

# Information about Pre-school Children with hydrocephalus and/or spina bifida

June 2005

This information is aimed at providing professionals with details on the types of provision available for pre-school children in the early years setting.

The Code of Practice regulations in Early Years settings are also included.

by J Grenfell, Regional Education Adviser  
ASBAH Northern Region

with special thanks to:-

Sue Goodhead, Early Years Educational Psychologist and  
Portage Co-ordinator for York Local Education Authority



## What are special educational needs?

A child has special educational needs if he or she has a learning difficulty which calls for special educational provision to be made for him or her.

### A child has a learning difficulty if he or she:

- a. has a significantly greater difficulty in learning than the majority of children the same age.
- b. has a disability which either prevents or hinders the child from making use of educational facilities of a kind provided for children of the same age in schools within the area of the local authority.
- c. is under five and falls within the definition at (a) or (b) above or would do so if special educational provision was not made for the child.

A child must not be regarded as having a learning difficulty solely because the language or form of language of the home is different from the language in which he or she will be taught.

### Special educational provision means:

- a. for a child over two, educational provision which is additional to, or otherwise different from, the educational provision made generally for children of the child's age in maintained schools, other than in special schools, in the area.
- b. for a child under two, educational provision of any kind  
(1993 Education Act, Section 156)

## A child with special educational needs may have difficulties in one or more of the following areas:

### 1. COGNITION AND LEARNING DIFFICULTIES:

- a. general learning difficulties
- b. specific learning difficulties

### 2. EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES

### 3. COMMUNICATION AND INTERACTION DIFFICULTIES:

- a. speech and language difficulties
- b. autistic spectrum difficulties

### 4. SENSORY AND PHYSICAL DIFFICULTIES:

- a. hearing impairment
- b. visual impairment
- c. physical and medical difficulties

## Early Years Services for Special Educational Needs

Every Local Authority has early years services for children with special educational needs. The people involved in providing these services are usually highly skilled professionals with extensive experience of working with families who have young children with special needs.

### Portage

Portage is a regular home visiting scheme that works with families who have pre-school children at home. Portage aims to help parents teach their children new skills and to support transition into early years settings such as a playgroup, early years centre or the local nursery.

- In Portage, parents meet the home visitor for about an hour
- Together you decide on 1 or 2 skills the child will work on that week
- Record the child's progress on a chart

### Pre-school Support

Pre-school support works in partnership with children, families and staff to help children reach their full potential in all early years settings. Pre-school support works with all agencies, including ASBAH advisers, in planning for a child with spina bifida and/or hydrocephalus and their successful transition into school.

- Pre-school support will ask for as much information as possible about the child's development and work so far achieved
- Will meet together on a regular basis with parents to plan for the child's needs
- Will need written permission from families to meet and work with the child
- Can provide advice and support about the range of education opportunities available and help plan placements
- Support staff working with children to increase skills and knowledge
- Will support in all early years settings - including private nurseries, schools and playgroups
- Can differentiate the curriculum - including targets for IEPs/IPPs
- Support transition into school
- Work with other agencies eg parent partnership
- Support with statutory referral process (statementing)

*NB All pre-school settings must have a designated special needs co-ordinator (SENCO) on their staff, who is responsible for liaising with other professionals in identifying and supporting children with special needs.*

### Other Information

Helpful information can also be obtained from "Right from the Start" an early years strategy for children with special educational needs. Also initiatives such as Sure Start which will target 0-4 year olds in areas of high deprivation and early excellence centres, which will aim to bring together child care and education and will be used as centres for training.

Sure Start is an initiative which aims to offer additional services and improve provision for children aged 0-4 and their families in areas of high economic and social deprivation. From that programme the children's centres will provide integrated services for children and their families up to 16 years of age. They also aim to ensure that all children in that area have access to high quality provision for education and play.

Further information from Sure Start Website [www.surestart.gov.uk](http://www.surestart.gov.uk)  
[www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk)

### Ofsted

Children with significant special needs in early years education, whether that be via playgroups, classes, childminders, or through Portage, will receive a specialist inspector to ensure standards are maintained and to enable recommendations to be made for all early years provision.

## Provision for children with Special Educational Needs in the Early Years

### Home based learning programmes

Portage, peripatetic teachers for hearing impaired or visually impaired

### Range of Early Years settings

playgroups, day nurseries, mainstream nurseries, early excellence centres with and without additional support and advice

### Specialist provision

in opportunity (play) groups, special schools, special classes in mainstream provision, small teaching groups in Health Authority premises

### Child Development Centre

advice from clinical psychologists, health therapists, pre-school teachers

### Family Centres

## Parents as Partners

Parents are children's first and most enduring educators. When parents and practitioners work together in early years settings, the results have a positive impact on the child's development and learning. Therefore, every setting should seek to develop an effective partnership with parents.

Early learning goals

DfEE and QCA 1999

ISBN 1 85838 379X

## Parents of children with Special Educational Needs

Parents hold key information and have a critical role to play in their children's education. They have unique knowledge and experience to contribute to the shared view of a child's needs and the best ways of supporting them. It is therefore, essential that ALL professionals seek to work with parents and value the contribution they make. The work of professionals can be more effective when parents are involved and account is taken of their wishes, feelings and perspectives on their child's development. THIS IS PARTICULARLY SO WHEN THE CHILD HAS SEN. All parents of children with SEN should be treated as partners. They should be supported so as to be able and empowered to:

- Recognise and fulfill their responsibility as parents
- Play an active role in their children's education
- Have knowledge of their child's entitlement within the SEN framework
- Make their views known about how their child is educated
- Have access to information, advice and support during assessment and any decision-making processes about SEN  
(Code of Practice, p16)

Copies of the Special Educational Needs Code of Practice November 2001 can be ordered from DFES, reference DFES 581/2001:

Tel: **0845 60 222 60** e-mail [dfes@prolog.uk.com](mailto:dfes@prolog.uk.com)

Ideally this should be read in conjunction with:

The Human Rights Act (re Education) and UNICEF's leaflets 'Convention on the Rights of the Child'

### Contact:

UK Committee for UNICEF, 55 Lincolns Inn Fields  
London WC2A 3NB 0171 405 5592

## Statutory Assessment in the Early Years

- Appropriate for "a very few children" (= 2% for whole spectrum of special needs, not just early years)
- Must only be requested after consultation with parents and external support services
- Can be requested by parents, schools and settings (NB Currently non-maintained settings can make requests for the 4 and 5 year olds receiving nursery education funding.
- The Local Authority then decides whether to proceed
- In a very few cases a request may be made to the Local Authority before there has been any early education intervention
- Has very strict time limits - see Code of Practice Chapter 7
- Parental perspective is particularly important - the Local Authority MUST make an assessment if the parent of a child under the age of 2 requests it

## Structures for Supporting Children with Special Educational Needs

Child presenting difficulties and receiving appropriate educational experiences

### Early Years Action

parents and providers identify needs and look for ways of supporting children

### Early Years Action Plus

characterised by the active involvement of outside support agencies

### Referral for Statutory Assessments

when parents, providers, or other professionals ask the LA to make an assessment

### Statutory Assessment

the period of time when the LA makes a statutory assessment)

### Statement of Special Educational Needs

When a document is drawn up obliging the LA to provide additional support and resources

### Review of Statement

the child's statement of special educational needs is fully reviewed annually, with an interim review every 6 months for children in the early years

## Individual Education Plans

(sometimes referred to as Individual Play Plans)

- Requirement of the Code of Practice
- Needed at Early Years Action, Early Years Action Plus, and when child has a Statement
- Advice for helping children with SEN to progress
- Describes interventions that are ADDITIONAL TO or DIFFERENT FROM the way the curriculum is offered to others
- Provides a clear focus for everyone who works in the setting with the child
- Should acknowledge child's strengths and achievements and pinpoint specific 'SMART'\* targets to work towards, which are...

Specific

Measurable

Achievable

Realistic/Resourced

Time-based

\* 'SMART'

## Reviewing Individual Education Plans

### Important

- IEPs should be kept CONTINUALLY under review
- It may not be possible to set fixed term or formal meetings for reviews
- However, IEPs should be reviewed at least 3 times a year
- Parents' views should be sought
- Parents should be consulted as part of the review process
- External support services will ask to see IEPs at Early Years Action Plus

- The LEA will ask to see the setting's IEPs when considering the need for a Statutory Assessment of a child's SEN

IEP's should focus on children's strengths and achievements as well as identifying areas for development.

## Triggers for Early Years Action Plus

- continues to make little or no progress in specific areas over a long period
- continues working at an early years curriculum substantially below that expected of children of a similar age (ref. Stepping Stones in Curriculum Guidance for the Foundation Stage, for children aged 3-6)
- has emotional and behavioural difficulties which substantially and regularly interfere with the child's own learning or that of the group, despite having an individualised behaviour management programme
- has sensory or physical needs, and requires additional equipment or regular visits for direct intervention or advice by practitioners from a specialist service
- has ongoing communication or interaction barriers that impede the development of social relationships and cause substantial barriers to learning

## Role of the SENCO

Early education providers have to identify a member of staff to act as the special educational needs co-ordinator (SENCO). In the case of accredited childminders who are part of an approved network, the SENCO role may be shared between individual childminders and the co-ordinator of the network. Settings may find it effective for the SENCO to be a member of the senior management team.

The SENCO should have responsibility for:

1. ensuring liaison with parents and other professionals in respect of children with special educational needs
2. advising and supporting other practitioners in the setting
3. ensuring that appropriate individual Education Plans are in place
4. ensuring that relevant background information about individual children with special educational needs is collected, recorded and updated
5. take the lead in further assessment of the child's particular strengths and weaknesses
6. take the lead in planning future support for the child in discussion with colleagues
7. take the lead in monitoring and reviewing the action taken
8. All early education providers are subject to regular OFSTED inspection.

## Implications of Hydrocephalus in the Pre-school setting

Hydrocephalus is when too much cerebro-spinal fluid or CSF is present inside the ventricles of the brain and it cannot escape through the normal drainage pathways. If the condition doesn't improve the surgeon may insert a shunt which helps to release the pressure and

drains the excess CSF often into the abdominal cavity. Shunts are artificial devices which can last for many years but they may stop working effectively or cause a blockage or infection.

Pre-school settings need to be aware of the possible complications that can occur if the shunt malfunctions. A helpful strategy is to have a readily available agreement of what to do in an emergency. Parents and Pre-school settings should ideally work together on this strategy, with help from ASBAH advisers if necessary, about the best way to deal with this potentially life threatening condition, should a shunt malfunction happen at school. Some children with hydrocephalus may also need strategies for coping with incontinence problems. Ideally schools should ensure they have parents' up to date contact numbers, including mobile phone numbers.

**ASBAH's free information sheet gives much more detailed information about hydrocephalus and shunt malfunctions. See [www.asbah.org](http://www.asbah.org) or our helpline on 0845 450 7755. Also see ASBAH's 'Hydrocephalus and Education pack' cost £3.00 inc p&p.**

## Awareness and Strategies - hydrocephalus

Pre-school settings need to be aware of the following possible implications of having a child with hydrocephalus and/or spina bifida. Not all of these observations will apply to every child.

### Safety

If a child receives a blow to the head or abdomen and does not recover as quickly as other children would, damage to the shunt should be considered. However, this is very rare. See Shunt Malfunction sheet.

### Short-term Memory

Limit the number of instructions given at any one time to 1 or possibly 2. Keep reminding the child where to put or to find equipment. Progress may be inconsistent. A "visual timetable" made up of pictures or symbols signifying particular events or aspects of a day or task can be useful.

### Fine Motor Skills

Co-ordination may be poor, so do activities which encourage grip usage ie blocks, magnetic trains, wooden tracks, multi links, etc. Use light felt pens, large handled paint brushes and, if necessary, special scissors. Give extra help with getting coats on and activities such as catching a ball. Handling malleable materials such as play dough and clay can help to build up strength and dexterity.

### Visual Perception

Some children may seem clumsy and have balance difficulties. They may need extra time and space to get around. Take care when using steps and outside activities. They may need to sit near books and/or objects. They may have difficulty in making sense out of fussy pictures.

### Concentration

Some children may be easily distracted or they may not stay on one activity for very long. Mention their name first and encourage them to repeat your instructions, where possible gaining eye contact.

## Behaviour

Not every child will present behavioural challenges. Children need to know boundaries and feel safe and familiar. Many children don't like change of any sort. They need lots of preparation, if possible, before outings or a change of person. Keep a notebook or diary. Use of simple sand timers, or electronic digital timers can help to give a child a clear visual reminder or count-down to a change of task, or a break time.

Some children may need more drinks than others or even something to eat and this may help a child who is irritable or extremely tired. Some children react very negatively to extreme noises and wherever possible should be warned or removed from the situation.

Youngsters may not relate easily to their peers but seem to prefer to be with an adult or much older/much younger child. It may take time to build up relationships because many youngsters don't have the initiative or motivation to make the first move. Adults too, need to know when best to support and when best to stand back and let the child develop some independence. However be aware that the child may have little concept of 'stranger danger'.

## Other problems

- lack of routine
- obsessive tendencies
- home/school diaries (parents as partners)
- reluctance to participate in new activities
- difficulty transferring skills

## Implications of Spina Bifida in the Pre-school setting

Spina Bifida is a fault in the spinal column when one or more of the vertebrae in the spine fail to form properly. This leaves a 'gap' or a "split" which may cause irreparable damage to the nervous system. For a more detailed explanation and the types of spina bifida please see information sheet, What is Spina Bifida from ASBAH House, 42 Park Road, Peterborough, PE1 2UQ or visit ASBAH's web site at [www.asbah.org](http://www.asbah.org).

Not all children with spina bifida are wheelchair users, but often the child will need physio/occupational therapy input. Those children who have some paralysis and loss of feeling below the damaged area of their spine may have bowel and bladder problems. Early Years settings may need extra support and seek further advice in such an instance. Often one reason for children not being offered a place in early years settings is because they are incontinent. Clearly when incontinence is a result of a child's disability the children shouldn't be disadvantaged or discriminated against. All schools including extended schools provision have to take note of the Disability Discrimination Act and Disability Equality Duty.

Parents too, need that extra support, particularly in cases when the child also has hydrocephalus.

Please contact ASBAH for further advice and information.

## Awareness and Strategies - Spina Bifida

Pre-school settings need to be aware of any possible gross motor skill problems the youngster may have. Many children are willing and able to safely use the floor and equipment to get around with physio/occupational therapy advice.

They should be encouraged to choose and move wherever they wish independently. Professionals will have been able to get advice about splints/calipers/rollators/wheelchairs if that is applicable but it may be the parents who make the most valuable contribution.

Unfortunately, probably the most contentious issue for those children with spina bifida, but who may or may not have a learning difficulty, is incontinence. Parents may find this the greatest barrier to gaining a place in a Pre-school setting. ASBAH Advisers will always be willing to offer support and advice as and when necessary.

The setting may be able to access funding to provide additional support/staffing.

## Link magazine

The essential magazine for people with hydrocephalus and spina bifida.

Link is published quarterly (Winter, Spring, Summer and Autumn) and is packed with the latest news, events and issues for individuals, carers and people living with hydrocephalus and spina bifida. To subscribe contact ASBAH's Helpline 0845 450 7755 email: [helpline@asbah.org](mailto:helpline@asbah.org) or visit our web site: [www.asbah.org](http://www.asbah.org) and click on the publications page.



# hydrocephalus action

**Codman and ASBAH are working in partnership to promote 'Hydrocephalus Action', a campaign aimed at heightening hydrocephalus awareness.**

## **Help us**

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**ASBAH relies on people's generosity and support so we can help our clients who depend on us for help and advice - people with hydrocephalus, spina bifida, their families and carers. To donate to ASBAH please visit [www.asbah.org](http://www.asbah.org) or call 01733 421327.**