, an **Individual Education Plan (IEP)** will be drawn up for the child. It sets out time limited targets and records strategies employed to enable the child to progress, and is reviewed regularly.

Stage 2: School Action Plus

If a child on 'School Action' is not demonstrating satisfactory progress despite the additional intervention provided, the IEP will be reviewed by the SENCO and colleagues, in consultation with parents. The child will enter 'School Action Plus' if a decision is taken to seek advice from external services, such as educational psychologists or specialist advisory teachers.

Stage 3: Statutory Assessment

This may also be known as the 'Statementing' process, though not all assessments lead to a Statement being issued.

This stage is triggered if a child on 'School Action Plus' is not making satisfactory progress despite the additional specialist input, and is considered likely to be in need of a Statement of Special Educational Needs. The Local Education Authority (LEA) will conduct the

assessment by collating reports from all the relevant professionals and the child's family.

Parents can request the LEA to conduct a Statutory Assessment directly, without necessarily involving the child's school. This may indicate a degree of parental concern that the child may not progress without a statement, despite alternative plans made by the school. The LEA may or may not go through with the assessment but it has a duty to consider the request and inform the parents their decision.

Stage 4: Statements of Special Educational Needs

'Where, in the light of the Statutory Assessment, it is necessary for the LEA to determine the special educational provision which the child's learning difficulty calls for, the LEA shall make and maintain a statement of his or her special educational needs.'

The general criteria for issuing a statement are when the child's needs cannot reasonably be provided within the resources normally available to mainstream schools. The statement will specify the additional provisions and the resources made available. On some occasions the child may be moved from mainstream to special education.

Statements are reviewed at least once a year.

If the findings of the statutory assessment conclude that the child's need can be met without a Statement, the LEA will issue a 'Note in Lieu' indicating the decision not to issue a Statement and the reasons for the decision.

Increasingly, the LEAs over the country are moving ('delegating') funds to individual schools to provide for children with special educational needs, resulting in little or no central funding being held by the LEA. Therefore it is no longer necessary to go through the 'Statementing' process to obtain funds to employ additional staff or purchase special equipment. In some Boroughs, the number of statutory assessments has decreased dramatically, as there is no financial incentive to go through this resource demanding process.

DLAAB NEWS

MEETINGS WITH OUTSIDE ORGANISATIONS

The Board meets regularly with outside organisations. At these meetings Board members with relevant skills, expertise or interest have discussions with representatives of various groups.

The Board invites specific groups and also welcomes approaches from any group who feels it would benefit from meeting the Board. We have met representatives from the RNIB.

We use the News and Update as a means of directly informing DM's of changes that are new or brought to the Board's attention. This is in addition to the information already available in the Disability Handbook.

Updates to the Disability Handbook are being made via ICT where appropriate. Meeting with the Board gives access to representatives of outside organisations to inform us of issues needing clarification.

NEWS

The Board has held a seminar for DMs at Warbreck House with another due to be held at The Adelphi in London in April.

Since the last issue Our Information and Development Group has been monitoring new developments and treatments for various conditions with the focus being on subsequent changes in the level of Care and Mobility needs.

Our website continues to include new publications by the Board and our latest Annual report has been posted. The conclusions of our study of Special Rules cases are also available on our site. We now have an internal search engine giving easy access to articles from all past issues of the News and Update as well as all Annual reports.

THE BOARD

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THE REMIT

The Board has three main functions:

- **To give advice to the Secretary of State on matters referred by him/her.**
- **To give advice to Department of Work and Pensions Medical Services doctors on cases referred for expert advice.**
- **To present an Annual Report on its activities over the year to the Secretary of State.**

INVITATION TO DM'S

If you have any specific questions or general queries please contact us via the Secretariat.

We wish to use the News & Update as a forum for discussion.

FOR YOUR INFORMATION

Please note- the articles contained in this news- sheet are written for the benefit of Decision Makers, to help them with their job.

The articles are **not to be quoted** in any decision or communication with members of the public or their representatives.

GETTING IN TOUCH

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