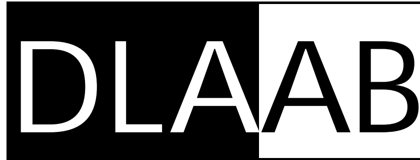
Issue 5 June 05



Disability Living Allowance Advisory Board

NEWS & UPDATE

INDEX

Topics for Future Issues of Update **page 1**
Introduction by the Chair **page 2**
The Care and Mobility Needs of Deaf People **page 2**
Sarah Playforth
Normal Development in children **page 8**
Dr. Ben Ko
DLAAB News **page 10**
Getting in Touch **page 11**
Invitation to DM's **page 11**

Topics for Future Issues

- Epilepsy
- Post Traumatic Stress Disorder
- Severe Mental Impairment
- Laryngectomies

If DM's have any questions on these issues, please contact us.

INTRODUCTION BY THE CHAIR

Hello everyone,
Welcome to this latest edition of DLAAB News and Update. This edition contains some interesting mat erial, written as a result of requests for further information from decision-makers. As we plan the contents for these newsletters we do try to cover topics that are known to cause some problems so we do value all suggestions.
Summer will have passed by the time the next edition is published, so keep the ideas flowing in and have a lovely summer.

Anne Spaight
Chair DLAAB

THE CARE AND MOBILITY NEEDS OF DEAF PEOPLE

Sarah Playforth: Access & Equalities Consultant/Trainer

Introduction

Almost nine million people in the UK are deaf (all statistics relating to adults from *Deaf Awareness course handout* number 5; 2003: Council for the Advancement of Communication with Deaf People [CACDP]).
Deaf children (facts and figures from the National Deaf Children's Society website, www.ndcs.org.uk).
Every year 840 babies are born deaf, meaning around 1 in 1,000 children are born with a severe/profound hearing loss. In the UK two or more babies are born severely/profoundly deaf every day and there are an estimated 34,800 deaf children and young people (0-25).

There are two main types of deafness:

- Sensori-neural deafness, or nerve deafness as it is sometimes called, is a hearing loss in the inner ear. This usually means that the cochlea in the inner ear is not working effectively.
- Conductive deafness means that sound cannot pass through the outer and middle ear into the inner ear. This is often caused by blockages such as wax in the outer ear, or fluid in the middle ear (glue ear). Glue ear is a very common condition, especially in pre-school children.
- It is possible for children to have a combination of sensori-neural and conductive deafness. It is also possible to have a permanent conductive deafness, but this is very rare.

Communication

90% of deaf children grow up in hearing families with little or no experience of deafness. Late diagnosis of deafness is proven to cause delay in language development. Children with hearing losses identified before 6 months of age have significantly better language development than children whose hearing losses are identified after 6 months of age.

Children with normal cognitive development whose hearing losses are identified before six months can develop language at the same or a similar rate to a hearing child.

Deafness in itself is not a learning difficulty. Learning difficulties arise when deaf children cannot access communication. An undiagnosed deaf child aged three will only know about 25 words, compared to 700 words for a hearing child of the same age.

Given that the majority of profoundly deaf children will grow up to use sign language (*Deaf Young People and their Families*, 1995. Gregory S, Bishop S, Sheldon J) and that most of their parents will have no prior knowledge of sign language, deaf children are prone to significant delays in developing language.

It is estimated that 81% of parents with a deaf child never learn to communicate with their child. Lip or speech reading provides some cues to language but, at most, only 40% of the sounds produced by English are visible on the lips.

Many deaf children even with intense auditory training, may learn only 5% of what is said to them. This language delay means that learning is severely compromised, with deaf children typically leaving school with a reading age of 8 and needing more intensive attention from their parents and other people for longer than hearing children to enable them to develop physically, socially, intellectually and emotionally.

Deaf Adults

Deaf Sign Language users
Around 75,000 people, born deaf or deafened before acquiring speech, often to Deaf parents, and whose first language is British Sign Language (BSL) may consider themselves not as disabled, but as part of the cultural and linguistic minority Deaf community and describe themselves as Deaf with a capital D.

Deafened People
About 123,000 people in the UK have suddenly lost all or most of their useful hearing after the acquisition of spoken language as the result of illness or injury. They will continue to identify with the hearing community and are likely to consider themselves as disabled by their loss of hearing.

Hard of Hearing People
Approximately 8.3 million people are hard of hearing. Over 6.5 million are aged over 60. Hard of hearing people have usually grown up speaking and reading their first language and are still able to do so, they retain some residual hearing and are likely to use hearing aids.

Deafblind/Dual Sensory Impaired
About 24,000 people in the UK have a significant degree of both sight and hearing loss. People in this group are the most isolated and are in greatest need of one to one support.

Care and Mobility Needs – deaf adults

Deaf people whether they are born or have become severely or profoundly deaf will need in most situations some form of communication support, which can be technological and/or from another person.
People deafened later in life will additionally have a period of emotional and intellectual adjustment when they are learning lip-reading, sign language or alternative means of communicating with other people.
For hard of hearing people, often losing hearing as part of the aging process, it may also be very difficult to adjust to wearing hearing aids. The period of adjustment may vary. In some it will not be successfully achieved and factors such as age, physical health, mental state and co-existing disablement may impair and prolong the period of learning and rehabilitation in an individual case.
Where lip-reading or signing is used in a one-to-one situation this involves speaking clearly and face to face or using sign language and would not normally be seen as attention. Use of a professional lip speaker or other third party communication support, such as a sign language interpreter, however, would be treated as attention.

Some of the problems that may be encountered are:

- Difficulty hearing what strangers are saying
- Difficulty hearing what friends or family are saying
- Not being able to follow TV programmes that are not subtitled
- Only being able to lipread a trained lipspeaker
- Needing to use an interpreter or other communication support
- Not being able to wake up in the morning or in the night if an emergency occurs
- Being in situations when help is needed for the person to understand what is being said, for example outdoors in crowded places when other people are speaking.

Help to communicate with other people may need to be provided by another person in their presence, for example:

British Sign Language (BSL)/English interpreting
An interpreter is a qualified professional who will both voice over what the Deaf person is signing and sign what a hearing person is saying in many situations, e.g. courts and tribunals, conferences, theatres.
Lipspeaking A professional lip speaker repeats everything that is said with clear lip patterns and no sound so the deaf person can see what is being said; they will not voice over.
A communication support worker in educational settings, the CSW provides both access to communication and additional explanations of what is being taught to support a person with low levels of English
Speech-to-text reporting This involves a person using a specially designed keyboard to type what is said on to a small or large screen for the deaf person to read
Informal help from friends or family It is not possible to have professional support for day to day living and friends and family will be the most common source of communication support

The important factor to consider is not the level of hearing loss, but the amount of help needed with communication.

Mobility

Various problems that may occur and can be considered when deciding whether to award the lower rate of mobility include:

- Being unaware when traffic is approaching or unable to hear warning sounds, such as car horns or sirens
- Needing someone to explain loudspeaker announcements
- Having difficulty understanding and following street maps or needing help to follow directions or having problems understanding and following written directions, reading or understanding street signs, bus numbers, timetables and destination boards: many born deaf people with a low level of language have difficulty with reading written information
- Needing another person to communicate with hearing people
- Having problems with strangers not understanding their speech when they ask for directions
- Having difficulties understanding a hearing person giving directions: if the hearing person cannot sign or speak clearly or written information is not accessible

Care and Mobility Needs – deaf children

For deaf children, a great deal of extra attention and supervision in all situations is necessary to keep them safe, to support their language,

social and emotional development and to help them to make sense of the world around them. It will take longer to achieve many milestones such as toilet training because of the need to explain things so the deaf child will understand.
The very young hearing child may be allowed to toddle further away, within earshot of the parent, but the deaf child will need much closer attention as they won't hear their name called. They will need to be supervised all the time if wearing hearing aids or implants under three, as these contain small parts and batteries that could be swallowed. These aids also need care and repair.
Language delay means they will need more help than a hearing child to understand concepts such as traffic danger. In order to understand people they need to get close to them, which makes them more vulnerable to stranger danger. When wearing hearing aids or using a cochlear implant sound outdoors is confusing and can be frightening. At nighttime, it takes longer to settle the deaf child as they will need to keep a light on to see the person with them and can't be reassured by voice. As the child grows older, extra communication support becomes more necessary, as most hearing parents of deaf children are not able to communicate with their child and there will be more settings outside the home where the child is in need of access to communication

Obtaining supporting evidence for decision making

For deaf people this evidence is most valuable when provided by someone who really understands the difficulties faced by the deaf person. The fullest evidence may be obtained not only from their GP but from a hospital doctor, audiologist, hearing therapist, social worker or other social care professional, or a communication support worker, close relative, or friend.

Technical and medical advances

For deafened people, advances in technology and medicine can help prevent the occurrence of deafness and remove some of the barriers to communication for deaf people (for example text phones; induction loops for hearing aid users; video interpreting; digital hearing aids; cochlear implants and hair cell regeneration). As yet, however, nothing is widely available that can fully restore lost hearing or significantly change the prognosis, care or mobility needs of an individual deaf person. Much still depends on the ability and willingness of hearing people to communicate clearly and to provide supporting technology.

The charity Defeating Deafness awards grants into research into the prevention, diagnosis and treatment of all forms of hearing impairment; the National Deaf Children's Society can provide information on the causes of deafness in babies and children and the Royal National

Institute for Deaf People is a useful source for information on technical and medical advances such as digital hearing aids and cochlear implants.

Conclusion

The most misunderstood issue for deaf people is the amount of extra concentration needed to compensate for the lost sense of hearing. Most people take for granted the information they get via hearing – they don't need to concentrate to get it. It takes three times as much mental and physical effort to lip read as to hear.

For deafened people there is always emotional trauma at their loss and this can result in serious depression and suicidal tendencies. It will depend on many factors, both external and internal, how soon and how well they begin to deal with the issue. Many will feel unable to go anywhere alone during the period of adjustment.

Lack of access to information and communication means that deaf people have a reduced social life and face difficulty getting involved in many activities – evening classes, sport and leisure, arts and entertainment, church and hobbies etc. Access to health and social services is compromised, as well as to business and commerce. Unemployment is very high for Deaf people and many deafened people lose their jobs as a result of their hearing loss.

NORMAL DEVELOPMENT IN CHILDREN

Dr Ben Ko: Paediatrician

Age	Vision and Manipulation	Hearing and Speech	Gross motor/mobility	Social behaviour, feeding dressing and toilet.
Birth to 3 months	**Vision**: At birth, closes eyes to sudden bright light, and turns towards diffuse light. By 3 months, looks at nearby human face **Manipulation:** Hands closed at birth. Watches and plays with own hands by 3 months, and may hold a rattle for few moments when placed in hand. May be able to hit pram beads.	**Hearing:** At birth, startle reaction to sudden loud sounds, 'freezing' reaction to weaker, more continuous sounds. Turns head to nearby speaker from 4-6 weeks **Speech:** Cries (birth), coos (4-6 weeks) and chuckles (10-12 weeks)	Minimal movements and posture control at birth. Head control develops from 6 weeks. By 3 months, able to lift head when lying on tummy, and possibly able to lift upper chest supported by arms. Should be keep head upright when held sitting by 3 months.	**Social behaviour:** Social smile while looking at mother from 4-6 weeks, and responds by making noises when spoken to. By 3 months, chuckles and laughs. **Feeding, dressing & toilet:** Feeding, winding and settling at 3-4 hourly intervals by day. Night - time feeding is normal for a newborn baby up to 3 months. Dependent on adult completely.
By 6 months	**Vision:** Visually very alert for near and far. Can fix on small objects on the table. **Manipulation:** Reaches for toys, grasps firmly with palms and looks at closely. Usually takes objects to mouth. Begins to transfer objects between hands.	**Hearing:** Able to turn to noises nearby at ear level **Speech**: Own vocalisations frequent. Shouts to get attention. Cries in protest.	Trunk control develops. By 6 months, can roll front to back and probably back to front. Keeps back straight when held sitting.	**Social behaviour:** Recognises mother from 3-4 months, from a few feet away. Responds happily to all friendly comers till about 6 months. **Feeding, dressing & toilet:** Night time feeding is beginning to be dropped from 3 months onwards
By 9 months	**Vision:** Visual acuity further develops. Follows adults across room, and able to fixate on small objects nearby and possibly at a distance. **Manipulation:** Hands competent to reach for and to grasp small toys, takes everything to mouth. By 9 months, able to explore objects with both hands and pass between hands.	**Hearing:** Ability to localise sounds further develops, above and below ear levels. Beginning to recognise own name when called. **Speech:** Babbles in increasingly long strings for self - amusement when alone.	Should be able to roll both ways (6 to 7 months). Sitting unsupported and attempts to crawl (8 to 9 months). Takes some weight on legs when held standing (8-9 months)	**Social behaviour:** Shows increasing reserve with strangers but very responsive to familiars. **Feeding, dressing & toilet:** Begins to finger feed e.g. holding own biscuit.

Age	Vision and Manipulation	Hearing and Speech	Gross motor/mobility	Social behaviour, feeding, dressing & toilet
By 12 months	**Vision:** Able to spot very small objects nearby, and at a distance. **Manipulation:** Uses both hands freely. Able to pick up very small object e.g. a raisin, with a fine 'pincer grasp' by 12 months. Points at objects (e.g. smartie) with index finger. Beginning to cast objects.	**Hearing:** Understanding of speech further develops. By 12 months, understands 'No' and possibly the names of familiar people **Speech:** Babbling with more different sounds and longer strings. First word may be spoken (e.g. 'mama ' or 'dada') by 12 months	Getting better at crawling. Can sit unsupported and lean forward to pick up a toy without losing balance. Begins to pull to standing and takes one or two side-ways steps against furniture. Some may be walking from 10 to 12 months.	**Social behaviour:** Plays 'peek-boo', and waves bye-bye and clap hands on request **Feeding, dressing & toilet:** Holds, bites and chews a biscuit. Puts hands round bottle when feeding. Tries to grasp spoon when being fed.
By 18 months	**Vision:** Continues to develop, approaching adult acuity **Manipulation:** Can use both hands together. Able to release toys from hands on request. Enjoys casting objects on floor and banging objects together. Can press large buttons on toys to make noises or flashing lights. Should have stopped putting objects into mouth indiscriminately.	**Hearing:** Able to understand simple instructions by 18 months e.g. 'Give me ball' **Speech:** Vocabulary increases, using a range of single words by 18 months	Most children will be walking by 18 months of age. Many will have developed a quick trot and can get up from falling without help. Can climb into an adult chair, and crawl upstairs. Can pull or push toys around the floor and can carry objects without falling over.	**Social behaviour:** Curious and likes to explore. Imitates simple adult actions e.g. brushing, sweeping and cleaning. Emotionally labile and closely dependent upon adult's presence. Needs constant supervision, as a result of increasing mobility and curiosity. **Feeding, dressing & toilet:** Can hold own cup for drinking, and attempts to spoon feed, but messy. Can pull off socks and shoes. No toilet awareness yet

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 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.

Since the last issue of DLAAB News and Update the Board has been engaged in a study of MS, and has met with representatives of Macmillan Cancer Relief. Our Research 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 is being improved and will be re-launched shortly.

THE BOARD

Chair:
Mrs Anne Spaight MBE
Vice-Chair
Dr Ian McGill
Co-Ordinators:
Dr David Cohen (Research)
Mrs Marion Westacott (Organisation)
Mrs Clair Poole (Education)

Members
Mrs Simone Baker
Mrs Jean Cooper

Members (cont)
Mrs Judith Holt
Ms Marilyn Howard
Dr Ben Ko
Dr Mohammad Obaidullah
Dr Audrey Oppenheim
Ms Sarah Playforth
Mr Douglas Ross
Prof. David Scott
Prof. Tom Sensky
Mrs Sarah Vines
Mrs Christine Whitehead

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

DLAAB at The Adelphi
1-11 John Adam Street,
London, WC2N 6HT

Telephone: 0207 962 8982

Email: DLAAB-consultation@dwp.gsi.gov.uk

Or on the web at: www.dlaab.org.uk