BATOD

British Association of Teachers of the Deaf

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The articles look at deaf children and young people who also have autism, foetal alcohol syndrome, a range of learning difficulties, multi-sensory impairment and meningitis.

There are also articles about special ways of assessing the hearing needs of this group of children away from the clinical environment as well as a parental perspective and a look at the support offered by the NDCS.

If you would like to make any contributions to a future edition of the Magazine on this or any other subject don't hesitate to submit your article or ideas to magazine@batod.org.uk

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Online... and up to date

Andrea Baker looks at the CPD log, how it started and why it needs to be revived now to ensure ToDs get recognition, plus using the feedback form about the modification of the language of examinations

Those of you who have been BATOD members for a number of years may remember the Continuing Professional Development (CPD) log which was developed in 2004. It was designed to give Teachers of the Deaf a framework on which to record activities they'd undertaken throughout the year to maintain and build on their specialism, expertise and knowledge. The aim of the log was to provide evidence of the commitment to improve and a record of the wide range of activities carried out by individuals working in the profession. Although few chose to take up the option of having their log registered with BATOD, many Teachers of the Deaf used it successfully to ensure their Performance Management recognised their role as a specialist teacher. Take-up in the first few years was encouraging and many felt that it gave authority and recognition to the specialist nature of their role.

When the School Teachers' Performance Management was revised in 2006 the log slowly fell into disuse as regulations and paperwork were imposed from above. Although initially it was relatively easy to incorporate the key elements of the log into the new system, these revisions were more prescriptive and increasingly linked to capability and classroom observation. There is a danger that recognition of some of the key features of the role of Teachers of the Deaf has been lost.

With this in mind BATOD NEC felt that it was time to revisit the log, bring it up to date and make it fit for purpose within the current context. As an increasing number of services are being managed by non-specialists – and an increasing number of Resource Bases are within Academies – it is essential that the expertise of Teachers of the Deaf is recognised within a framework of identified goals to ensure appropriate in-service training is accessed so that we remain up to date with technology, research, pedagogy and resources. By the end of this year we aim to produce a document which will feed into the wide variety of Performance Management formats across the Regions and Nations and align it strongly to the Specialist Teaching Standards underpinning the Mandatory Teacher of the Deaf Qualification. Being a good Teacher of the Deaf requires us to stay abreast of so many areas – technology, audiology, child development, curriculum, government initiatives..... We hope the new CPD log will enable you to identify key areas for your personal development and gain recognition for those specialisms which are essential to our role.

As I write this, the hot topic of the moment is examinations. Whilst this year's candidates are just about completing their written papers there is much discussion around the somewhat depressed results for last year's deaf candidates. We know that the new style examinations with reduced coursework and an increase in end of course written examinations do not play to the strengths of deaf students. Unfortunately this is now a fait accompli so it is now even more important that deaf students are not further disadvantaged by the structure and wording of the examination question papers. Ovingdean Trust supports BATOD to train and support Language Modifiers who are available to all Examination Boards and they provide excellent guidance. There are occasions, though, when papers may slip through the net. If you are aware of any particular examination or question paper which you felt disadvantaged deaf candidates we would like to hear about it and feed back to the Exam Boards. There is a feedback form available on the BATOD website at http://www.batod.org.uk/index.php?id=/resources/exams/langmod-form.htm

Feedback from Teachers of the Deaf 'on the ground' is an essential part of the process and we greatly value your input.

As we start the new term it's time to look ahead to the 2016 BATOD Conference. This will be held in Cardiff on 12th March and the theme is Working with Technology. It promises to be another excellent day and one which will feed into your Continuing Professional Development. Do mark the date in your diary!

Andrea Baker

Simple but complex: a conundrum

In this leading article Wendy McCracken gives an overview of the issues related to children with additional and/or complex needs

As ToDs it could be argued that our role is to positively intervene to secure learning in any child or young person (CYP) who, because of their deafness, is at risk. This would mean looking at the whole child, the family and educational setting and working with a wide range of professionals and other agencies to ensure support is tailored to meet the individual needs of a specific deaf child/young person. Complexity comes in many forms as every individual is by their nature complex. So in seeking to understand and provide services to deaf CYP the first question would seem simple. Is the degree of deafness, irrespective of any other need, likely to affect progress? If the answer is yes then a ToD should be involved.

What do we mean by complex? It is perhaps useful to think of specific groups because as a starting point this can be very useful. There are those where a significant amount of information is freely available: syndromic deafness, those where a virus/infection and the causal agent is known. There is a group where the medical needs are paramount – medically fragile children and those who have profound and multiple needs. There is a newly named group of SWANs – CYP with a **s**yndrome **w**ithout **a** **n**ame. There are those where the cause of complexity is unclear – for example, children affected by Foetal Alcohol Syndrome or drug abuse and children who have been involved in road traffic accidents or treated for cancer. This simple grouping is a starting point only. Where the causative agent is known a wealth of information is now available. It would be simple for a large authority or group of services to look at the prevalence of specific syndromes or conditions and to identify an individual who could research one of these areas and then pool resources. What amongst the evidence is important for a ToD to know and will impact their support; it might be a child who has pica (eating nonedible objects) or needs diffuse lighting, will have significant difficulties in understanding 3D objects or may have hypersensitivity to sound? Information is electronic and easily shared and if the task is spread it is easier to achieve. Students at the University of Manchester prepare INSET packages and may well choose a syndrome that they have come across on placement. They produce informative, evidence based information; for example, this year on Alport, Usher and Pendred syndromes; perhaps this is a resource that could be more widely shared?

For all parents complexity brings a vast range of emotional demands. For medically fragile children hospitalisation dominates their early experiences. Reflecting on the importance of early childhood experiences – eye contact, reciprocity, attunement, the first smile and early babbling – this group of children is reliant on medical interventions for their survival. It is more than being in hospital for extended periods; it is the sterile environment and lack of opportunity to visually explore or have close physical contact that means early experiences are quantitatively and qualitatively different. In addition to the very significant stress parents and siblings have been through these parents have also gained skills in medical interventions. This will have been taught to them before their child left hospital and families are then sometimes surprised when a ToD is not familiar with dysphagia or a gastrostomy. Such situations mean ToDs need to be absolutely secure in what they are bringing to the child and family.

Groups such as those children affected by Foetal Alcohol Syndrome *(see article on page 22)*, and drug abuse are seldom mentioned or discussed but can have life-long problems that can be ameliorated by sensitive support. Children who survive cancer may also then acquire deafness as a result of the ototoxic effects of the platinum-based chemotherapy treatments. In this case the child will have acquired spoken language prior to the illness and then after the trauma of treatment may develop a profound hearing loss. Clearly the type of support offered would need to be mindful of the child and family's journey. Similarly children involved in road traffic accidents may acquire a hearing loss, typically affecting the high frequencies, but the overriding concern will be survival and gaining independence, rather than hearing status.

It is impossible to cover every complexity, and no consideration has been given to mild impairments, poverty, mental health of the child or parents which will impact the child or children who are sexually abused or live in care. There are multiple layers of need – some made more challenging because they progress, because the progression cannot be predicted and this makes planning and advice more difficult. Additionally, all children are unique and have qualities and potential that may be hard to understand and to exploit and are within families that in themselves are complex. So given this can we, as ToDs, effectively work with this diverse group in a meaningful way that promotes development?

It is not only possible but also a responsibility. Every child with any degree of hearing loss/deafness has a right to appropriate services and this includes those of a ToD. So what is it a ToD should be doing? This is the simple bit – it helps if you like playing detective. ToDs are specialists so:

- Go to the child's setting and assess its suitability for a deaf child – quality of lighting, room acoustics of all the learning environments
- Find out which professionals are involved, names, specialisms and contact details
- Contact and if possible meet parents/carers and explain your role
- Look at communication skills – use the appropriate developmental journal and check exactly where the child is up to so you can baseline and measure progress against this
- Does the child have personal hearing aids? Does everyone in contact know how to manage these, how to retube, report problems and understand battery routines and child locks?
- Observe auditory responses and if you are unsure liaise with the audiologist – do tests and responses add up?
- Does the child have the opportunity to use aids in a quiet environment every day?
- Does the child have access to a radio aid and if not why not? Can they hear in the taxi or their parents' car when it's noisy or be plugged into an iPad for their favourite app or television for that special programme?
- Is there music therapy at school and how is the child accessing this?
- Is the school using Makaton? Would it be more helpful to consider BSL? Does the child have the receptive skills to use this (has their vision been checked?); do they have the physical ability to make signs? If not what exactly will they use to make requests or comment?
- INSET for all staff as the INSET would potentially improve the environment for all the children; hearing aids are not optional, do make a difference and should be worn at all times
- Do parents know about Parent Place for additional needs on the NDCS website?

In other words, be a Teacher of the Deaf with all your skills and knowledge and make a positive difference in the life of all deaf children. The needs are complex but you have skills, knowledge and understanding that can change lives.

Wendy McCracken is Professor of Education at the University of Manchester.

Top tips when working with deaf children with complex needs

Jo Franklin shares some thoughts from her long career working with deafblind children

I can still recall very vividly (even though it was nearly thirty years ago) the first deafblind little boy that I met. I remember my realisation that all the skills that I had relied on as a young Teacher of the Deaf lay useless before me as I began to understand how small this little boy's world was and how cut off he was from my hearing-sighted world. I have since recognised in the eyes of fellow Teachers of the Deaf on occasion the same struggle that I had – to know how to go about working with these very complex children. I thought it might be helpful to distil a 'Top Ten Tips' from my subsequent career that I offer here to anyone who recognises themselves at that point now.

Assess with an open mind. Most of the deafblind children whom I have worked with, I have first met in a letter from an audiologist or a colleague which often simply has question marks next to the word 'Hearing'. After much effort and often months (or even years) of trying, many subsequently turned out to have hearing that was very different from initial thoughts. One child was assessed in one setting, on one day, as having a possible mild loss, which was described the very next day in another, as profound. Assessing such complex children's hearing is an art form and 'objective' tests can mislead. I have found that it requires us to take all information from objective assessments as part of a bigger picture which needs to be equally filled in by adding our own observations of the children's hearing in their real worlds and particularly also listening to those who know that child…

Listen to those who know the child! It still surprises me that we 'professionals' sometimes seem to start from a position where, because we have a 'chunk of knowledge' about something (hearing loss), we sometimes lack the humility to realise that we don't have the sort of detailed intimate knowledge of any child that their families do. Building an honest, open, empathetic relationship with a child's family is the most useful tool which we have in unlocking the puzzle of that child's needs and abilities.

Hone your observation skills. I was lucky enough to learn the art of waiting from one of the masters in this field (David Brown). Learning to be still and not to jump in too soon are often the key skills with deafblind children. Watching and trying to imagine what the experience might be like from that child's perspective (hard though this is – we must try) can give us the insight that we need. So often, a child does something wonderful, just the second after I had begun to think that I should leap in and interfere (or 'teach'!). So many opportunities would have been lost if I hadn't been prepared to wait for 'almost too long'.

Follow the child. Once we observe and really try to 'get inside' the child's experience then we can follow their lead. We can join them in an activity, shadowing their behaviour, following the traces of their movements and link with them through their interests. Then we can share the lead with them – sometimes altering something slightly to see if we can take them with us (which will teach us so much about them) but always ready to relinquish the lead back to them before we ruin the interaction.

Understand the problem. It is really important that we educate ourselves about deafblindness: what the effects of the visual loss are likely to be in combination with the child's hearing loss… and their likely other complexities – both those relating to physical difficulties and those relating to their personalities. We need to talk to all the many professionals who make up the team around each child. We all need to share our observations and insights. We need to look up what that curious medical term means and apply our ToD understanding to what the impact might be; then share it. If ever there were children who require of us good liaising skills and teamwork it is these children. Of course we do also need

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- ask for ideas for presenting curriculum information
- get help from colleagues across the UK
- discuss
  - *– buying and using radio aids for use at home*
  - *– issues relating to pay and conditions of Teachers of the Deaf*
  - *– speech discrimination testing*

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Reminder for current and future members:
BATOD manages this forum which is hosted by the Department for Education. Any information about changes of email address or other enquiries should be sent to ToD@batod.org.uk

to remember the limits of our own training and not give advice that is beyond it. We will, however, find out some very interesting things through these children if we are prepared to ask and listen.

Emphasise the positive. Deafblind children and their families have plenty of experience of being told, or being able to see for themselves, what their child can't do – the onus on us as educators is to find out what they CAN do. Obviously we don't want to become overly optimistic Pollyannas, but we do need to find out what the children like and become the champions of what they are able to do. In this way we will ensure these children are not underestimated (which is very common). We will also be providing things that those around them feel they can do to help them develop and we may help alleviate the downwards spiral towards depression which for some of our families is a very real threat.

Use all the child offers you. Deafblindness is a disability of access – we need to find ways of enabling the child to make contact with and begin to understand the world. Using other modalities to help the child get access can be really useful, but we need to do so carefully and knowledgeably. Touch can be a very powerful way of reaching the child but used thoughtlessly it can turn children off – we must use respectful touch. We also can't presume that a deafblind child's use of touch is the same as ours – we must observe and if necessary be prepared to modify ourselves. We cannot expect the child to change; the only person we can change is ourself and by doing so we will hopefully elicit change in the child. Use of smell and taste are even more fraught with potentially counterproductive elements. It may seem like such a good idea to use a specific perfume to aid in recognition of a particular activity, but we don't know what connotations that smell may have for that child. The temptation to find additional sensory 'routes' for our children has led to some pretty wild and overwhelming multi-sensory environments bursting around individual children. In my experience 'less is more' is a very useful dictum. We also need to be aware of the impact of the hidden sensory modalities of balance and proprioception (our sense of where we are in the world) – but that is a whole different article!

Create reactive environments. For deafblind children to learn they need to find out that their actions create reactions. They need to know: that if they pat a toy in a Beactive Box it will make a noise; that if they bang their chain-draped legs on a resonance board it will resound through their bodies; if they use an Object of Reference or a sign a responsive person will do something that they want them to do – the message will have got through. Things need to happen when they try to make things happen. Reactive environments, however, are as much (if not more) about the people in the place rather than just the place. The people around a deafblind child are vital to their success. A specialist trained 1:1 person who works with a deafblind child to bring the world to them if they cannot get to the world is called an intervenor. Most deafblind children will need someone to fulfil this role. They will need someone who interprets their behaviour and enables their communication and facilitates their mobility.

Enjoy the privilege of working with some very special children. There have been children in my career who have appeared to be able to do so little but who have shown me huge depths of humour and understanding. There have been children who 'on paper' have such long lists of difficulties and disabilities but who have been some of the brightest and most intriguing children I have met. I have lost count of the children who have surpassed all expectations and I have never encountered a deafblind child who didn't leave me a little wiser for knowing them.

So, my final 'tip' is …**Trust yourself.** If we bring our knowledge as Teachers of the Deaf to the child and really look at who they are, where they are now, what their experience of the world might be (as nearly as we can imagine it) and what we want to try to open up for them, we have the skills, we can adapt them and we can make a real difference to these children and their families. Have fun!

Jo Franklin was originally a Sense Advisory Teacher and more recently the deafblind Service Coordinator in Wandsworth.

FM tags

Emma Mathes describes how the use of themed tags with an FM system helped develop both conversations and friendships

Anna, Elsa and the radio aids – how Disney helped me talk to my friends.

I began to work with Beth (then aged 5) as a TA; she had a severe deteriorating visual impairment and was rapidly losing her vision. My work helped bridge the gap in access to the curriculum. Her visual function varied throughout the day raising multiple challenges in the busyness of a mainstream school day. I provided incidental learning opportunities, identified and filled concept knowledge gaps and helped to enrich her learning through the use of all her senses. At this time professionals were beginning to consider that she may have a permanent hearing impairment (following grommet insertion).

Delays in responsiveness

Working closely with Beth as she began to learn braille, I got to know her better and became more aware of her struggles with hearing at a level not previously identified. Her slow answers were sometimes considered to be due to her visual impairment or reluctance. All children have times like this but there was a surprise and confusion about her when she was being challenged that concerned me.

The words 'talk to your partner' would on a regular basis lead to silence from Beth. This was confusing to the partner eager to share and discuss ideas. It would often need assistance from an adult voice but even then Beth would become withdrawn in the buzz of noise and not say anything.

At the end of year one, doctors and parents agreed that hearing aids would help meet her moderate conductive/mixed hearing loss. This moderate loss was more serious in impact because of her severe visual impairment. Beth did not see the interactional signals such as eye contact or body language which helped other pupils monitor conversation and this made her friendships even more difficult.

Year 2 – the impact of hearing aids

It was amazing to see the impact of Beth's hearing aids on her confidence and expression of her personality. She was very happy to wear them and was delighted by some of the sounds she could now identify. Initially fatigued by all she was processing, she soon developed more stamina and stopped taking them out for part of the day.

Her processing speed, language and literacy skills improved and she was happier, more outgoing and developed a sense of humour. She was also much more involved with her classmates.

Despite these positives she struggled with background noise.

The problem with FM systems

An FM system was introduced with three microphones – I would wear the initiator set, the class teacher the second set and a third was used with a multidirectional microphone. This meant that Beth could hear the teacher teaching, my voice supporting her and her peers in discussion work.

Problems arose as the mic packs seemed to highlight Beth's disabilities to her peers and were seen as an aid to a disability rather than an opportunity to talk and be properly heard.

As a deafblind person, combined hearing loss and visual impairment meant that she was less aware of what to talk about with her peers and her peers were too young to cope with the way they would need to communicate to help Beth enter into conversation. They expected Beth to know what they were talking about; they would ask questions but Beth's short responses stopped conversation and caused them to lose interest.

Tags

The idea of using character tags to label the FM system came about when Beth wanted to take more control and responsibility and hand them to the wearers. Attaching brailled tags was a simple way of labelling them so the right person got to wear the right one.

But they came into their own when we decided to use them to help Beth express her interests and personality. Beth and I decided that each term she would choose a different character for the tags and I sourced and laminated suitable pictures. Thus the first microphone became Little Miss Dotty, the second, Little Miss Princess and the multi-directional microphone, Mr Chatterbox. Other themes chosen were Christmas and then in particular the Disney film 'Frozen'.

Suddenly her peers saw the character labels and forgot about the mic. It sparked immediate enthusiastic conversation and raised awareness of Beth's interests. Using a talking label (RNIB 'Penfriend') transformed them into interactive tags, I recorded excerpts of the characters' songs. This made them 'cool' and they became known as 'gadget tags' amongst some of Beth's peers.

The labels of Anna, Elsa and Olaf from the Disney film 'Frozen' (which Beth loved) were a big breakthrough! At last Beth had an immediate and powerful way of showing her peers that she was just the same as them in her passion for the characters and songs from the film (universally popular with children and staff).

The mp3 player linked to Penfriend was loaded with music from the film and provided a popular sing along feature on the tags for wet playtimes and so on. Beth no longer needed an adult to scaffold her conversation. Her peers now initiated conversation from a common enthusiasm and understanding of the characters and story.

Moving on from Frozen

At the end of year 3 it was great to get Beth to think about what she would like people to know about her, what music she liked, to choose the next age appropriate theme.

'One Direction' tags have now been made (access all areas concert tour passes with tactile silhouettes of each band member are the chosen conversation topic). Recently the tag themes have moved on further to the Roald Dahl book Matilda, a favourite recent read for Beth. These have had some questions about the characters brailled and printed on them providing further opportunities for discussion and interaction.

It was simple and fairly quick to make the tags but they have had a significant, effective impact in supporting the development of friendships and conversation between Beth and her peers and teachers. With them as consistent conversation starters and stepping stones, Beth's have taken more of a leading role in her life. They have changed what people see when they look at the FM system and raised awareness of Beth as a person rather than her disabilities.

Liz Hodges (advisory teacher, deafblind children):
"Beth's enthusiasm for the tags alone made them worthwhile, in terms of acceptance of equipment. As a deafblind child she is at so much greater risk of isolation from her peers and this simple idea of Emma's has really made both her social interaction and her organisation (who should have which microphone) easier. While Beth is deafblind, this idea would work for any child."

Comment from Beth:
"I like my tags because they tell my friends about me and tell me if they like what I do. My best tags were Elsa and Anna because they have their songs on. My friends like my new Matilda ones – we talk about what we like about the book and the Miss Trunchball one is funny."

Emma Mathes is an Intervenor with the Hertfordshire Sensory Team.

NDCS and families of children with complex needs

Judy Trayford explains the role of the NDCS with children and young people with complex needs and their families

The National Deaf Children's Society (NDCS) believes that deafness in itself is a complex need because (i) children learn through hearing so being deaf presents complex challenges to the child and those involved in teaching them; and (ii) it requires co-ordinated inputs from health, care and education specialists. This was confirmed by the Doran Review (Interim Report 2011) commissioned by the Scottish Government: 'Strategic review of learning provision for children and young people with complex additional support needs'.

However we also know that 40% of deaf children can have an additional need and the spectrum of these needs can range from mild/moderate to severe/profound. Even a mild/moderate need can add considerably to the complexity of providing deaf children with the right support. In this article we will focus on deaf children with additional needs that are severe to profound.

Families tell us they experience many challenges when a deaf child has additional needs. The child's deafness can sometimes be overlooked or minimised, as stated in the 2011 report 'Complex Needs, Complex Challenges' (McCracken, 2011). This highlighted the difficulties families face when attempting to access services for their children, particularly related to their deafness. Many professionals appear overwhelmed by the complexity of need and address what they see as the primary issue, paying too little attention to the child's deafness. The research showed examples of some children being refused interventions such as hearing aids or cochlear implants on the grounds of their additional needs.

This was reflected during a web chat hosted jointly by NDCS and the Down's Syndrome Association. A parent had repeatedly requested a bone conduction band for her daughter who was unable to wear her hearing aids but had been refused. Our audiologist provided her with an explanation of why a bone conduction band may be more appropriate for children with Down's syndrome.

Ensuring NDCS Services are accessible

NDCS operates an inclusive membership approach: parents of children with any level and type of hearing loss can access NDCS services and advice. We try to ensure our helpline, information services, children and family support, advocacy and young people's services can support deaf children with a wide range of additional needs, signposting to and sometimes working in partnership with other specialist organisations (eg Down's syndrome, autism).

We have resources to help others become more deaf-friendly and can offer deaf awareness advice. Deaf young people with additional needs do attend our activities for young people but, as a charity, we do not have the competencies to cater for children requiring healthcare and support from medically trained staff. However, we continue to look for opportunities to work with disability organisations to help them offer the support that deaf children need to participate in their activities.

Specific and targeted NDCS services

Finding out your young child has a range of disabilities or complex needs can be a bewildering time. Those early days can be filled with anxiety and uncertainty of what support might be available. That's why we host weekends for families of young deaf children with complex needs. Parents can meet each other and share experiences and attend workshops covering topics including communication, technology, learning through play and how to get the right support. They are introduced to NDCS's range of resources, publications and information designed to help families who have a deaf child with complex needs.

Finding the right school can be a challenge for any parent; even more so when a child is deaf and has complex needs. Knowing how to ensure the child's entire needs are addressed is important. Our UK wide team of children and family support officers and central team of education advisors can support families through the maze of obtaining and understanding their child's education, health and care plans. Our website provides information and support to parents and professionals on this and other subjects. Our resource 'Supporting the Achievement of Hearing Impaired Children in Special Schools' is available as a download to members.

Our free helpline offers advice to families and professionals and can signpost to other services. Where more targeted support is required, our officers can work closely with children and families, offering advice on benefit decisions, a technology loan service and providing an online parent forum. For more information on how we can help and to access a wide range of information, visit our website at www.ndcs.org.uk

Judy Trayford works for the National Deaf Children's Society as an Inclusion Advisor.

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Early CaLL: Early Cognitive and Listening Links

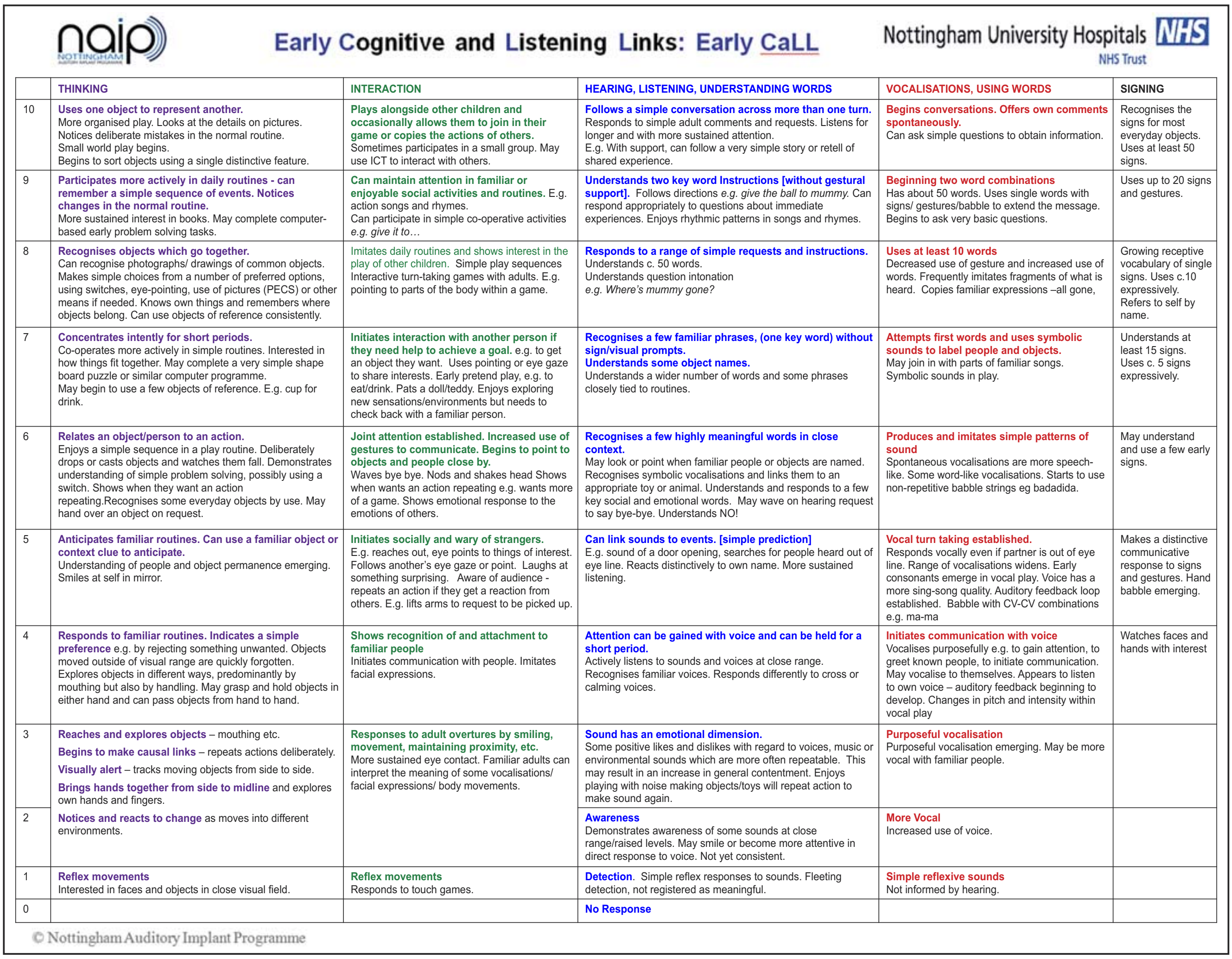
Karen Durbin describes the development and use of a profile for children with cochlear implants who have cognitive difficulties

Early CaLL is a population-specific profile to record the long term progress following cochlear implantation of children with severe to profound and multiple learning difficulties. It was developed by a multi-professional group from the Nottingham Auditory Implant Programme comprising Gill Datta, Chris Bones and Karen Durbin, Teachers of the Deaf; Amanda Odell, Speech and Language Therapist; and Cathy Grant, Clinical Psychologist.

Meeting challenges

In our 25 years of experience of cochlear implantation at the Nottingham Auditory Implant Programme we have provided cochlear implants to many children who have difficulties in addition to deafness. An audit by Jayne Ramirez Inscoe and Chris Bones in 2012 indicated that 47% of our paediatric population, as reported by their families, had at least one additional difficulty and 11% had three or more. Many deaf children with additional difficulties achieve listening and language outcomes in line with the general population of implanted children and we have materials such as the Nottingham Auditory Milestones (NAMES) which help us in their assessment and monitoring. However, we were aware of the need to develop materials for use with children who have more complex needs.

We designed the Early CaLL profile specifically for deaf children whose primary difficulty (in addition to deafness) is with cognitive development. This specific group of children either present with severe-profound learning difficulties in the assessment phase or subsequently receive this diagnosis. Many have additional physical and medical needs and a proportion have a diagnosis of autism. It is a heterogeneous group of individuals with a range of difficulties which form a



Early Cognitive and Listening Links: Early CaLL

	THINKING	INTERACTION	HEARING, LISTENING, UNDERSTANDING WORDS	VOCALISATIONS, USING WORDS	SIGNING
10	**Uses one object to represent another.** More organised play. Looks at the details on pictures. Notices deliberate mistakes in the normal routine. Small world play begins. Begins to sort objects using a single distinctive feature.	**Plays alongside other children and occasionally allows them to join in their game or copies the actions of others.** Sometimes participates in a small group. May use ICT to interact with others.	**Follows a simple conversation across more than one turn.** Responds to simple adult comments and requests. Listens for longer and with more sustained attention. E.g. With support, can follow a very simple story or retell of shared experience.	**Begins conversations. Offers own comments spontaneously.** Can ask simple questions to obtain information.	Recognises the signs for most everyday objects. Uses at least 50 signs.
9	**Participates more actively in daily routines - can remember a simple sequence of events. Notices changes in the normal routine.** More sustained interest in books. May complete computer-based early problem solving tasks.	**Can maintain attention in familiar or enjoyable social activities and routines.** E.g. action songs and rhymes. Can participate in simple co-operative activities *e.g. give it to…*	**Understands two key word Instructions [without gestural support].** Follows directions *e.g. give the ball to mummy.* Can respond appropriately to questions about immediate experiences. Enjoys rhythmic patterns in songs and rhymes.	**Beginning two word combinations** Has about 50 words. Uses single words with signs/ gestures/babble to extend the message. Begins to ask very basic questions.	Uses up to 20 signs and gestures.
8	**Recognises objects which go together.** Can recognise photographs/ drawings of common objects. Makes simple choices from a number of preferred options, using switches, eye-pointing, use of pictures (PECS) or other means if needed. Knows own things and remembers where objects belong. Can use objects of reference consistently.	Imitates daily routines and shows interest in the play of other children. Simple play sequences Interactive turn-taking games with adults. E.g. pointing to parts of the body within a game.	**Responds to a range of simple requests and instructions.** Understands c. 50 words. Understands question intonation *e.g. Where's mummy gone?*	**Uses at least 10 words** Decreased use of gesture and increased use of words. Frequently imitates fragments of what is heard. Copies familiar expressions –all gone,	Growing receptive vocabulary of single signs. Uses c.10 expressively. Refers to self by name.
7	**Concentrates intently for short periods.** Co-operates more actively in simple routines. Interested in how things fit together. May complete a very simple shape board puzzle or similar computer programme. May begin to use a few objects of reference. E.g. cup for drink.	**Initiates interaction with another person if they need help to achieve a goal.** e.g. to get an object they want. Uses pointing or eye gaze to share interests. Early pretend play, e.g. to eat/drink. Pats a doll/teddy. Enjoys exploring new sensations/environments but needs to check back with a familiar person.	**Recognises a few familiar phrases, (one key word) without sign/visual prompts.** **Understands some object names.** Understands a wider number of words and some phrases closely tied to routines.	**Attempts first words and uses symbolic sounds to label people and objects.** May join in with parts of familiar songs. Symbolic sounds in play.	Understands at least 15 signs. Uses c. 5 signs expressively.
6	**Relates an object/person to an action.** Enjoys a simple sequence in a play routine. Deliberately drops or casts objects and watches them fall. Demonstrates understanding of simple problem solving, possibly using a switch. Shows when they want an action repeating.Recognises some everyday objects by use. May hand over an object on request.	**Joint attention established. Increased use of gestures to communicate. Begins to point to objects and people close by.** Waves bye bye. Nods and shakes head Shows when wants an action repeating e.g. wants more of a game. Shows emotional response to the emotions of others.	**Recognises a few highly meaningful words in close context.** May look or point when familiar people or objects are named. Recognises symbolic vocalisations and links them to an appropriate toy or animal. Understands and responds to a few key social and emotional words. May wave on hearing request to say bye-bye. Understands NO!	**Produces and imitates simple patterns of sound** Spontaneous vocalisations are more speech-like. Some word-like vocalisations. Starts to use non-repetitive babble strings eg badadida.	May understand and use a few early signs.
5	**Anticipates familiar routines. Can use a familiar object or context clue to anticipate.** Understanding of people and object permanence emerging. Smiles at self in mirror.	**Initiates socially and wary of strangers.** E.g. reaches out, eye points to things of interest. Follows another's eye gaze or point. Laughs at something surprising. Aware of audience - repeats an action if they get a reaction from others. E.g. lifts arms to request to be picked up.	**Can link sounds to events. [simple prediction]** E.g. sound of a door opening, searches for people heard out of eye line. Reacts distinctively to own name. More sustained listening.	**Vocal turn taking established.** Responds vocally even if partner is out of eye line. Range of vocalisations widens. Early consonants emerge in vocal play. Voice has a more sing-song quality. Auditory feedback loop established. Babble with CV-CV combinations e.g. ma-ma	Makes a distinctive communicative response to signs and gestures. Hand babble emerging.
4	**Responds to familiar routines. Indicates a simple preference** e.g. by rejecting something unwanted. Objects moved outside of visual range are quickly forgotten. Explores objects in different ways, predominantly by mouthing but also by handling. May grasp and hold objects in either hand and can pass objects from hand to hand.	**Shows recognition of and attachment to familiar people** Initiates communication with people. Imitates facial expressions.	**Attention can be gained with voice and can be held for a short period.** Actively listens to sounds and voices at close range. Recognises familiar voices. Responds differently to cross or calming voices.	**Initiates communication with voice** Vocalises purposefully e.g. to gain attention, to greet known people, to initiate communication. May vocalise to themselves. Appears to listen to own voice – auditory feedback beginning to develop. Changes in pitch and intensity within vocal play	Watches faces and hands with interest
3	**Reaches and explores objects** – mouthing etc. **Begins to make causal links** – repeats actions deliberately. **Visually alert** – tracks moving objects from side to side. **Brings hands together from side to midline** and explores own hands and fingers.	**Responses to adult overtures by smiling, movement, maintaining proximity, etc.** More sustained eye contact. Familiar adults can interpret the meaning of some vocalisations/ facial expressions/ body movements.	**Sound has an emotional dimension.** Some positive likes and dislikes with regard to voices, music or environmental sounds which are more often repeatable. This may result in an increase in general contentment. Enjoys playing with noise making objects/toys will repeat action to make sound again.	**Purposeful vocalisation** Purposeful vocalisation emerging. May be more vocal with familiar people.	
2	**Notices and reacts to change** as moves into different environments.		**Awareness** Demonstrates awareness of some sounds at close range/raised levels. May smile or become more attentive in direct response to voice. Not yet consistent.	**More Vocal** Increased use of voice.	
1	**Reflex movements** Interested in faces and objects in close visual field.	**Reflex movements** Responds to touch games.	**Detection**. Simple reflex responses to sounds. Fleeting detection, not registered as meaningful.	**Simple reflexive sounds** Not informed by hearing.	
0			**No Response**		

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Fig. 1

continuum of increasing need. We wanted the profile to assist us with the challenges of assessment (during the **assessment** phase and during monitoring if they are implanted), **decision making** and **expectation counselling** for this group of children.

Family Views

The work by Manchester University (2011) and the interviews conducted by the Ear Foundation (2011) supported the need to devise a population-specific profile. Families wanted recognition of the impact of their child's deafness, alongside an understanding of their individual abilities and needs. In the assessment phase, families identified the need for counselling about realistic outcomes tailored to an understanding of what would constitute auditory benefit for their child and how this could contribute to an improved quality of life. Post implant, they wanted information on progress informed by evidence which was relevant, clear and accessible.

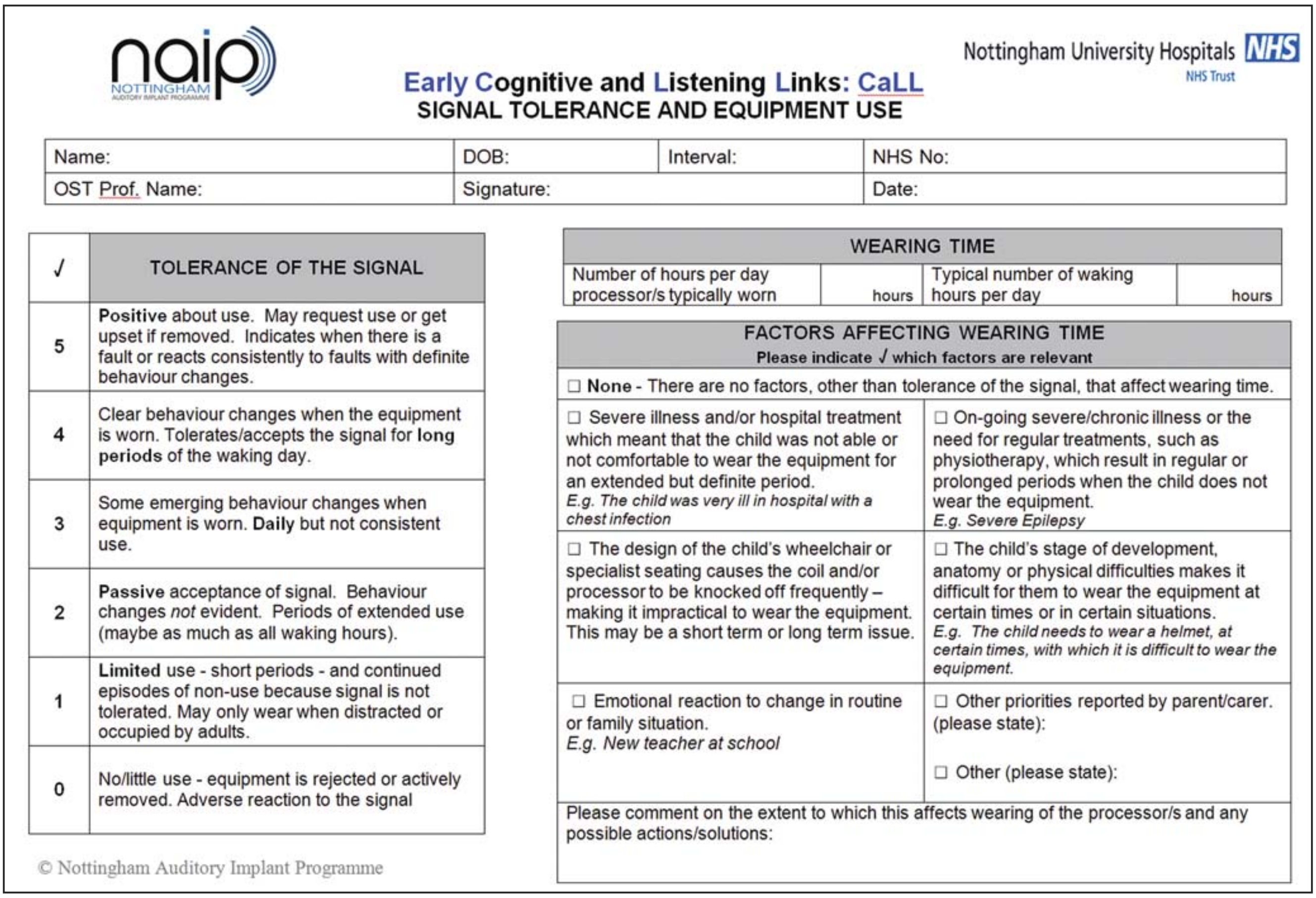
A framework to share expectations about outcomes

The families of children with significant additional difficulties enter the cochlear implant assessment process, like all others, with their central focus on the desire to address their child's deafness. They are unlikely to have a clear idea of expectations post implant, as the vast majority of information currently available focuses on the typically developing population. This can create a misleading picture of a direct link between the provision of hearing via the equipment, leading automatically to listening, understanding and talking. Families are often aware of the potential additional complications presented by their child's additional needs. However, a clearer framework was needed in order to facilitate a more informed discussion about the potential benefits of cochlear implants.

A key aim of the Early CaLL profile is to explain to families, in an accessible, positive but realistic way, the fundamental inter-relationship between their child's likely level of benefit from cochlear implantation and their current cognitive and communicative abilities. The profile demonstrates to care-givers and non-specialists that the development of listening and understanding depends very much on the child's thinking skills and ability to process the signal. It can help with difficult discussions. For example, a child who is at stage one in terms of their 'Thinking and Interaction' can only make basic reflex responses to sensory stimulation. These limited responses make the provision and programming of cochlear implants very challenging. It can also help to explain why a cochlear implant may be able to improve a child's detection of sound, but that this may not develop into the ability to understand and use spoken language.

Profile design and organisation

The profile consists of two sections: A developmental profile and a record of signal tolerance and equipment use.



naip NOTTINGHAM AUDITORY IMPLANT PROGRAMME

Nottingham University Hospitals NHS
NHS Trust

Early Cognitive and Listening Links: CaLL
SIGNAL TOLERANCE AND EQUIPMENT USE

Name:	DOB:	Interval:	NHS No:
OST Prof. Name:	Signature:		Date:

✓	TOLERANCE OF THE SIGNAL
5	**Positive** about use. May request use or get upset if removed. Indicates when there is a fault or reacts consistently to faults with definite behaviour changes.
4	Clear behaviour changes when the equipment is worn. Tolerates/accepts the signal for **long periods** of the waking day.
3	Some emerging behaviour changes when equipment is worn. **Daily** but not consistent use.
2	**Passive** acceptance of signal. Behaviour changes *not* evident. Periods of extended use (maybe as much as all waking hours).
1	**Limited** use - short periods - and continued episodes of non-use because signal is not tolerated. May only wear when distracted or occupied by adults.
0	No/little use - equipment is rejected or actively removed. Adverse reaction to the signal

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WEARING TIME			
Number of hours per day processor/s typically worn	hours	Typical number of waking hours per day	hours

FACTORS AFFECTING WEARING TIME Please indicate ✓ which factors are relevant	
☐ **None** - There are no factors, other than tolerance of the signal, that affect wearing time.	
☐ Severe illness and/or hospital treatment which meant that the child was not able or not comfortable to wear the equipment for an extended but definite period. *E.g. The child was very ill in hospital with a chest infection*	☐ On-going severe/chronic illness or the need for regular treatments, such as physiotherapy, which result in regular or prolonged periods when the child does not wear the equipment. *E.g. Severe Epilepsy*
☐ The design of the child's wheelchair or specialist seating causes the coil and/or processor to be knocked off frequently – making it impractical to wear the equipment. This may be a short term or long term issue.	☐ The child's stage of development, anatomy or physical difficulties makes it difficult for them to wear the equipment at certain times or in certain situations. *E.g. The child needs to wear a helmet, at certain times, with which it is difficult to wear the equipment.*
☐ Emotional reaction to change in routine or family situation. *E.g. New teacher at school*	☐ Other priorities reported by parent/carer. (please state): ☐ Other (please state):
Please comment on the extent to which this affects wearing of the processor/s and any possible actions/solutions:	

Fig. 2

Developmental Profile (Fig 1)

This is the central record which draws information from a number of sources as well as our own observations and experience accrued from working with this group of implanted children. The profile places five developmental strands alongside each other on a chart, so that progress within each strand can be compared.

The five strands are:

- Thinking
- Interaction
- Hearing, Listening and Understanding Words
- Vocalisations and Early Words
- Understanding and Using Signs.

There are ten inter-related developmental stages which help to show progress for each child through the five strands. The child's progress is measured only by comparison with their own previous achievement. Overall, the content of the profile correlates approximately with developments across the first two years of life for a typically developing child. At each stage there are statements describing skills which are likely to emerge. It is not a detailed, comprehensive profile covering all aspects of development but rather a profile highlighting how particular developmental areas inter-relate and impact on the development of listening, interaction and communication.

It is recognised that at these early stages of development, divisions between thinking and interaction are somewhat artificial. However, in this profile they were separated in order to help identify those children where there was an emerging additional difficulty with social understanding/communication.

Hearing is the central strand as it directly quantifies the added value provided by cochlear implantation. In the early stages this strand is broken down into greater detail than the other areas. It begins with detection but from stage three onwards, when sound becomes emotionally meaningful, quality of life improvements really begin to emerge.

The child's ability to vocalise and later to use words also relies on a number of additional factors. Some children may not have the physical capacity to produce speech sounds. For other children, the sounds of spoken language may be less meaningful than the visual representation of ideas in signs or symbols. It is therefore important to look at progress in this strand in comparison with the child's abilities to use a visual representation system.

The strand 'Understanding and Using Signs' allows the balance between modalities to be examined. This should help to identify where the child's strengths lie and any changes over time will impact on the advice shared.

For all strands the stages are set out in a simplified form on the main chart but appendices are provided which give more detail alongside examples to provide extra guidance.

Recording and scoring achievements:

- The child's progress is recorded at assessment intervals on the basis of observations and activities, discussions with care-givers and local professionals and shared information from detailed profiles held locally.
- The stage at which all or most of the key indicators for that child are rated as established is recorded for each strand. These need to be interpreted flexibly given the heterogeneous nature of this population.
- When reporting back to families or local professionals, the established stage is given but if skills from the stage above are emerging this is also noted.

Record of Signal Tolerance and Equipment Use (Fig 2)

This summary sheet is completed at each assessment interval. It looks at the child's tolerance of the signal on a scale from active rejection of the equipment through to full acceptance and enjoyment of the sound. Wearing time is recorded as a proportion of the child's waking day and it gives the opportunity to record reasons, other than signal tolerance, for why consistent use may not have been achieved. For example, severe epilepsy, times when life threatening conditions take priority over wearing the equipment or the use of high support chairs which can make it difficult to keep sound processors in place.

It is important to monitor these factors as they directly affect outcomes. The record provides us with evidence when we need to talk to other professionals about how things, such as seating, can be improved.

Implementation and future plans

We have been developing and trialling these materials for more than three years. Profiles have been completed for all the children for whom it was appropriate. The materials have helped us, as a team, to counsel families and local professionals more effectively, particularly in the assessment phase. They have given us a more consistent way of assessing and monitoring the progress of this specific group of children, celebrating their achievements over time. We now have sufficient outcome data collected to enable us to investigate long term outcomes in a more systematic way which can help us provide more targeted and evidence based information for families seeking advice in the future.

Karen Durbin is a Teacher of the Deaf with the Nottingham Auditory Implant Programme.

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Patience, consistency and resilience

Sarah Norris considers some of the challenges in working with deaf children with complex needs and who have cochlear implants

Working with children and young people requires patience, consistency and resilience. Working with children with complex needs requires more patience, more consistency and more resilience. There needs to be a clear understanding that you may not be following the same path that children and young people without complex needs may be following. We all know it is not an easy decision for any family to make about whether or not they should pursue a cochlear implant for their child but for a child or young person with complex needs it is just much more… complex. As with all implants no outcomes are guaranteed but with complex children and implants what does the future hold? So with this in mind one family decided to say yes.

Sam (not his real name) was born at the start of 2003 and was diagnosed with Down syndrome a few days after his birth, he has Hirschsprung's disease, and he failed his Newborn Hearing Screening. He was issued with bilateral hearing aids and after a long period of testing, retesting and increasing the gain on his hearing aids he was diagnosed with a bilateral profound sensori-neural hearing loss towards the end of his fourth year confirmed by ABR. Additionally he has a visual impairment and has been prescribed glasses.

After much discussion with medical and educational professionals, many appointments and thorough investigations, a unilateral cochlear implant was agreed and carried out. No one said it was going to be easy but this young man has had a couple of set backs with regards to his implant: his magnet dropped and had to be surgically removed and then reinserted. Then after his second switch on a severe ear infection just two months later further delayed the consistency needed for wearing his speech processor.

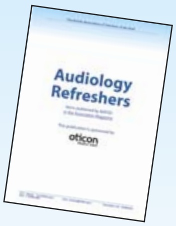
Up until June of 2012 (four years post implant) he was wearing his speech processor for short periods of time throughout each day. Then something happened – he refused it and would become extremely distressed and upset even seeing it. We don't know why he stopped using it – he can't tell us. He is non-verbal. He has a few Makaton signs but is not a consistent communicator. Through a recommendation from his Auditory Implant Program (AIP) Teacher of the Deaf his local Teacher of the Deaf followed a desensitisation programme which enabled him to tolerate looking at it, even putting it on but not switching it on. Now three years from that point he is using his speech processor for half a day at school!

There is not just one thing that has supported his regular use of his speech processor but quite a few; not least of all a full time intervenor (due to his dual sensory loss it has been included in his Statement from January 2013) which has made a tremendous difference; she supports him completely throughout his day at school. She is able to make adaptations to his support based on his needs alone. For example, she has recently made what appears to be a minor adaptation but it has had a major impact on his ability to use his processor for longer periods of time. He uses a body worn processor and often his decision to not wear his processor involved taking it off and throwing it across the room. His intervenor has attached his body worn processor to a retractable key chain. This allows him to remove it but doesn't allow him to throw it across the room. This minor adjustment has had a major impact. He now no longer has the interest in removing it as frequently as before.

He is responding to some amazing things through audition alone! His eye contact has improved tremendously! He now looks quite intently at adults when they are speaking. He is responding to his name more regularly, he is following simple instructions through listening alone, he is playing turn taking games where he is copying and attempting to imitate sounds. He has begun to vocalise initial consonant sounds for example, m-m for more and b-b for bird when being read one of his preferred stories at school.

So it may surprise some to hear having just reached half of day of usage of his speech processor seven years post switch on is a success – but it is! Look how far he has come and what he has managed to overcome. Yes these beginning steps of success have come from working closely with many people: his class teacher, intervenor, AIP Teacher of the Deaf, and his family, but mostly because all of these people have been patient, consistent and resilient.

Sarah Norris is a Teacher of the Deaf with the Wandsworth Hearing Support Service.



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A curriculum for multi-sensory impaired children

Heather Murdoch describes the structure and rationale of the Victoria School MSI Unit curriculum

Children with multi-sensory impairments (MSI) have hearing and visual impairments which have a potentially devastating impact on their interaction with people and the world around. Sight and hearing are the senses which give information about the environment beyond arms' reach; when both are impaired, there is little or no access to incidental information or warning of events about to happen. Further disabilities often compound the problems.

MSI slows the pace of learning because it limits the information available from experiences. It affects all areas of development because of the global impact on perception. It obstructs the generalisation of learning because children cannot compare different contexts. Children with MSI need specific help to learn to interact with people, to explore their environment and to develop and generalise concepts. They need help to learn how to learn.

Victoria School MSI Unit curriculum

At the MSI Unit at Victoria School in Birmingham we have developed a curriculum which aims to do just that. The Unit is a regional resource, established in the mid-1990s and educating up to 15 children with MSI from five local authorities. Those attending the Unit have a range of conditions and needs, but all need a specialist environment in order to thrive. There are very high levels of staffing – 1:1 whenever appropriate – and of expertise, with ongoing specialist training for all staff.

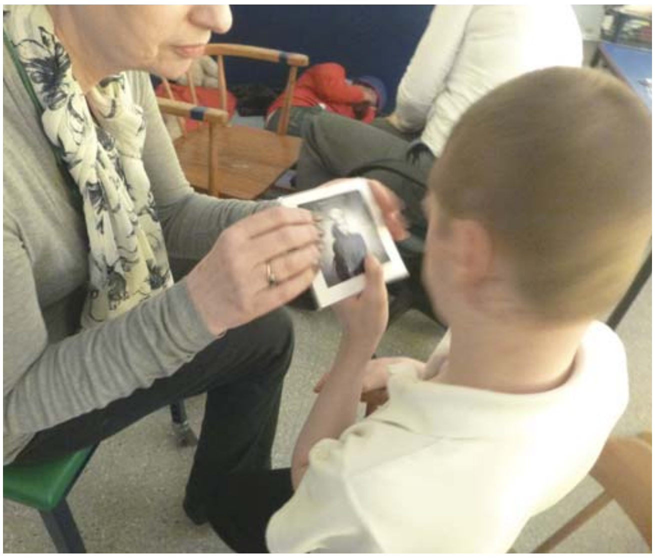
The curriculum at the Victoria MSI Unit has always been child-centred and specialist. The written version, titled *A Curriculum for Multi-Sensory Impaired Children* (Murdoch et al, 2009), just describes and structures the practice which was already happening. Whilst this sounds straightforward, it took several years to structure, write, trial, evaluate, pilot, revise and (through Sense) publish the curriculum and the accompanying assessment profiles.

It is structured into eight domains: *Social relationships and emotional development; Communication; Conceptual development; Sensory responses; Understanding of time and place; Orientation, movement and mobility; Ownership of learning, and Responses to routines and changes.* Some of these, clearly, are equally relevant to all children; others reflect areas of particular need for children with MSI. Many other structures would have worked equally well; this was the first we found that worked well for us.

Children progress through four curriculum phases, from the earliest stages of development to the equivalent of P Level P8. At each phase, for each domain, the curriculum details ways of overcoming the barriers to learning faced by a child with MSI. These approaches include staff behaviour and expectations; the range of physical environments used; teaching objectives and strategies; the complexity of information provided to pupils and the balance between group and individual work.

In terms of *Ownership of learning*, for example, early in Phase 1 pupils act without intention. In response:

- *Keyworkers are the ultimate reactive environments for pupils with MSI, providing consistent, accessible feedback ...*
- *Staff use the 'burst-pause' pattern of pupils' activity to begin work on turn-taking ... Initially their actions are likely to mirror those of the pupil. From this basis staff work to develop pupil-centred routines as a basis for anticipation and communication ...*
- *Staff attribute intention to pupils' actions where appropriate ...*
- *Pupils are given frequent opportunities to experience cause and effect ... For pupils with fluctuating hearing and/or visual losses, activities and equipment must be carefully chosen to ensure that pupils experience the same effects each time.*
- *Environments which provide immediate, amplified*



feedback about pupils' actions (for example, resonance boards, Little Rooms) are used when appropriate with support from familiar staff.

- *Pupils are given the opportunity to become aware of new activities before they are asked to join in with them ...*

In contrast, for *Ownership of learning* at Phase 4:

- *Pupils are supported in identifying and communicating the specific types of help they need – for example, switching lights on in corridors ...*
- *Pupils are given responsibility for specific roles in the class group ...These roles are frequently varied, to avoid reliance on routine and so that the sense of challenge and responsibility is renewed.*
- *The physical environment is arranged in a way that supports pupils' independence ...*
- *Timetabling takes account of the need of most pupils with MSI for additional time to complete activities independently.*
- *Pupils' awareness of safety and danger is fostered ... Specific individual safety issues (for example, due to poor sight or epilepsy) are identified and incorporated ...*

(and much more)

These factors are not groundbreaking, just good practice for children with multi-sensory impairments. Put together, however, they create learning environments in which children can interact with, learn from and control the events around them. They also encourage constant evaluation by staff of children's reactions and of their own practice.

Pupils' progress through the curriculum is recorded using assessment profiles developed for each phase, which list typical achievements linked to each curriculum domain. These achievements are broad, not SMART, describing abilities rather than behaviours. Children with MSI receive radically different information about their experiences from typically developing children, and the behaviours which indicate learning may also be radically different from the norm. These are known as functionally equivalent behaviours – similar in function, different in form. Three levels of progress are recorded for each assessment profile item: *aware, achieved in specific contexts* and *generalised.*

The MSI Unit curriculum focuses on how to help children learn, rather than on what to teach them. This frees staff to choose the most appropriate activities for individual pupils, but adds an extra layer of demand to planning. Staff need a good knowledge of child development and of the global impact of MSI. Breadth, balance and relevance are addressed specifically in the curriculum, and monitored for individual pupils. Some are included with other groups for specific activities – an after-school club for social support, for example; a KS1 session for playing with a group of children; a KS4 science lesson for experience of working in a larger group. 14-19 pupils work towards ASDAN qualifications via their MSI curriculum programmes.

The aim of the curriculum is to give pupils the awareness, understanding and learning skills they need to access more conventional curricula successfully. It is primarily an access curriculum for pupils with MSI working at P Levels P1-P8, underpinning the National Curriculum for this group. We give equivalences between P Levels and Phases and between our curriculum domains and traditional subject areas, but these are ranges rather than direct correspondences. Pupils with MSI often deviate for a while from traditional developmental paths, because of the need to develop compensatory strategies for learning.

The curriculum in practice: Eddie

Eddie is profoundly deaf and severely visually impaired, with learning and sensory processing difficulties. He is fifteen, and has been educated in the MSI Unit for the past five years.

When he entered the MSI Unit, Eddie understood and used a few signs and would take adults to things he wanted. He was highly impulsive and showed little interest in his peers. A breakthrough was his interest in watching an adult draw round his soft toys, which encouraged him to watch and to interact, albeit on his own terms. A second breakthrough came the following year, when he realised that his glasses improved his sight considerably, and began to wear them much more willingly. This in turn enabled the development of joint attention, because with his glasses he could see both an adult and an object at the same time.

Eddie's communication now is effective and social. He uses signs, gestures, facial expressions, symbols, photos and contextual cues to understand and interact with his environment. Crucially, he has learned to negotiate, rather than to see only the two poles of immediately getting what he wants or feeling utterly denied. This has greatly reduced his challenging behaviour and made him happier and more relaxed, less urgent and impulsive. He still needs support to communicate effectively – adults help him to structure interactions and stay on track, keep his symbols available and understand his sometimes idiosyncratic signs – but his confidence that he can make and effect real choices in his life is now very clear.

In terms of our curriculum, Eddie has progressed from Phase 2 to Phase 3 and is beginning work on Phase 4. His current annual targets include talking about his feelings and emotions with a familiar adult, attempting to repair breakdowns in communication, shifting attention between different people in a small group (demanding because of his visual impairment), understanding when and how to ask for help from an adult and, with support, identifying when familiar skills can appropriately be used in a new context.

These and his other targets (two or three for each curriculum domain) form the basis for his individual timetable and the learning objectives for each of his activities. Activities are planned around Eddie's specific learning needs and interests. He has difficulty managing his arousal levels, so movement and massage are incorporated into his routines at strategic points. He tires easily in busy contexts because of the visual demands they make, so these are interspersed with individual, visually uncluttered sessions. He and his classmates are very interested in food, so snack time includes literacy and numeracy work and co-operative working with peers.

The curriculum in practice: Signing choir

Once a week, Eddie attends signing choir with other pupils selected from the Unit's three teaching groups. 'Signing choir' is something of a misnomer: some children still in order to listen to the music; some rock or dance in time. Each child works 1:1 with an adult. Most of the children in the group have no sight, so signing is usually hand-under-hand, with the child's hands resting on top of the adult's. Children choose the next song in turn, using signs, symbols and/or switches.

Signing choir gives Eddie experience of the creative, cultural use of sign. He loves the repetition, the patterns of signs which emerge. He sits opposite Carole, watching her sign and sometimes copying. Seated close to the speakers, he is aware of airborne vibrations and the rhythm of the music. Eddie has favourite songs and enthusiastically chooses these using signs or symbols presented on a 'choice board'. Initially he always wanted to choose first, but he is used to the size of the group now and confident that his turn will come.

Signing choir, like all our teaching activities, is cross-curricular. Its primary focus, recorded in planning, is *Communication*, with aims from *Sensory responses* and *Ownership of learning* also addressed. The equivalent National Curriculum subjects are English, PSHE and citizenship and Music. Each child participating in the session (eight of the eleven students in the Unit) has individual objectives, linked to their long-term targets. Eddie's objectives, for example, are to recognise and follow familiar verbal sequences in different songs, intermittently copying signs, and to maintain his attention throughout the session despite distractions. He works in this session with Carole, the choir leader, so the resources for choosing songs are kept by their seats. When Carole moves across the room to ask another child for their choice, Eddie finds it hard to wait for her without diving into the box of resources. To help him maintain focus, he has a card which shows him who is currently making a choice – the child's photo is velcroed to a card which reads 'choose next', with *Let's Sign and Write* symbols which Eddie understands.

Present and future

Where might Teachers of the Deaf come across the MSI Curriculum? Using it as we do, to plan, deliver and evaluate learning across the board, requires high staffing levels and flexibility of timing and approach. We know that the curriculum is currently used in this way in several specialist settings for pupils with MSI.

The curriculum is also used by many advisory teachers as a resource when offering guidance – because it details how to provide a good learning environment and it can be read as a good practice guide for children with MSI at particular stages of development. Interestingly, we also know of settings for pupils with complex needs other than MSI who are using the curriculum to help them provide consistent, supportive, responsive learning environments.

The Victoria MSI Unit curriculum is freely available to download from the Sense website at www.sense.org.uk/ To date, and to our surprise, there have been around 1800 downloads. Meanwhile, our practice has continued to develop in the six years since the curriculum was printed. At present the written version is still a good summary of practice, tested now by the turnover of pupils in the Unit since the curriculum was written. At some point in the future we may need to consider a revised version – but not just yet!

Heather Murdoch is Head of the MSI Unit at Victoria School and Specialist Arts College, Birmingham, and an Honorary Lecturer at the University of Birmingham School of Education.

ASD and deafness

Jane Douglas talks about the challenges of diagnosing and assessing hearing loss in autistic children

I think the main question we need to ask is how do we support a deaf, autistic child? Here at Seashell our students are likely to have multi-morbidities and are very complex young people. Are we meeting their needs when they exhibit challenging behaviours or is this something intrinsic to the child/young person?

The prevalence of hearing loss is considerably higher when there is a diagnosis of ASD. Profound/severe bilateral hearing loss or deafness has been diagnosed in 3.5% of all ASD cases. It is also thought that about 60% of autistic patients are affected by hyperacusis, but our findings often suggest that young people are more likely to be phonophobic (fear of unpredictable sound) rather than affected by true hyperacusis. Middle ear problems are also more prevalent with ASD, with an estimated 23.5% of patients requiring auditory evaluation.

Loudness hyperacusis occurs when sounds are actually perceived as louder than normal. However, in cases of ASD it is thought that the sound is perceived as normal loudness but is more annoying or irritating than normal.

The auditory behaviours of children with autism are still relatively unexplained and not well understood. It is difficult to understand their auditory world. The literature describes it as blooming, buzzing confusion, with unpredictable and transient sounds that they find very difficult to filter out and regulate.

It is likely that these children have limited environmental awareness, reduced social awareness and a sense of ‘disconnectedness' with the outside world. They also can be preoccupied by certain sounds that they can hear.

Children with severe ASD and deafness are very difficult to test audiologically as many are unable to give a response to sound so that results are often uncertain and inconclusive. These children will have significant sensory processing difficulties and very easily become sensorily overloaded, often triggering behaviours. It is almost impossible to know how a patient with ASD and a hearing loss actually uses his or her residual hearing. Sound may carry very little meaning as it is transient and difficult to quantify. Vision (if the patient has useful functional vision) often is dominant as it is temporally available for longer and more information can be extracted.

Because of the complex nature of hearing, there is a danger of clinicians making inaccurate assumptions based on functional listening tests alone. There can often be a poor correlation between objective hearing test results (OAEs and ABRs) and observed behavioural responses which can be due to a number of variables and most likely relates to the underlying aetiology and medical diagnosis.

Co-operation of a range of professionals is often an element of a successful assessment procedure. At Seashell we also use a very comprehensive auditory assessment form for observing students in their everyday environments and look for their full auditory response repertoire.

Amplification and fitting hearing aids is challenging, requiring a certain element of pragmatism. Young ASD patients are typically inflexible about when and where amplification is tolerated and often find it difficult to accept amplification for new situations. They can get very ‘stuck’ with rejecting hearing aids/CIs that may not reflect the potential benefit that they gain from them. Observations suggest that they may have a ‘cut off’ point when sounds suddenly become intolerable (similar to recruitment).

Setting up hearing aids for this population can be very difficult and may often require trial and error and audiologists may need to consider under-amplifying to avoid sensory overloading.

Autistic young people can be very fixed on limited sessions where they will accept amplification and this is likely to be more about feeling in control of their sound environment rather than poorly fitted hearing aids. Use of amplification can be very ‘compartmentalised’ and these children can find it very difficult to use hearing aids/CIs in different environments such as school and home.

Transition generally can be very difficult for autistic people who can find it very challenging to accept different and new environments. It is likely that students with ASD have under-developed skills to ignore some stimuli and cope with overload by shutting down. Other contributing factors may also include:

- Anxiety about an unfamiliar environment
- Fear of unpredictable sounds
- Hearing aids amplifying environmental and background noise
- Sounds distorting due to overstimulation and multi-sensory processing problems (overload)
- Being out of routine
- Inability to filter out extraneous stimulation.

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Children with FASD

Margaret Delaney introduces a study into Foetal Alcohol Spectrum Disorder

This is a small part of the detailed work undertaken for the INSET component on FASD undertaken by this student at the University of Manchester as part of the PG Dip Deaf Education programme.

Foetal Alcohol Spectrum Disorder (FASD), as the name suggests, ranges from mild to severe in its effects. FASD is the most common non-genetic cause of learning disabilities in the UK (Carpenter, 2011) and is 100% preventable. The most serious effect is brain damage which has significant implications for the child. Whilst some children have characteristic facial features others may show no obvious features. In Canada and the US there has been extensive guidance for the support of this group of children but this is lacking in the UK. FASD has a pervasive impact across many learning domains particularly within the social/behavioural and cognition areas. As in the area of hearing loss, early intervention can significantly improve the outcomes for children affected by FASD (Streissguth et al, 2004) by preventing or ameliorating the development of secondary disabilities (Swart et al, 2014).

Specific areas affected are: executive function and working memory (Rasmussen, 2005), speech and language (Timler, Olswang and Coggins, 2005) and adaptive behaviour (Kjellmer and Olswang, 2013). When teachers were asked to identify the main challenges presented by children with FASD they listed: hyperactivity, short attention span, erratic mood swings, poor memory, lack of social skills, auditory and vocal skills, visual sequencing, sensory integration difficulties, poor retention of task instructions and numeracy/mathematical difficulties (Carpenter, 2011). Effective interventions rely on staff understanding the underlying neurocognitive effects of FASD rather than being intentional (Green, 2007). Interestingly children with FASD may be classified as autistic, ADHD or OCD.

In multiple studies children with FASD show higher rates of intermittent hearing loss (75-93%) compared to the general paediatric population (12%) (Katbamna, 2010). Conductive hearing loss occurs potentially due to abnormalities with the Eustachian tube as a result of craniofacial defects such as cleft palate, which result in FASD children being more prone to otitis media with effusion (Cone-Wesson, 2005). Studies also show that children with FASD are at risk of developing a sensori-neural hearing loss (7-29% depending upon whether they are on the mild or severe FASD scale) (Katbamna, 2010) due to abnormalities or loss of sensory hair cells in the cochlea. Therefore, it is important for the ToD to be aware of the different types of hearing loss in order to understand the temporary or permanent impact on receptive and expressive language needs.

Recorded cases of FASD are on the increase in the UK. In 2012-2013 there were 252 diagnoses of FASD compared with 89 in 1997-98. Diagnosis of FASD is

▶ *Continued opposite*

▶ *ASD and deafness – continued from bottom of previous page*

Ear defenders are a controversial issue in audiology. If an ASD patient becomes overattached to ear defenders, it is likely that the sound attenuation will reinforce avoidance behaviour. Not only will the young person miss important sounds/speech, they will find normal sound levels louder than normal once they remove the headphones as the brain has habituated to near silence.

Noise and sounds are notoriously difficult to manage for autistic children. Children with ASD often suffer with multiple sensory problems and may cover their ears or startle and react to moderately loud sounds. Typically sounds like babies crying and dogs barking can make these young people very anxious. In extra-sensitive individuals, such noise exposure is likely to induce increases in levels of stress hormones such as adrenaline, noradrenaline and/or cortisol.

Habituation is the key to those students affected by sound hypersensitivity. Providing continuous low intensity signals (pink noise, Mozart etc) in the living environment and gradually increasing the intensity and exposure time can be a good start for sound intensity management.

Despite difficulties in the areas of socialisation and communication, there is evidence to suggest many individuals with ASD show a strong and early preference for music and are able to understand simple and complex musical emotions.

Music that is simple with clear and predictable patterns is the most effective in eliciting responses to joint attention in children with autism in the severe range of functioning.

The rhythmic component of music is very calming and helps individuals diagnosed with autism to regulate and control their sensory systems. It appears that 2/4 beat is the most motivating and engaging rhythm. Autistic young people tend to show elevated pitch discrimination ability and superior long-term memory for melody.

Jane Douglas is Senior Audiologist at the Seashell Trust.

carried out in the UK by geneticists who are trained in dysmorphology and neuro-developmental assessment. However, as children with FASD do not show facial dysmorphology, diagnosis is often missed. Additionally, even though the rate of hospital admission of women aged 15-44 in the UK for alcohol related conditions has increased by 41% between 2002/3 and 2007/8, there have not been significant increases in FASD diagnosis (Morleo et al, 2011). FASD may be under diagnosed due to difficulty in diagnosis if facial abnormalities are not present as in the case in full blown FASD, a lack of understanding of the surrounding FASD related disorders in the UK and the reliance on honest reporting of alcohol consumption during pregnancy, in order to make an accurate diagnosis. (Morleo et al, 2011). Nonetheless, given the increase in recorded cases of children with FASD, many of whom will have hearing loss, it is likely that ToDs may increasingly come into contact with such children. Providing support to the family is complex as parents' feelings of guilt or denial add challenges; helping to prevent breakdown of relationships can be particularly difficult for professionals in that training is this area is not readily available. This situation is further exacerbated where there is no clear diagnosis (Clarren, 2000).

As a generalisation, FASD poses primary disabilities in three main areas: cognition, social skills and behaviour. Strategies to improve cognition include providing visual prompts. Visually organising tasks by colour coding and labelling of tasks helps reinforce stages in learning, particularly arithmetic which requires ordering of numbers. If the order and function cannot be held in working memory then a child with FASD will struggle to complete these mathematical tasks. (Kalbert & Buckley, 2007). Understanding triggers to behavioural issues will help the child to moderate his/her behaviour and take ownership of the situation. Providing an environment of predictability and understanding helps provide safety and reassurance for the child (Kalberg & Buckley, 2007). Children with FASD need help in learning and building skills in self-regulation of emotion and behaviours as well as modifying their external learning environment e.g. clear labelling of work areas, a clearly defined learning space (Green, 2007).

Practical strategies such as using 'fidget items' (Blackburn, 2009) help improve concentration and regular physical activities help channel hyperactivity. Positioning of the child's desk away from certain distractions or near the teacher may also be beneficial and improve behaviour. Help with scripting of future events and role playing a future social situation will help provide scaffolding for a child with FASD, a skill often absent in their toolbox of social skills. In order to assist with cognitive-behavioural strategies the ToD may act as an 'external brain' (www.fasarizona.com) as a method of helping with social skills, identifying emotions and anger management. This involves teachers acting as the brain of the child in social situations in order to model appropriate behaviour in various social settings. Willford et al (2004) also found that children with FASD struggled to absorb new verbal information via auditory channels and had difficulties in storing this information for use at a later date. Hence, the importance of visual cues in providing scaffolding for a child who struggles with auditory skills.

Outcomes for children with FASD in education are particularly poor when caregivers and school are unable to provide specialised educational programmes. (Pei et al, 2013). Such deficits are documented in studies on executive functioning (ibid), memory (Quattlebaum & O'Connor, 2013), adaptive behaviour (Kjellmer & Olswang, 2013) and speech and language (Timler, Olswang & Coggins, 2005). ToDs should also play a key role when a child with FASD starts in a new school, begins primary school or the transition stage from a primary to a secondary setting. Such milestones for children with FASD require intensive support in order to help facilitate a successful transition (Olson et al, 2009). By being aware of the complexities involved in learning for any child with FASD a ToD can, as part of a team, offer positive intervention and support to help secure learning.

Margaret Delaney has just completed her training as a Teacher of the Deaf at the University of Manchester. She has a particular interest in FASD.
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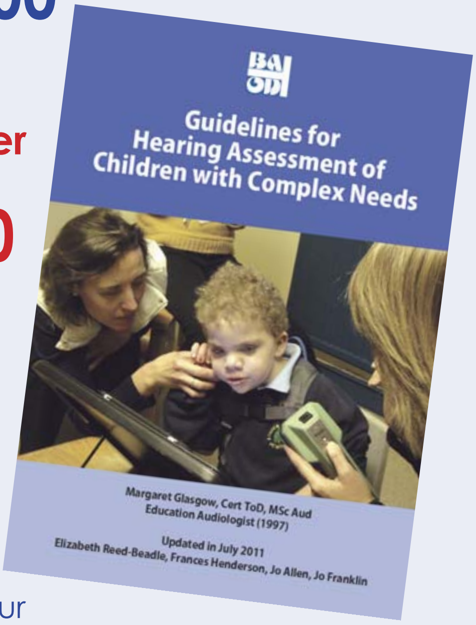
A full list of references available on the BATOD website.



Deafness and autism: a personal journey

Following her recent talk at the BATOD SIG group in Cheadle Hulme, Stephanie Dawson describes life so far with her deaf and autistic son

Matthew
My son Matthew is 14 years old. He has a wonderful sense of humour and is a sensitive and caring young man. He is bright and academic, and adores music. He is an accomplished pianist who is currently working towards his Grade 6 exam. He is also very gifted in IT showing an amazing capacity to solve IT problems by thinking outside of the box. This is Matthew's story so far.

Matthew's Early Years
Matthew was born prematurely at 32 weeks, weighing 2lb 10oz. He was cared for in the Special Care Baby Unit for two months and came home on his 'due date.' From the beginning he was bright and alert – revealing the shape of things to come, and giving his parents great hope!

During the first 15 months Matthew thrived and although he had poor muscle tone which required intensive physiotherapy, he met all of his milestones. He crawled and walked on time and even passed his nine month hearing check!

At around 18-24 months we began to realise that Matthew was a little different from his peers. He had very limited language, was difficult to understand, and at times it was hard to get his attention. But, he was also happy, smiley, affectionate and could make good eye contact.

At Matthew's two year check the Health Visitor echoed our concerns about his development and first mentioned the possibility of autism. Matthew was referred for Speech and Language Therapy and a multi-disciplinary assessment. Our concerns centred on his lack of speech and strange pronunciations – we had not considered that he might be autistic.

In special care, November 2000

Matthew aged 10 months

Assessment for autism
Waiting for the autism assessment was extremely difficult – it was so hard to enjoy Matthew. We found ourselves analysing everything he did. He was three years old before he reached the top of the waiting list and by this time we had convinced ourselves he was autistic. But the outcome of the assessment was the best news we could have hoped for – Matthew was NOT on autism spectrum! We were thrilled.

We enlisted the help of a private speech and language therapist who saw Matthew a minimum of once a week until he was seven. She used 'Cued Articulation' (a system devised by Jane Passey which involves using a different sign for each sound where the sign mimics what you need to do in your mouth in order to produce the sound). In the starter session Matthew produced the sounds 'c','s' and 't' for the first time!

As part of the assessment we also requested hearing

Matthew, aged 5

and eye tests. Matthew needed glasses and failed the initial hearing test.

Diagnosis of deafness
Over the next six months Matthew failed two further hearing tests. He had been congested on both occasions so we weren't particularly worried by these results. He was subsequently referred to the hospital for investigation with the expectation that he would need grommets.

The diagnosis of a bilateral, sensori-neural, moderate to severe hearing loss, and the prescription of hearing aids, was an enormous shock. But immediate help was at hand from our Teacher of the Deaf (ToD), who contacted us within an hour of getting home on the day of diagnosis. It was probably the most welcome phone call we've ever received!

After the initial shock had subsided we had feelings of both relief and clarity. The diagnosis of deafness answered all of our questions about Matthew. He readily accepted his hearing aids and with his regular SALT and weekly visits from his ToD he went from strength to strength. He was reading before he started Reception and had a fabulous vocabulary.

Primary School
Nursery was a happy and successful year but in Reception it became apparent that break times and unstructured times were very difficult for Matthew. There were many misunderstandings and skirmishes with peers which resulted in very high levels of anxiety for Matthew.

We had numerous meetings with school who felt that the issues were most likely to be behavioural. We requested Educational Psychologist involvement and a referral was made to the Emotional and Behavioural Disorder team. After all, it couldn't be autism...

Second Assessment for autism
Year 1 was an even more challenging time. It was now obvious that Matthew was different. He had trouble with friendships, was highly anxious and showed many unusual behaviours and reactions to both people and the environment.

He was bullied by a group of boys in his class. His class teacher was supportive but the SENCo and the Head Teacher were unsympathetic suggesting that parenting issues were the cause of Matthew's difficulties. We requested a second multi-disciplinary assessment because we felt sure that there was something we were missing, and Matthew was diagnosed with Asperger's Syndrome at six years and nine months. The second diagnosis was far worse than the first – we knew very little about autism and we were frightened by what we read.

Matthew was also falling behind academically and we were keen to request a Statutory Assessment. Our initial request for Statutory Assessment was turned down but we met with our LA officer who advised us to rewrite the paperwork. The school declined to change the paperwork, so the ToD, my brother (who was a SENCo) and I rewrote the paperwork ourselves. We submitted it and a Statement of SEN was finalised just before Matthew's eighth birthday. We then moved Matthew to a new primary school.

Change of school
The new school was amazing but unfortunately we had to say goodbye to our ToD, which was very hard indeed. However our new ToD was also fantastic!

Matthew was referred to the autism outreach team and for the first time he had excellent support for his deafness and his Asperger's. He also had the best TA in the world! Matthew thrived and left in Year 6 having made some good friends, getting the highest mark in the Maths SAT and the second highest in the English SAT. All round success!

Secondary school
Matthew currently attends an independent secondary school out of borough which is paid for by the LA. The school has small classes, is academic, and some of the staff were said to have Post Graduate qualifications in Asperger's. A new Head Teacher brought changes of staff and unfortunately those who had specialised in Asperger's left. But although it was a bumpy start Matthew is happy and doing very well there now.

Matthew is supported by a ToD half-termly and receives weekly SALT which supports the development of good social communication and is also a platform for him to air any concerns. There is no other autism specific support; however, there is a growing awareness among the staff.

What really helped us
It was the professionals who listened and valued what we knew about our child that helped the most. Our greatest support has come from our ToDs, our autism outreach teacher, SALTs, and the TA and Head Teacher in Matthew's new primary school – all of whom often went beyond their remit to listen to us and to help us achieve the best outcomes for Matthew.

Meeting other parents in similar situations has also been really helpful, although we haven't met many parents of children who are deaf and autistic. Meeting parents of children with any other additional need is really important in helping to combat isolation.

Doing research and not giving up was another great help. This is so important in building the confidence and strength to keep on going and being sure that you are doing the right thing.

What did not help
The attitude of 'I am the professional and you are only a parent' was very unhelpful. When you are ignored you lose your confidence and that is no help to your child.

Viewing Matthew's unusual behaviours and responses as intentionally naughty behaviours was also very difficult. What we needed were open-minded professionals who were prepared to learn alongside us.

Being told 'he doesn't listen' or Matthew being reprimanded for 'not listening' was also difficult because it felt as though his diagnosis of deafness was not being acknowledged or understood.

What we need
More parent support groups would be really helpful. There are currently two online groups:

- Deaf-autism-group-subscribe@yahoogroups.com
- Facebook – Deaf and Autism Support Group

We also need increased awareness of deafness and autism as co-existing conditions. When Matthew was diagnosed we felt totally isolated – and we were!

More attention should be paid to the real experts, the deaf and autistic individuals and their families, and what they say. As Gloria Prest (2008) said, "We won't have all the answers but we will probably ask the right questions."

Stephanie Dawson is a peripatetic Teacher of the Deaf in Birmingham. She is the Team Lead for Deafness and Autism and hopes to graduate with her Master's Degree in Special Education: Autism later this year.

Reference

Prest G (2008). *Autism and Deafness Conference*, The National Autistic Society, Nottingham.

Further information from the training day kindly hosted by the Seashell Trust can be found on the BATOD website.

Evaluations included:

'Good balance of professional, parent and research. Lovely to see video of children – it brings it to life.'

'Very informative today, fantastic to share first hand experiences + seek advice.'

If you wish to join this professional network and/or have experience working with deaf children and Alternative and Augmentative Communication (AAC) we would love to hear from you. Please contact me at burwood@ewing-foundation.org.uk

Joyce Sewell-Rutter, Facilitator


roger
PHONAK

Special clinics

Kathryn Gilgallon brings an update about Wandsworth's special school paediatric booth

This is an update of where we are now in Wandsworth following on from Jo Franklin's insightful article published in the BATOD Magazine January 2010 'Special' School Clinics (p10).

To recap: Wandsworth was performing joint education and health audiological assessments for children with hearing concerns in addition to a wide variety of complex needs. For nine years, the special clinics had been assessing the hearing abilities of a range of children with complex needs using a multitude of testing strategies. As discussed in Jo's article, it was found that children were often less stressed coming to clinics in a familiar school environment. Also, as individuals well-known to the child were welcomed in the assessments, even subtle reactions to sounds could often be noted rather than missed.

From special clinics to a specialist audiology booth in a school

Over time some ongoing issues were identified with testing in schools, such as the inevitable noise that comes from being in a school setting as well as the amount of equipment needed to be brought to each assessment – something that St. George's Hospital Audiology staff generously carried out. A very positive outcome was that families and professionals were finding that the results from children being tested in schools were often more reliable than when tested in a hospital setting. This put the idea in motion for creating a specialist paediatric audiology booth within an appropriate school, which would be used specifically for children with complex needs. Since Jo's article was written, Wandsworth Hearing Support Services have built such a booth at Linden Lodge, a special school in Wandsworth.

Linden Lodge is a specialist school for children aged 2-19 who are visually impaired and includes the Harris Centre for children with profound and multiple learning disabilities and The Alba Centre, Wandsworth's specialist facility for children with multi-sensory impairment. Many of the children at the school are similar to those most of us have on our caseload as they have question marks next to their hearing status. This makes a natural starting point for us when deciding who to test.

Professional collaboration

Wandsworth Hearing Support Services procured the funding, and with help from St. George's Audiology staff, a specialist sound-proof room was built that met all specifications. The room includes a viewing booth to allow parents or professionals to observe the assessment and further has a CCTV set-up so people in the viewing booth can both hear the sounds played and closely see the reactions of the child during the assessment.

Joint work with St. George's Hospital was needed to buy the correct equipment for the paediatric hearing assessments. This included a tympanometer, Visual Reinforcement Audiometry (VRA) and speakers and an Otoacoustic Emissions (OAE) machine, all of which needed to be specific for the size of the room. Meetings were organised between audiology staff and Teachers of the Deaf who were experienced in working with children with complex needs to discuss a variety of appropriate distraction and visual reinforcement toys. Further meetings were held with occupational therapists to explore chair options for use with children who would require supportive seating.

Multiple uses of a paediatric audiology booth in a school setting

Alongside the termly audiologist-led special clinics, the paediatric booth is used daily in a variety of ways to support our knowledge of children with known or yet-to-

be-diagnosed hearing loss. As the testing room is located in a school, weekly activities can take place in the room to support children's ease with the procedure of getting their hearing tested – almost a 'trial run' to the assessment. The room is also used to play games that help children learn to show conditioned responses to sounds. The regular Teacher of the Deaf-led activities help children become familiar with the room so they are more relaxed on the day of the assessment. The sound-proofed room also ensures children have access to an optimal environment for listening games and activities.

Family perspective

James is a seven year old boy who has Kabuki 2, a rare syndrome that includes multiple complex needs as well as a visual impairment and a moderate hearing loss. His mother Sue supports the in-school audiology testing, stating:

> *The implications of having hearing tests done at school are far reaching. I envision it would have enormous benefits and most essentially give a far more accurate result of a child's level of hearing/hearing loss. It would inevitably reduce the child's stress levels which a hospital appointment so often involves with unfamiliar people/environment etc. A school setting would be immensely preferable in providing a calm routine to maximise the hearing test outcome.*
>
> *At present the Audiology appointment area has a mixture of adults and children. It is invariably noisy, stuffy, and busy and has limited access to play areas for kids with special educational needs in wheelchairs. Waiting times are long and by the time my son gets seen it is often difficult to engage him fully as he is hot and bored despite my efforts to keep him entertained and calm.*
>
> *Accessibility to 'changing areas' for children in wheelchairs is poor with no hoist facilities and is often too unclean to want to change one's child on the floor (even on a picnic rug which we normally use in these situations).*
>
> *My son James has a rare diagnosis of Kabuki 2 which means at times he is under the care of up to 16 consultants and has very complex special needs. As a result, ANY hospital appointments are time consuming and result in time lost from his school curriculum and routines both in collecting him from school to allow time to find a parking spot and preparing his gastrostomy feeds – as well as including spare nappies, clothes, etc to allow for delays. He attends other clinics at the school and they are seamless and easy. It makes sense to be able to allow for a hearing test in school as well.*

Sue's thoughts are similar to many of the other families we work with, with time, stress of the hospital and an unfamiliar place and the ease of it being at school being amongst the top reasons we have worked so hard to improve on our special clinics in a school setting.

Multi-agency working and going forward

While a paediatric booth is a fantastic resource for the Wandsworth Hearing Support Team, we continue to strive for the gold standard of audiological knowledge and practice with the children we see with complex needs. There is a lot of collaboration that is involved with the child, including the highly skilled audiological technician, Teacher of the Deaf, parent, class teacher and LSA to enable us to get a whole view of the child. We provide ongoing support to the child before and after the hearing assessment takes place (if necessary). We also rely on the feedback from family members and others who know the child well to help us determine if the child is responding (however subtly) to a sound. It may take the child and the experienced team multiple assessments to build a picture of the child's hearing, but as Jo said in her article it is the determination of the team to 'make it work' that is really vital to the assessment.

Further reading

We continue to use the BATOD publication *Guidelines for hearing assessment of children with complex needs* (1997, revised in 2011) as a foundation on which we build our adaptations to suit the individual needs of the child.

For more details on any aspect of this article, please contact Wandsworth Hearing Support Services at info@wandsworthhis.org.uk

Kathryn Gilgallon is the coordinator for deaf children with complex needs, including multi-sensory impairment, for Wandsworth Hearing Support Services. A special thank you must be given to St. George's Hospital Audiology Team who have supported and ensured the paediatric booth and special clinics have continued to be a valuable and important part of our work with children in Wandsworth.

Support after meningitis and childhood deafness

Ffion Haf and Cathy Hill introduce Jasmine and describe the work of Meningitis Now in supporting young people and their families

Jasmine's story
"I'm Jasmine, I'm 15 and I'm a meningitis survivor. My experience of meningitis was in 2001 when I was diagnosed with pneumococcal meningitis and became profoundly deaf.

I contracted meningitis a week after my first birthday. At first I was misdiagnosed with gastroenteritis as I didn't display textbook symptoms of meningitis. It was only due to the gut instincts of a young registrar who asked to do a lumbar puncture and administered antibiotics that I was saved from any further damage. It took six weeks for a precise diagnosis of profound hearing loss, which came as a shock to my mum. It was such a tough time for her.

I was fast tracked for a cochlear implant as hearing aids were of no use as I had no residual hearing, and I was 'switched on' at 18 months old. After that, and with the help of Meningitis Now, we were able to access Auditory Verbal Therapy in central London at Christopher Place in Euston. I now have knowledge of sign language and passed Level 1 BSL, but I still prefer to communicate through oral speech. Speech has always been a more natural form of communication for me and has allowed me to fit well into mainstream education albeit with a statement of support.

We moved to Plymouth in 2004 and Mum became involved in the Plymouth & District Deaf Children's Society. In 2011 she became the Chairperson of the Society, which inspired me to become Youth Spokesperson for the charity, helping other deaf children and their families.

Meningitis Now has always been a big part of my life, and probably always will be. Meningitis never goes away and keeps surprising me with new challenges I'm not expecting, such as acquired brain injury.

Meningitis Now has helped me and my mum through some very tough times. My mum accessed specialist counselling very soon after the meningitis and this was

fully funded by Meningitis Now. I was given Art Therapy when I was in Year 6 and it was really helpful to get through a difficult period in my life. Meningitis Now even funded singing lessons with a young theatre group to help improve my voice quality. More recently, at a Teenagers' 'Believe and Achieve' Weekend in Swindon, I got to meet other young people who had meningitis as children. It was really comforting knowing other young people were out there too.

Mum and I have been supported collectively and continually over the 14 years of surviving meningitis and these gifts have made a world of difference to our lives. We are so grateful for everything Meningitis Now has offered. So becoming a Young Ambassador for Meningitis Now is my way of giving something back to them for all their support. As a Young Ambassador, I've had the opportunity to speak in the House of Commons about my experience and explain about the after-effect of the disease.

Although I am deaf because of meningitis, I don't consider it a negative part of my life as I have been given the chance to help others, whether it's through Plymouth & District Deaf Children's Society or Meningitis Now."

As Community Support Officers for Meningitis Now, we meet courageous young people like Jasmine every day, young people who have battled with so much in their short lives, and still continue to do so every day.

Meningitis is a life-threatening disease, which usually strikes quickly and unexpectedly. It can affect anyone, but babies and young children are most at risk, with around half of all cases occurring in the under-5s, but teenagers and young people are also at increased risk.

There are about 3,200 cases of bacterial meningitis and related septicaemia each year in the UK[1]. The disease causes inflammation of the meninges, the membranes that surround and protect the brain and spinal cord. Most people who have meningitis or related septicaemia (blood poisoning) will recover, but 10% will die and a further 15% will be left with serious, lifelong after-effects, including deafness, epilepsy and limb loss.

Deafness is the most common of the after-effects of meningitis. The disease causes sensori-neural deafness when the infection spreads to the cochlea and damages the hair cells, or when the auditory nerve becomes inflamed during the infectious process.

Meningitis Now's MOSAIC study (Meningococcal Outcomes Study in Adolescents and Children)[2] looked at the physical, cognitive and psychological outcomes of meningococcal group B disease (Men B), the most common cause of bacterial meningitis and septicaemia. Among the findings it showed that children who had Men B were five times more likely to have significant hearing loss and 2.4% had bilateral cochlear implants.

But the research also demonstrated that children who survive Men B are significantly more likely to also experience a range of other outcomes. These include:

- A borderline low IQ (<85), both verbal and non verbal.
- Deficits across all aspects of memory, both long and short-term.
- Poorer executive function leading to problems with organisation and planning.
- They are five times more likely to experience speech and communication problems.
- A significant risk of anxiety and behavioural disorders.

Regular holistic assessment of children and young people and an understanding of the full potential impact of meningitis will help to ensure that the appropriate timely support is provided for those who require it.

At Meningitis Now we recognise the devastating impact the disease can have on all aspects of life, for the individual, their family and school.

Our vision is to reach out and improve the lives of everyone affected by meningitis and minimise the impact of the disease.

Some of the ways we're able to do this include:

Confidential helpline: We know facing meningitis can feel lonely. Specially trained staff can talk to anyone on aspects of the disease, including after-effects, from 9am to 10pm every day.

We can help anyone who has suffered from meningitis/meningococcal septicaemia, including family, friends and carers and any professionals working with them.

Home visits: We have Community Support Officers (CSOs) in all the UK regions who are committed to supporting sufferers, whatever their experience and whenever it was. A home visit can provide vital support and a chance to discuss how we can help.

Educational needs: Many families feel that the educational needs of their child following meningitis are not fully understood and can be overlooked. Some benefit from arranging for a CSO to visit their school to discuss meningitis, its impact and resources available to help children after meningitis.

Counselling and emotional support: Counselling can be helpful if you have had meningitis yourself, or if you are close to someone who has had the disease, and can be used by adults, couples together, young people and children. All the counsellors are members of professional bodies and have appropriate skills, experience and insurance. Sessions are available throughout the whole of the UK, are fully funded by Meningitis Now and there are no waiting lists.

Creative and complementary services: Following an experience of meningitis, many children will not want to talk about what has happened to them, but changes in their behaviour, sleeping, eating and interaction with others will suggest that they are experiencing some form of emotional distress. Access to a creative therapy can help children express their feelings in a gentle, supportive environment. We can make a referral to a professional therapist who can use art, play, drama or music to help a child make sense of what has happened. This can also be very helpful for siblings, who may be experiencing the impact of the disease on their own lives.

Family Days: Family Days happen in various locations throughout the UK and throughout the year, and are an opportunity for families with children up to the age of 12 who have been affected by the disease to meet one another in a fun and relaxed environment.

Believe and Achieve weekends: Our popular regional Believe and Achieve weekends are action-packed events for young people aged 11 to 18-years-old who have had meningitis or meningococcal disease.

Financial Support Grants: Perhaps one of the most significant impacts of meningitis can be financial. To counter this we have set up our Financial Support Grants system to provide practical help with things including:

- Therapeutic and re-training activities: such as speech and language therapy, physiotherapy, sign language classes and driving lessons.
- Special aids and equipment: including special beds, wheelchairs, and sensory equipment.
- Computer equipment; including specialist software such as touch screen and special needs educational software.
- Education: if a child has identified special educational needs, and is waiting for an SEN assessment, short-term educational support may be possible.
- Home adaptations: for example, stairlifts and bathroom adaptations.
- Respite care: for those who care for a family member with disabilities caused by meningitis.

For more on how we support families fighting back from meningitis, call our helpline on 0808 80 10 388 or visit www.MeningitisNow.org

Meningitis now

Ffion Haf is Community Support Officer for Meningitis Now in Wales. Cathy Hill is Community Support Officer in the South West region, covering Cornwall, Devon, Somerset, Dorset, Bristol, Bath and North East Somerset and the Scilly Isles.

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1. UK estimated average annual number of cases 2001 – 2012
2. MOSAIC study
   http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(12)70180-1/fulltext

Deafness & Education International

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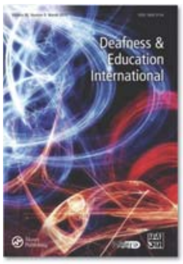

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ReSound

Intervenors

Jenny Fletcher describes the role an Intervenor plays in supporting deafblind children and young people

Jenny Fletcher, Deputy Head of Children's Specialist Services at Sense explains the essential role an Intervenor plays in supporting successful living, learning and development for deafblind children and young people.

For children who are born with a sight and hearing impairment, or for those who develop sight and hearing loss before they have developed language in their early years, life can be especially challenging.

In any group of congenitally deafblind people, each has his or her own ways of communicating and of understanding the world – one may use British Sign Language (BSL), another hand-under-hand, another may have a personal system of signs, and another may, for example, blink or clench his body to show like or dislike. Some will be fully mobile, others may use a wheelchair. A few will have no vision or hearing at all, others will have a whole range and degree of sensory impairments. Some will have profound learning difficulties, others may learn quickly. There's no one template for the way that someone with multi-sensory impairments interacts with the world.

As a result, even in a setting designed for deafblind people, each individual deafblind person needs help that is specific to them in order fully to participate. A person who works one-to-one with a deafblind child is called an "intervenor". This highly trained professional provides individualised guidance and support, directed by the individual to enable the person to do as much for themselves as possible. They get to know them well, learning about the subtle nuances of their communication style, and they use their knowledge to bridge the gap between the deafblind person and the rest of the world. Without that support, a child born deafblind could be completely isolated, unable to communicate and achieve the full life that they deserve. Unfortunately, not enough deafblind children, of whom there are only 4,000 in the UK, receive this type of specialist, skilled support.

The key principle underpinning intervention is not doing 'for', but doing 'with'.

Intervenors must understand the needs and development of children, young people and adults who are deafblind/MSI. They will gather and analyse information about the person's preferences, skills and needs, and use this to develop and review individual plans.

An intervenor must be able to:

- promote a trusting and secure relationship with the individual and the other people in their life
- encourage effective communication and enable the reception of clear information
- work closely in partnership with parents and carers, offering support, guidance and encouragement
- encourage a child or young person's potential for learning, building of relationships and increase confidence
- support people with their social and emotional needs and to navigate their surroundings
- work in a non-obtrusive way.

For deafblind, MSI children, identification and early intervention is critical. Local authorities have duties under the Children and Families Act 2014 to make provision for children with Special Educational Needs and Disability. They also have a statutory responsibility under the Deafblind Guidance to:

- identify deafblind/MSI children in their area
- identify a senior manager with responsibility for deafblind services
- provide specialist assessments by a suitably qualified person
- provide appropriate information and specialist services designed to meet the needs of deafblind/MSI children and young people, including one-to-one support services and equipment.

Unfortunately, research from Sense shows that only 10 per cent of children who are deafblind have been identified by local authorities and only three out of the 10 per cent are getting the intervenor support they vitally need[1].

The provision of a trained intervenor makes a real difference to deafblind children by helping them to gain independence and develop skills. There are examples of good practice across the country, but the provision of such services are not common place, despite the statutory duties in place. Sense is concerned that the under-identification of deafblind/MSI children by local authorities means that children who would benefit from intervenor support are not receiving that crucial provision.

Jenny Fletcher is the Deputy Head of Children's Specialist Services at Sense, where she has worked since 1988. As chair of the National Organisation of Intervenors, one of her key roles is developing and delivering intervenor training throughout England.

Reference

1. http://www.sense.org.uk/content/why-does-child-who-deafblind-need-intervenor

NDCAMHS

Emma Parker looks at teaching in an alternative provision and the relationship between the Wandsworth Hospital and Home Tuition Service (WHHTS) and the National Deaf Child and Adolescent Mental Health Service (NDCAMHS)

Many of you will be aware of, and may have accessed, the support and services provided by the National Deaf Child and Adolescent Mental Health Services (NDCAMHS) teams across the country. There are currently four main centres (York, London, Dudley and Taunton) and six outreach centres (Newcastle, Manchester, Nottingham, Cambridge, Oxford and Maidstone). These centres see deaf children and young people with complex difficulties such as emotional, behavioural and other developmental or mental health issues and provide help, support and advice for them and their parents/families and professionals that are working with them. If a child or young person requires in-patient care they may be admitted to Corner House which is based at Springfield Hospital, London.

What is the Wandsworth Hospital and Home Tuition Service (WHHTS)?

The WHHTS is provided by Wandsworth Council as part of the Department of Education and Social Services (DESS) Education Inclusion Service. Its role is to provide education provision for the three child and adolescent in-patient wards based on the Springfield Hospital site – Wisteria (National Eating Disorders Unit), Aquarius (Regional Acute Psychiatric CAMHS Unit) and Corner House (NDCAMHS) – as well as the hospital classroom at St George's Hospital, Tooting. The service also provides education and reintegration support across Wandsworth for students who are not able to access school due to illness, school phobia, complex mental health issues and/or teenage pregnancy. The service is a medical pupil referral unit and was rated "Outstanding" by Ofsted in September 2013. The inspectors found that the achievement of pupils, the quality of teaching and the service's leadership and management were all of the highest quality.

They concluded: "Pupils make rapid progress. From a wide range of different starting points, pupils make significant gains in their skills, knowledge and understanding."

"Pupils make excellent progress in a wide range of subjects. The accelerated pace of learning is due to small class sizes and outstanding teaching. Time in the classroom is used very well."

"Parents and carers hold the service in high regard. They are particularly pleased about how well staff engage pupils with learning while in hospital and the quality of relationships that staff form with them."

On the Springfield site education is provided within the CAMHS Campus School. The school has four classrooms, two of which are acoustically treated, and teaches students aged 6-18. Education staff are deployed across the whole service according to need; however, the core Corner House team includes two Teachers of the Deaf, one trainee Teacher of the Deaf and two specialist higher level teaching assistants. Most staff within the wider education team have a minimum of Level 1 BSL, while staff directly teaching deaf students have a minimum of Level 2 BSL. The educational provision on offer for students across the service benefits from being able to access the wide ranging expertise of the whole education team, who have specialisms in a vast array of specialist subjects at both primary and secondary phase, including A Level as well as SEN expertise.

WHHTS and Corner House/NDCAMHS?

Corner House is a six-bed national specialist assessment and treatment unit for deaf children and adolescents with severe complex emotional and psychological problems, aged six up to their 18th birthday. Young people are initially admitted for a six week assessment period and their care is reviewed by staff, family and professionals on a six weekly basis. The unit works not only with the young person but also their parents and wider family to provide the best outcome. The length of admission varies from six weeks up to one year. As well as nursing staff the wider team includes psychiatrists, psychologists, social worker, occupational therapist, interpreters, family therapists and other allied professionals.

The WHHTS is involved in this work from referral. Staff contribute to weekly multi-disciplinary team meetings, the six week reviews, assessments and visits to children and young people in their home environments. Once an admission is confirmed school staff will liaise with a child or young person's school (if appropriate) to discuss background, progress and work to be covered. If planning is not available/appropriate with their home schools we provide individualised work through their personalised curriculum plan for each young person. All pupils will complete baseline assessments in English, Maths and Emotional Well-being within the first few weeks of admission. Individually set targets are reviewed every half term to advance the progress that each individual student has made since their admission. Additionally, each young person benefits from access to the Emotions and Deaf Studies curriculum.

As well as providing education provision in core and enrichment subjects to A level, the service also uses the AQA Unit Award scheme, Arts Award and Extended Project Qualification (EPQ) to certify learning experiences.

What does a typical day look like?

The typical school day runs from 9.30am – 3.30pm with a 30 minute break mid-morning and 90 minutes for lunch. This allows young people to access therapeutic groups and clinical professionals throughout the day. Each young person is risk assessed by the ward staff, who take the decision as to whether each individual is able to access the school or if they require tuition on the ward. Ward staff are available for support if a young person is struggling to access school during a session.

Education staff will deliver individualised planning based on the baseline assessments carried out on admission. The curriculum includes: English; Maths; Science; Computing; Art/DT; PE; Deaf Studies and Emotions.

Once the school day has finished young people will return to the ward for additional therapeutic groups and 1:1 work, as well as social time and to complete their homework! If well enough young people go home at the weekends, leaving at lunch time on Fridays and returning to the ward for an 11am start on Monday.

How do I refer/What is the referral process?

For more information on the referral criteria and process please see www.dcfs.org.uk. Referral forms and contact details for both the outreach and in-patient services are available on the site. If you have concerns about a child or young person whom you are working with please contact your regional service for more information or to make a referral. Referrals cannot be accepted without consent from those who have parental responsibility.

For colleagues working in Wales, Scotland and Northern Ireland access to local mental health services is via Child, Adolescent Mental Health Services (CAMHS). The NDCAMHS service is commissioned by NHS England and referrals are accepted from within the UK. For referrals outside England funding will need to be agreed with the local CAMHS team.

Case study

Zoe was a Year 12 young person who came to the unit having successfully completed her GCSEs and planning to take A levels and BTEC at 6th form. She was high achieving and motivated to learn. Her cochlear implanted listening levels enabled her to use spoken English although she reported difficulties in accessing group conversations and being understood by everybody in her school. Both Zoe and her parents felt that discussing their worries at home was a challenge. Some of these issues have been identified in research studies (Anmyr et al, 2012).

Zoe's worries and isolation both within school and at home led to her attempting suicide. Her level of anxiety in all situations had led to her experiencing abnormal perceptions; these included experiencing her own thoughts as external voices (Atkinson et al, 2007) and being aware of smells and sights that did not relate to events in the environment. Zoe's family and teachers were unsure how to help her manage her difficulties.

Whilst at Corner House Zoe's programme included:

- Psychological therapies to help her link her thoughts, feelings and behaviours.
- Work with Zoe and her family to discuss how they could share their worries and support each other.
- Therapeutic community activities to develop Zoe's skills in managing her anxiety during practical activities such as shopping and travel; communication in different situations with different audiences and managing peer relationships (Kushalnagar et al, 2011).

Alongside this, education staff liaised with Zoe's school, local team and family to enable her to reintegrate back into school when ready. We worked with her on her A level courses and supported her in re-taking her English Language GCSE. Therapeutic strategies identified by Zoe and the team were used during school sessions in order to ensure that Zoe would be able to use these strategies with confidence after discharge.

Both school and the unit liaised with Zoe's 6th form to enable her to transition from Corner House to school smoothly.

On discharge Zoe told us that she "had had the urge to die and now has the urge to live"; she expected to have worries and problems in the future but felt that she would now be able to manage them. She is now confidently taking part in age-appropriate activities. She is due to begin 6th form and because of the high ratio of staff to young people in school, is able to take up her A Level and BTEC choices confident in her knowledge on the subject.

Many deaf children and young people with mental health needs will not need to access NDCAMHS teams and even fewer will need an in-patient admission. More information and resources for use in schools are becoming more widely available eg NDCS "Healthy Minds" (ndcs.org.uk).

Whilst a challenging topic, Teachers of the Deaf are well placed to discuss mental health and well-being with young people and their parents.

Emma Parker is a Teacher of the Deaf in the Wandsworth Hospital and Home Tuition Service and the South region representative on BATOD NEC.

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DEAFEXPO 2015

Ann Vickers and Lisa Durrant describe a very successful recent event held in Kent for hearing-impaired children, young people and their families

Background:
Several years ago, as part of a CHSWG meeting, a multi-agency working party was set up to look at the Early Support audit toolkit as a way of reviewing services for hearing-impaired (HI) children. As a result of this work, a list of questions arose:

- How can we ensure parents can access unbiased information on a range of issues related to hearing impairment including communication and changes in technology?
- How can we provide opportunities for HI pupils to meet other HI children?
- How can we develop our multi-agency working and understanding of other people's roles?
- How do we provide opportunities for parents of HI children to meet with other parents?

....and the list kept on growing! Rather than just identifying these areas, we looked at how to address them and the idea of DEAFEXPO was born.

DEAFEXPO 2015
The 2015 event was organised by a multi-agency team from Education, Sensory (Social) Services, Kent Deaf Children's Society (KDCS) and parents, with support from Health through events on the day. We obtained funding through Kent Short Breaks Programme and Kent Deaf Children's Society. In addition, Maidstone Leisure Centre provided an excellent package of support with greatly reduced rates for hall hire, assistance in setting up and free swimming on the day for all families attending.

On a bright sunny Sunday morning in March, we took over the sports hall and several other areas at the leisure centre for the day…

We were fortunate to have Phil Gallagher (also known as Mr Maker from BBC CBeebies and patron of KDCS) to open the event.

There was an exciting programme of activities for children including circus skills, bouncy castle and soft play, outside sports, stage make-up and face-painting along with craft tables and many more activities.

The programme gave parents an opportunity to have a relaxing break whilst watching their children participate in a range of activities with other HI children. It also provided the opportunity for parents to chat to others and gather information from any of the 40 stalls.

The range of stalls offered the latest advice and information related to hearing impairment, such as speech and language therapy, various communication approaches, assistive equipment and the support available from education (specialist services and schools with resource bases), health and voluntary organisations.

At various times throughout the day a caricaturist provided quick sketches and there was an amazing magician wandering around for the children to look out for. There were very popular sing and sign sessions for children and their families. One of the highlights of the day was a performance by a signing choir which brought the hall to a standstill for a while.

Health colleagues provided ear-mould clinics throughout the day thus reducing the need for parents to take time off work or children to miss school.

Throughout the day there was a programme of talks in a quiet area including: 'Hearing tests and what the results mean' – presented by Health; 'SEND reforms and EHC plans'; 'Communicating with your deaf child' – presented by a deaf parent of two deaf children where BSL is the main mode of communication and a presentation by

DELTA. Interpreters were available for all the talks and around the stands in the hall to ensure everything was accessible to all.

What was the result?
A great day was had by all. Over 500 people attended and 100% said how valuable and informative the day was and wanted to know when the next event would be held!

What families found valuable about the event:

There were many positive comments from parents including:

“An amazing amount of information is here; nobody should feel they haven’t been given all the facts.”

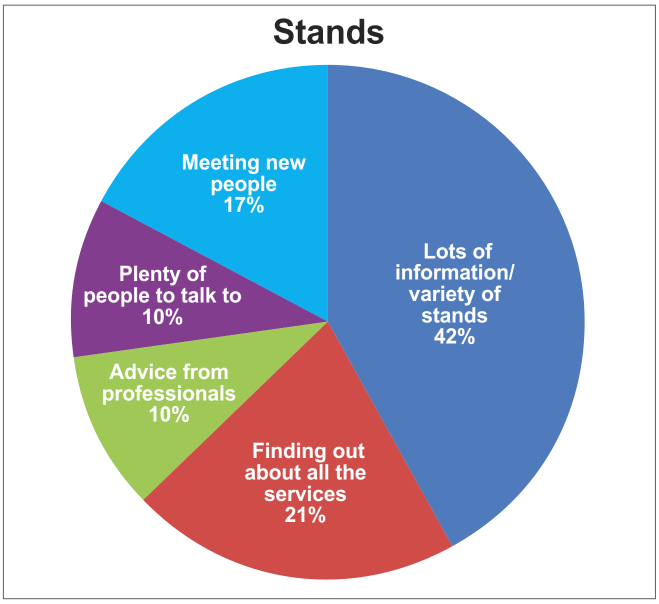
“A very informative day, we stayed all day.”

One comment from a parent of a recently diagnosed profoundly deaf baby made everything worthwhile, *“It was so good seeing deaf children running around doing normal activities like other children”.*

Comments from professionals included: *“Good networking opportunity and to learn about the difficulties deaf people have,”* and *“Met lots of families and young people”.*

Since DEAFEXPO some children in mainstream schools who were reluctant to use amplification have changed their attitude and are now wearing hearing aids. Some children have requested an FM system as a result of seeing other HI children and talking to manufacturers.

What would we do differently?
This was the third DEAFEXPO in the last seven years and each one has got bigger and better as we learnt from our experiences. Next time, we would develop a working group of young people who would be involved in generating ideas for DEAFEXPO and would also play a role in promoting and the running of the event. This would promote independence, confidence and social skills and may increase the attendance of young people at the event.



Would we plan another DEAFEXPO? The short answer is yes! From the feedback it is clear that the aims originally set were well met. Seeing the children and their families enjoying themselves and hearing their positive feedback outweighed the additional work and sleepless nights. What became clear from this event is that hearing-impaired children and young people, parents, professionals, charities, organisations and companies are all able to gain from opportunities to network in this way.

If you are interested in organising a similar event in your area, please do not hesitate to contact us: Ann.vickers2@kent.gov.uk

Ann Vickers is the County Co-ordinator for HI in Kent and Lisa Durrant is a Specialist Teacher for HI.

The impact of mild/moderate deafness on children, their families and their education

Sue Archbold of the Ear Foundation writes about research commissioned by NDCS

"I would say we were most vulnerable when we thought it's mild to moderate, it's only little, and we did think... it's nothing, and we were only told it's only mild to moderate you will be fine. No, mild to moderate deafness, he is still deaf." (Parent Interview)

The implications of mild or moderate hearing loss may be underestimated in spite of an increasing amount of evidence to illustrate its impact on educational performance. Evidence, including from NatSIP (2013), suggests that in some cases, children with mild or moderate loss are not doing as well as expected compared to other deaf children. This is borne out by anecdotal evidence from some specialist education services for deaf children.

There are concerns that children with mild/moderate losses are not picked up by newborn hearing screening and may be missed, as may those who have progressive losses. Additionally, in times of financial challenges for educational services, and where services are being prioritised, it is important that we gather evidence from parents and teachers on their perspectives and experiences of the impact of a mild/moderate hearing loss at home and in the classroom, and how these children and young people can best be supported. We carried out a survey through questionnaires and interviews of parents and teachers to explore these issues.

With support from the National Deaf Children's Society (NDCS), we surveyed parents of children with mild/moderate hearing loss, and teachers were surveyed through our own database and that of BATOD. We used online questionnaires with open and closed questions and interviews. 614 parents of children and young people with mild or moderate hearing loss responded to the survey. The children and young people represented a range of ages, educational and communication backgrounds and needs. 166 teachers who are involved with the education of children and young people with mild or moderate hearing loss responded to the survey. For both groups, a high level of thoughtful open responses was given, which underwent analysis. Many respondents indicated that they would be willing to take part in further research. Following this, 12 parents and 14 professionals were interviewed.

The terms mild and moderate imply little impact of the hearing loss, but the results of both questionnaires and interviews repeatedly reveal that this is far from the truth. Both parents and teachers gave many examples of this, both from the family perspective and from the educational perspective:

- *"The term mild does not reflect the difficulties some children have. Needs can be overlooked in schools especially if not aided. Poor acoustics and listening conditions. Often acceptance issues; child does not want to identify with deafness." (Professional Survey)*
- *"There is an assumption with many that mild deafness is not a big problem which is contrary to the truth" (Professional Survey)*
- *"It is difficult because it is not a disability that people see or understand...." (Parent Survey)*
- *"Most people don't get it. They think because she responds that her hearing is fine ('she heard that' being a favourite comment)." (Parent Survey)*

The following table shows the themes which emerged from the questionnaires and interviews and which are fully discussed in the full report.

Themes	Subthemes
Impact on family	Diagnosis
	Lack of recognition and impact
	Emotional impact: on family and child
	Challenging situations
	Family adjustments
	Managing the technology
Impact on education	Listening in difficult conditions
	Lack of recognition and awareness
	Speech, language and learning
	Social and emotional impact
	Educational assessment and outcomes
	Family and professional roles and relationships
Educational support	Referral to educational support
	Support in school Support by ToD Support by Teaching Assistant
Audiology and technology management	Referral to audiology
	Audiology visits
	Fluctuating losses
	Use of aids
	Use of assistive devices
Looking to the future	Deaf awareness training
	Peer group support
	Information and resources
	Technology training and management

The main issues which arose were:

- The terms ‘mild’ and ‘moderate’ used to describe the hearing loss do not describe the impact described by parents and professionals at home and school.
- There is a bigger impact of mild/moderate hearing loss on family and education than generally recognised by others. *“Massive (impact). He is underachieving academically and socially in the school environment.” (Parent Survey)*
- Children and young people with mild/moderate hearing losses in school have to use greater levels of effort than generally realised.
- Mild/moderate hearing loss frequently has a social and emotional impact on the child or young person.
- Family adjustments are often required to meet the needs of the child or young person with mild/moderate hearing loss.
- 60% of parents felt that they wanted more support for their child: they most commonly wanted more individual 1-1 support in education.
- When asked about information, 66% of parents considered that the child’s teacher or form tutor had sufficient information about hearing loss.
- There is a major lack of deaf awareness in mainstream schools for children and young people with mild/moderate hearing loss in particular. *“Phonics a nightmare but no flexibility in teaching.” (Parent Survey)*
- Children with mild/moderate hearing loss experience diagnosis and fitting of aids later than in other groups, with an apparent lack of care pathway and liaison between professionals:

  “From birth my son never passed newborn screening, after repeated screening and my husband and I getting angry, it was confirmed.” (Parent Survey)

  “I would say you have to push and push and inform yourself unfortunately. You have to do all the reading and you have to advocate for your child. It is unlikely that any one else will do it. You will be lucky if you find someone who does.” (Parent Interview)
- There is a need for parents of children and young people with mild/moderate hearing loss to be particularly pro-active: parents were unaware of the roles of Teachers of the Deaf and teaching assistants.
- There is an increasing use of technology, including bone conducting hearing implants, for children and young people with mild/moderate hearing loss and there is a need for up to date information and training for those working with them, including audiologists.
- While hearing technologies are very effective in this group, they may appear not to need them, and appear to ‘hear’ without them. This can lead to confusion for them and their parents and teachers and possible non-use in later years. *“I would say embrace hearing aids – they are your friends.” (Parent Interview)*
- The impact of fluctuating, conductive losses and unilateral losses is often not recognised.
- Parents and young people valued support groups for families and young people with mild/moderate hearing losses; their needs may be different from those of the profoundly deaf.
- With financial and service cutbacks and prioritisation of services, there appears to be a particular impact on support for children and young people with mild/moderate hearing loss. *“No support as need is not recognised...” (Teacher)*

The findings of this study are revealing and thought provoking about this group of often overlooked children. For Teachers of the Deaf, one of the most important points to take away is how few parents knew about Teachers of the Deaf or specialist classroom assistants. This report can inform parents, teachers and other professionals about the impact of mild to moderate hearing loss on the lives of children or young people with mild to moderate hearing loss.

- *“It is important to stand up for children with mild and moderate losses”. (Teacher)*

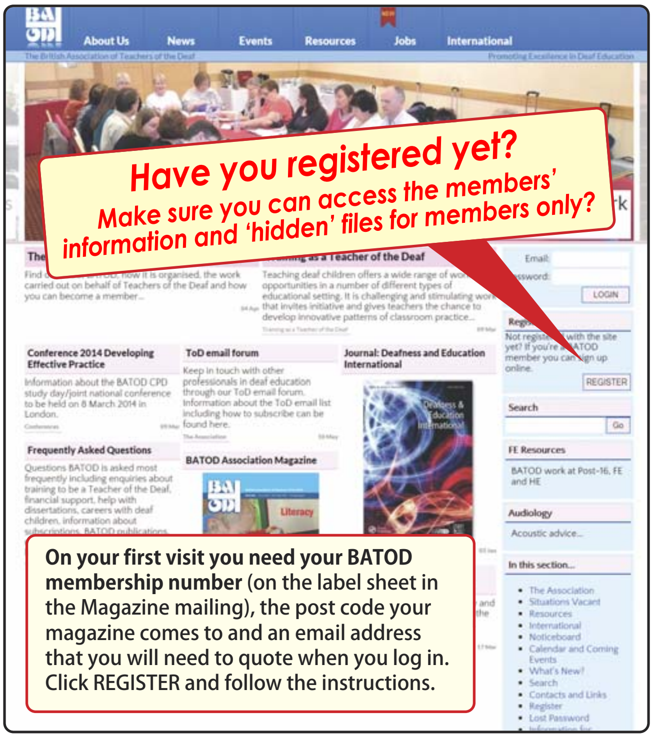
With thanks to all the parents and teachers who helped with this study.

The full report is available to download from the NDCS website at www.ndcs.org.uk/research

Information for families about mild/moderate hearing loss is also available from the NDCS website at www.ndcs.org.uk/mildmoderate

The research was carried out by: Sue Archbold, Sue Gregory, Zheng Ng, Suzanne Harrigan, Tina Wakefield and Lynda Holland.

Sue Archbold is the Chief Executive Officer of the Ear Foundation.



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Research at Mary Hare

Joy Rosenberg reports on the wealth of research that is done at Mary Hare

'Securing the future for deaf children and young people', the strap line for Mary Hare, embodies the rationale behind the research that happens here.

This article represents the work of many people connected to Mary Hare. Our staff volunteer Research Committee vets all external research inquiries, and some contribute to the research body in their own right. Our school pupils participate as subjects in many projects. Our postgraduate students past and present have contributed to the body of research in education of the deaf by virtue of their dissertation writing. And the past and present faculty of our postgraduate courses affiliated to the University of Hertfordshire and Oxford Brookes University have taught, inspired and supervised dissertations for professionals in education of the deaf, educational audiology, and early years and deafness for over a decade and a half.

Postgraduate Master's Dissertations
For the past decade and a half, a cohort of students who have completed their postgraduate diplomas opt to continue to Master's level and complete a dissertation each year, investigating an original research question. Some have worked within their local education authority to complete a classroom-based project, others have liaised with local audiology to do a technical study, and still others have worked with nationally known researchers on a project related to that researcher's grant or lab. To date, they have produced nearly 50 dissertations. The abstracts of two are described in more detail in this brief article, and a list of the others with links to abstracts can be found on the Mary Hare website at http://www.maryhare.org.uk/research-publications

In 2014, Will Potts wrote a dissertation on 'Reasons for the non-use of hearing aids amongst hearing-impaired children aged 9-14 years who attend mainstream schools'. He reviewed literature indicating that the benefits of hearing aid amplification for school-aged children is well-established, but the topic he proposed had not been well researched. He used mixed-methods research with six participants from mainstream schools and found multi-layered reasons for non-use, principally related to stigma, and also related to listening in noise. He advised ongoing counselling especially in secondary school and improved deaf awareness training for teachers and peers.

And in 2010, Jane Hoyer wrote about 18 hearing aid refusers in mainstream secondary schools. Using quantitative methods, she found five themes emerging that were factors for hearing aid refusers. These were visibility of deafness, lack of confidence, coping with hearing impairment, using support, and making choices. Her research showed that discussing speech-in-noise results with pupils can help them realise their need; or can help adults understand their refusal. She also found it essential to have pupil input in agreeing support levels to enable informed choice.

Research and/or publications by staff at Mary Hare
A number of the Master's dissertations described above were completed by postgraduate students who were also teachers at Mary Hare School. Besides Master's level work, four doctoral studies have been or are being undertaken by staff. As well, staff participate in a variety of other research opportunities. Many of these have been published in the BATOD magazine, and others as conference posters, peer-reviewed journal articles, website contributions, and BSA guidance documents and in the future potentially as MESH guides (see www.meshguides.org.uk). A few of this variety are presented below chronologically. For an entire list please see http://www.maryhare.org.uk/research-publications

Tinnitus in Children Practice Guidance (BSA 2015) was the result of research on the topic undertaken by a working party of which the author of this article was a member. Very little research exists at present on paediatric tinnitus. Drawing upon related research, guidelines are suggested for clinical diagnosis and management and classroom management, especially relevant to Teachers of the Deaf as tinnitus appears to be twice as common in children with hearing loss (see also the May 2015 edition of this magazine, page 11).

Phonological Awareness (PA) and Deaf Children was explored by Lorna Gravenstede in the March 2014 *BATOD Magazine*. She considered the many unanswered questions about deaf children's PA and its relationship to literacy learning as well as differing research results in this specific area. In terms of implications for ToDs she advised optimising literacy learning using a battery of skill development tools including PA; and reviewed a published study on PA training and deaf children.

Transition from preschool to school was the topic of an e-bulletin written by Helen Nelson on Mark Marschark's website 'Raising and Educating a Deaf Child' (courtesy of Oxford University Press) which aims to provide an evidence base for practice and policy. Implications for the role of the ToD include being aware of and maximising efforts to overcome potential barriers to inclusion and curriculum access in the early years, in spite of the positive outcomes of technological advances. The e-bulletin includes a call for further research to look at effective practitioner processes and parental perceptions.

Technology to Support Learning was the topic of a May 2013 BATOD magazine article by Viv Ogg, Katherine Clements and Simon Thompson. It followed a conference workshop that allowed discussion of pros and cons of new resources for classroom use along with some hands-on use of these new technologies. The format of the workshop and article was based on a typical day at Mary Hare School, beginning with form time through to lessons, lunch time, more lessons, speech and auditory rehab therapy sessions, and after school activities. Some of the technologies covered included personal amplification monitoring devices, visualisation techniques using interactive whiteboard, e-books, reading databases, touch-typing programmes, laryngographs, lipreading and listening activities, iPad apps and an essential metal detector for locating lost hearing instruments on the playing fields.

Cortical responses as a measure of listening effort were investigated by Tracy James (nee Draper) in 2010 in conjunction with Kevin Munro, Bram Van Dun and Harvey Dillon. Her poster was presented at the British Academy of Audiology conference. She investigated whether aided cortical evoked potential measurements with speech stimuli would inform clinicians, educators and parents about the appropriateness of hearing aid fittings in cases where behavioural information or verbal feedback cannot be obtained, for example for infants or children with complex needs. This was a preliminary study and the conclusion was that more analysis needed to be done with larger groups to establish more definition about the method's usefulness, although clinicians could use likelihoods defined in the poster to supplement other information about the subject.

Research involving Mary Hare pupils as subjects

With a student body of nearly 200 children and young people who are deaf, Mary Hare commands a great deal of attention from researchers across the country who are interested in improving the quality of life and education for these children and young people with their investigations. Their studies cover a range of topics from social/emotional issues to literacy learning to listening effort. Because of the growing number of requests for access to such a unique subject base, volunteers from the staff of Mary Hare formed a Research Committee in early 2011 to vet the various project requests for mutual benefit. The purpose of this committee is to oversee and coordinate all research projects carried out across the

Researcher tests a subject from Mary Hare in the University of Southampton's mobile research unit primary and secondary school. This is to ensure that research carried out has been considered beneficial and that the interests and time of the participating pupils are protected and respected.

Through the efforts of this committee, the subjects are carefully screened so as not to overtax them and are rewarded for their time by the researcher. The studies themselves are carefully screened to ensure the best use of subjects' time and contribution to the field.

A few of this variety are described below. For an entire list please see http://www.maryhare.org.uk/research-publications

Catherine Barnett and Ros Herman from City University London in 2014 worked at Mary Hare on their research related to deaf children and dyslexia. Because of the lack of reading tests particularly designed to assess deaf children, they aim to develop standardised reading tests to check progress for deaf children.

Margaret Harris and Emmanouela Terlektsi in 2009 with the help pupils from Mary Hare and other schools as subjects explored the reading and spelling abilities of deaf adolescents. They found differences in educational setting and type of hearing instrument used impacted reading levels which were not predicted by age of diagnosis or degree of hearing loss.

Terezinha Nunes and cohorts piloted games at Mary Hare in 2006 related to working memory intervention. She wrote that Mary Hare have been very helpful over the years and that there have been many publications about the different aspects of the work she carried out with the support of the pupils (some in the BATOD magazine). One of these such studies (2008) established that deaf children could benefit from instruction that supports use of informal mathematics knowledge; and another proposed a relatively successful intervention.

Conclusion

Translational research, applying scientific conclusion to real-world practice, has become a centrepiece for government, academic and even industrial investment. It goes a long way toward helping professions, indeed our very own ToD profession, consider why we do what we do. For some excellent examples, see www.meshguides.org. Mary Hare staff and students are at the forefront of translational research related to deafness, working jointly with audiologists, educators and researchers across the country and beyond to contribute to the body of literature which will help to see this generation of deaf children and young people securely into their future.

Joy Rosenberg is Programme Tutor for the MA/MSc in Deaf Education Studies at Mary Hare, partnered with University of Hertfordshire.

References – For a full list, please see http://www.maryhare.org.uk/research-publications

Teaching Writing to Deaf Learners

Connie Mayer looks at what is effective in encouraging writing in all learners and applies it to deaf students' writing development

It is probably fair to say that most of us find writing more difficult than reading. While many of us read for pleasure and to relax, writing is not typically viewed in the same positive way, and students often see writing as ‘work.’ Yet writing is a very important form of communication for school, at work and in everyday life for both hearing and deaf individuals. With the increasing use of text-dependent technologies and media (eg email, texting, Facebook etc), it is becoming even more important to be able to write clearly.

While learning to write can be challenging for all students, the challenges for deaf students seem to be even greater, with research indicating that many deaf individuals do not write well (Mayer, 2010). That being the case, it is surprising that relatively little research and pedagogical attention has been paid to the teaching of writing to deaf students. About the only thing that can be said in defence of this state of neglect is that it is typical of literacy instruction for hearing learners as well (Troia, 2007).

In this article a model for teaching writing to deaf students will be described. This is a flexible model that can be implemented across the age range from the early years through high school, in mainstream and classroom settings, with both stronger and less able writers. Before describing this model, it would be important to emphasise the role that language plays in learning to write. Age-appropriate (or near age-appropriate) competence in a face-to-face form (spoken and/or signed) of the language to be written is the necessary foundation for all beginning writers. This does not change because the student has a hearing loss. At the risk of putting it too bluntly, students cannot be expected to write down a language they don’t know. Developing this language base is the requisite first step in teaching any student to write (Mayer, 2007; Mayer, in press; Mayer & Trezek, 2015).

A process model for teaching writing

The model for teaching writing proposed here is informed by what we know about what skilled writers do – that writing is a process involving planning, independently composing, writing multiple drafts, then reviewing and revising numerous times based on feedback from others along the way (Wong & Berninger, 2004). In other words, students must come to see developing a piece of text as an activity that not only allows for reviewing, rethinking and rewriting, but encourages it. This runs counter to how many deaf students see writing – as an exercise in filling up the page with a focus on correct spelling and grammar.

Such a process approach to teaching writing can be realised in practice in different ways (Writers' Workshop, Calkins, 1994) depending on the age and abilities of the writer. For example, a more capable writer will typically produce a longer, more complex text, review and revise multiple drafts, and may work on the same piece over a length of time. In contrast, less able or younger writers will produce shorter, simpler texts, engage in less revision, and spend less time on one piece.

Additional hallmarks of a process approach are the integration of reading and writing instruction, the development of a sense of audience, and establishing a balance between a focus on meaning and form, with an emphasis on using writing for genuine purposes, viewing accuracy and correctness as secondary to making meaning. Further information on implementing a process approach can be found at these two websites: http://www.eworkshop.on.ca/edu/core.cfm and http://www.readingrockets.org/

Writing for a purpose

Given this privileging of meaning over form, it is critical to have students identify the reasons for writing in the first place, so that they come to see text as an important and powerful means of communication. These purposes can be as diverse as the writers themselves, and apply irrespective of the age or ability of the writer.

A useful tool for thinking about the range of reasons for writing is Halliday’s (1975) hierarchical, developmental framework in which he outlines the uses of face-to-face language from the earliest developing instrumental (What do I want) and regulatory (Do as I say) functions to the more complex heuristic (Tell me why) and informative (I’ve got something to tell you) functions (see also Mayer, in press). For each function, it is possible to identify genres that could be used to accomplish the intended goal. For example, using writing for the regulatory function could be as simple as a warning sign (eg Do not touch) or as complex as the directions for building a model. In both cases the writing serves the same purpose (ie to provide direction), with the complexity being dependent on the ability, not the age of the author. Halliday’s framework provides a useful model for systematically thinking about how to broaden the types of writing that are done in classrooms (eg beyond journals), for incorporating both narrative and expository texts, and for meeting the needs of a diverse groups of learners.

Instrumental (I want)	Request, cajole, persuade	Lists, memos
Regulatory (Do as I say)	Direct behaviour	Posters, instructions, signs, Advertisements
Interactional (Me and you)	Disagree, promise, criticize, compliment	E-mail, letters, notes, texts
Personal (I feel)	Complain, justify, express emotions	Letters, cards, journals, diaries
Imaginative (Let's pretend)	Tell stories, role play	Poetry, plays, stories
Heuristic (Tell me why)	Request clarification predict, probe	Essays, response papers
Informative (I've got something to tell you)	Describe, compare, discuss, suggest	Biographies, summaries, retells

Strategies

It is beyond the scope of this brief article to describe in detail the range of specific strategies that can be used in implementing a process approach (ie at the planning, text generation, and revising stages). For the most part, these do not differ from the strategies that would be efficacious with hearing writers (ie differentiation not difference). For example, at the planning stage, graphic organisers can be very useful not only in developing a piece of writing, but also for analysing a text that has already been written (eg a compare and contrast essay). This allows the student writer to scrutinise a piece of writing and examine how a skilled author has constructed a text. Some examples can be found at: http://www.eduplace.com/graphicorganizer/

At the composing stage, dictation can be used when students have challenges in getting their ideas down on paper, and think-alouds can be used to model the process of text generation. Conferencing, an essential feature of implementing a process approach, is critical at the revising stage. Conferences are brief – individual meetings between the teacher and the student writer in which the teacher provides feedback and identifies the strategies that a student might use to improve their text. These are not lessons with preset teaching goals, but rather sessions in which the focus is identified in response to what the student has written. (For a more in-depth discussion of these and other strategies see Mayer, in press.)

Final Words

Both teaching writing and learning how to write well are complex activities that warrant more attention in both research and practice. The focus in this article has been on applying what is known about effective writing instruction for all learners to the context of deaf education, and to propose a process approach to the teaching of writing. It has also been suggested that this is a flexible approach that can be adapted and differentiated to meet the needs of a diverse range of learners, and can be seen as a positive pedagogical step in addressing the ongoing challenge of teaching deaf students to write.

Connie Mayer is Associate Professor and Academic Coordinator of the Deaf and Hard-of-Hearing Teacher Education Program at York University, Toronto.

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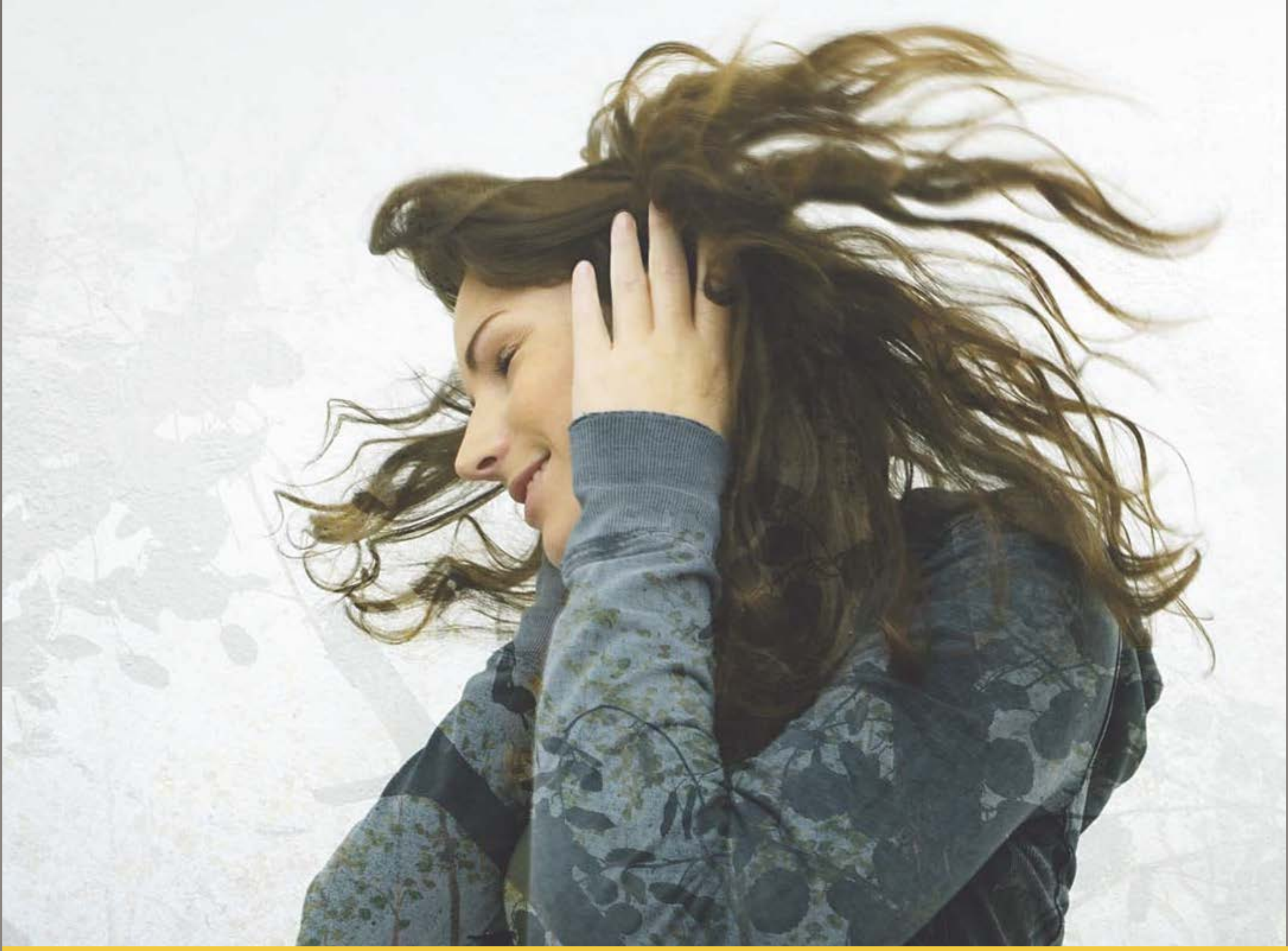

FM and wireless streamers

Jeanette Martin and Kathy Owston report on how new technologies can best be used to help hearing-impaired children

'To FM or not to FM?' that is the question! With the continuing advancements in new technologies, the range of assisted listening devices for hearing-impaired children is always on the increase. Keeping up to date with what is available from the manufacturers and knowing if it is compatible with the child's hearing aids or speech processors, how to connect it and whether it is the right, or best, device to use will always be a significant part of a Teacher of the Deaf's workload.

Now that Cochlear has released the wireless accessories for the Nucleus 6 speech processor, we now have to consider FM systems, Digital systems, Roger AND wireless streaming devices.

The radio aid system is, and should continue to be, within the remit of the local service for hearing-impaired children. The local service or specialist provision that provides the radio systems is responsible for ensuring they are supplied, maintained and used effectively. Where a child has a cochlear implant, this should be done in conjunction with the Implant Centre Teacher of the Deaf. Cochlear Implant centres may have differing protocols regarding fitting of radio systems. At St Thomas' Hearing Implant Centre our policy is to follow the NDCS Quality Standards:

QS4 –'Initial fitting and setting up of FM systems with a CI should be carried out by an appropriately trained CI centre professional'.

We would always recommend objective verification of an FM system, by balancing the FM system with the speech processor using a test box, where possible. This can be done by local services, if it is not possible for the implant centre professionals to do it themselves.

The new Cochlear N6 wireless accessories are available direct to the child without the need for any professional involvement. The 'mini microphone', 'phone clip' and 'TV streamer' deliver the audio signal from the accessory, directly to the hearing instrument, via digital radio frequency transmission on the 2.4 GHz band.

Currently N6 users are being offered one free wireless accessory, which will result in many children, who are N6 users, having a 'mini microphone' which will wirelessly stream from the mini microphone directly to their processors. http://www.cochlear.com/wps/wcm/connect/us/recipients/nucleus-6/nucleus-6-accessories/cochlear-wireless-mini-microphone

The 'mini mic' should be free of interference, has a range of seven metres and the gain can be adjusted up to 10dBHL using the remote control. It could be useful in noisy nursery environments, in educational settings where no FM system is available and also for clubs and activities outside of school, such as family bike rides and car journeys, for example.

However, as with any assisted listening device, we need to be sure that the signal being received by the user is clear, free from interference and at the correct level. The 'mini mic' cannot be objectively verified through a test box so caution should be used when using it with young children who cannot yet report on sound quality. The Cochlear Implants FM Training Tool from RNTNE and Phonak UK is a useful resource to develop children's skills in reporting sound quality. https://www.uclh.nhs.uk/OURSERVICES/SERVICEAZ/ENTS/CIM/Pages/FMTrainingTool.aspx

With all the different options available to parents and local services, ensuring effective communication between the local service, parents, and ICToDs, about what is best and most appropriate for the child, on a case by case basis, is what is needed.

When considering any FM device in conjunction with cochlear implant speech processors, it must be remembered that the technology is different from when fitting radio aids with hearing aids. For cochlear implant users, only the child or young person themselves can tell whether the system is operating effectively, without interference and giving additional benefit. The child needs to be able to have the language skills to be able to report on sound quality. We would recommend to always use the FM ChIP designed by the Linked uP group, which can be found on the BATOD website at: http://www.batod.org.uk/index.php?id=/resources/audiology/fmsystems/fmchip.htm

The most important things to remember are –

- Is the child ready to use an assisted listening device?
- Which system works best for the child not just technically but also practically?
- Is it used effectively? Provide training to all users of the equipment
- Monitoring and maintaining the equipment are crucial and the responsibility of all of the adults involved with the deaf child using the radio aid system or other assisted listening device.

Jeanette Martin and Kathy Owston are Implant Centre Teachers of the Deaf at St Thomas' Hearing Implant Centre, London.

Safeguarding

Helen Donnellan shows how safeguarding is everyone's responsibility

This short overview of this huge subject is based on three questions:

- Do I have any responsibility for safeguarding?
- What am I responsible for?
- How do I find out more about my responsibilities and what to do if I suspect abuse?

The accepted definition of safeguarding comes from the Children Act 2004 and the statutory guidance in 'Working together to safeguard children[1]:

- protecting children from maltreatment
- preventing impairment of children's health or development
- ensuring that children are growing up in circumstances consistent with the provision of safe and effective care
- taking action to enable all children to have the best outcomes.

As well as protecting them from deliberate harm, safeguarding also includes children's health and safety, the use of reasonable force, meeting children's medical needs and first aid.

'Working together to safeguard children'[1] makes clear that we all need to be alert to signs of abuse and neglect and know what to do when we suspect possible abuse. Each of us, regardless of our role or where we interact with children, is responsible for keeping children safe.

The challenges faced by all victims of abuse, whether they are currently experiencing abuse and neglect, or are victims of historic abuse, cannot be under-estimated and are greater for deaf and disabled victims. Some of the challenges are:

- recognising that what is happening is abusive
- making a disclosure
- convincing adults that the issue is safeguarding – not the effect of disability

Myth	**Fact**
Nobody would abuse or neglect a disabled child...	Research shows they are more than three times more likely to be abused.
Disabled children are well protected because of all the helpers they have…	Because they rely on so many people to help them, often with personal care, they are at greater risk of someone abusing their trust.
Disabled children are not attractive to abusers…	Abusers are usually driven by desire to dominate and some disabled children can be seen as particularly helpless.
You can't expect disabled children to be as well dressed and turned out as other children…	When loved and cared for disabled children are as well turned out as any other child.
Disabled children won't be believed… and will not be able to give evidence in court…	Many abusers think this – but with the right help and support all disabled children can tell or show what happened to them [and this is admissible evidence].
If the child cannot speak s/he cannot communicate…	A wide range of communication systems and equipment is available and skilled people to help children communicate.
You can't be expected to get the views of disabled children, as you can't be sure that they are expressing their own views and opinions…	Article 12 of the United Nations Convention on the Rights of the Child is very clear: Every child has a right to express their views regarding all matters that affect them and for those views to be taken seriously.
Abuse doesn't have the same effect on disabled children…	The betrayal of trust and hurt is as acutely felt as by any other child.

Reproduced from the Scottish Government Ministerial Working Group (2014) Child Protection and Disability toolkit.

- overcoming barriers to access support.

Deaf and disabled children are at greater risk than their peers[2], due to reliance on others for communication, for some, their need for intimate or personal care and limitations to resist, or seek help or understand what is happening. It is hardly surprising that a report by the University of Edinburgh for the NSPCC[3] found significant levels of under-reporting by deaf children of abuse, given the greater risks and challenges in making disclosures.

Safeguarding, child protection and abuse are rarely out of the news. The unending stream of chilling, uncomfortable and sad tales exposes failings and the need for more actions to protect and safeguard children. The Department for Education's (DfE) statutory guidance in 'Keeping children safe in education'[4] advises an attitude of 'it could happen here,' which applies to all children in all settings.

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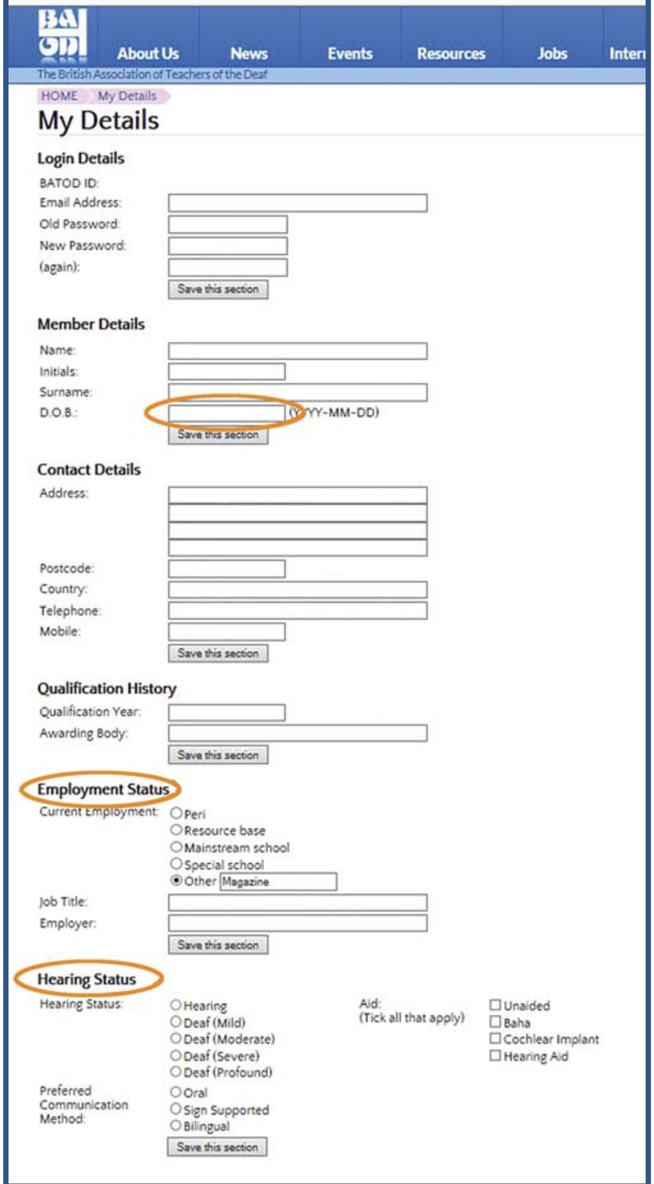

Current Employment: ● Other Magazine

Miller and Brown's (2014) 'We have the right to be safe' report for the NSPCC looked at safeguarding of deaf children and recognised the need to understand their complex needs. Other research shows that deaf and disabled children are at greater risk of abuse than their peers.[2]

In March 2015, the NSPCC published a study[2] to address 'a significant gap in current understandings of deaf and disabled children and young people's experience of the child protection system'. It found that abuse of deaf and disabled children is 'underreported and often hidden and a range of myths and stereotypes surround their abuse.' This is no surprise, so let's consider those myths and facts.

What is abuse?

Abuse is defined as 'maltreatment of a child' and can be by inflicting harm or failing to prevent harm. Abuse may be physical, emotional, sexual or through neglect or any combination of these. The types of abuse and neglect are set out in part one of 'Keeping children safe in education'[4].

Specific safeguarding issues

These are varied and the list of concerns continues to grow. 'Keeping children safe' lists: child sexual exploitation; bullying including cyberbullying; domestic violence; drugs; fabricated or induced illness; faith abuse; female genital mutilation; forced marriage; gangs and gang violence; gender-based violence/violence against women and girls; mental health; private fostering; preventing radicalisation; sexting; teenage relationship abuse and trafficking.

Part one of 'Keeping children safe in education'[4] contains links to more information about each of these forms of abuse as well as information for everyone working in education. It is recommended that all staff read at least part one of that document, regardless of their role or the type of education setting where they work.

What to do if abuse is suspected?

'What to do if you're worried a child is being abused: advice for practitioners'[5], is easy-to-read guidance designed for everyone working with children and families, in the statutory, voluntary or independent sectors. It includes information about signs of abuse and neglect and the appropriate action to take when concerns arise. A major change from April 2015 is that 'any practitioner' can make a referral to the children's social care team in the relevant local authority.[4]

What are my responsibilities?

While each of us has a responsibility to safeguard children and different roles carry specific responsibilities, part one of 'Keeping children safe'[4] makes clear that all staff have responsibilities to be aware of safeguarding arrangements at the setting; provide a safe environment for learning; identify children in need of extra help and those suffering or likely to suffer significant harm and to take appropriate action when concerns arise. People working in a number of settings need to be aware of arrangements at each setting and know whom to speak to when there are concerns. Teachers' Standards 2012 explicitly state that teachers and headteachers have a duty to safeguard children's wellbeing and Ofsted regards safeguarding as part of its core business, also giving inspectors responsibilities[6].

Headteachers and school governors have a duty to appoint a designated safeguarding lead and to provide cover for this role, in practice meaning that two people need to be appointed.

School governors' responsibilities are listed in part two of 'Keeping children safe'[4]. These include ensuring that at least one member of every appointment panel includes at least one person trained in safer recruitment and that appropriate checks are made to prevent people who pose a risk of harm from working with children. These include Disclosure and Barring Service, or Disclosure Scotland checks. Audits of safeguarding by governors enable them to evaluate a school or college's safeguarding practice and their value has been recognised in recent inspections.

What resources are available?

In addition to the statutory and non-statutory guidance referred to in this overview, materials are widely available to support professionals, families, those working in the voluntary sector and children. These include child-friendly DVDs (some using sub-titles, signing and Makaton), lesson plans, research papers and extensive information about different types of abuse.

One of the responsibilities of each Local Safeguarding Children Board (LSCB) is to provide training and resources. Membership of each Board is broad and section 13 (4) of the Children Act 2004 includes one representative who is 'the proprietor of a non-maintained special school'. Do non-maintained special schools for deaf children know or use the resources of the LSCB and how does the LSCB take the needs of deaf children and those working with them into account?

This article makes no reference to particular abuse cases and no attempt to describe how to identify types of abuse. Each of us has a responsibility to keep children safe, be aware of signs of potential abuse and know what to do if we suspect abuse.

Every child has a right to be safe and protected.

Helen Donnellan is a retired Teacher of the Deaf, who served for many years on BATOD's NEC, and now works in a consultancy specialising in safeguarding and safer recruitment training.

Resources

www.barnardos.org.uk
Barnardo's – extensive resources and support

www.ceop.police.uk
Child Exploitation and Online Protection (CEOP), ThinkUKnow toolkit of resources

www.gov.uk/government/organisations/department-for-education
Keeping children safe in education, 2015
Information sharing: advice for practitioners, 2015
Safeguarding disabled children: practice guidance, 2015
What to do if you're worried a child is being abused: advice for practitioners, 2015

DfE also provides extensive guidance on each of the particular safeguarding issues referred to in this article

www.impacttriangle.co.uk
– training in safeguarding, safer recruitment and safeguarding audits for school governors

www.gov.uk HM Government
Working together to safeguard children, March 2015
The National Minimum Standards for Residential Special Schools

www.gov.uk/government/organisations/disclosure-and-barring-service
Home Office: Disclosure and Barring Service – information on disclosure and barring and how to check potential employees and volunteers

www.lucyfaithfull.org.uk
Lucy Faithfull Foundation – runs many projects, including Stop It Now and Parents Protect

www.nspcc.org.uk
NSPCC Safeguarding resources, research and support

www.ndcs.org.uk
National Deaf Children's Society resources and support

The Local Safeguarding Children Board for the relevant local authority

References

1. HM Government, *Working together to safeguard children* (March 2015). Chapter 1, 14

2. Jones L et al (2012), *Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies.* Lancet 380 (9845); 899-907

3. University of Edinburgh/NSPCC Child protection research centre, *Deaf and disabled children talking about child protection*, March 2015

4. DfE, *Keeping children safe in education, statutory guidance for schools and colleges* (March 2015)

5. HM Government, *What to do if you're worried a child is being abused. Advice for practitioners* (March 2015)

6. Ofsted, *Inspecting safeguarding in maintained schools and academies* (April 2015)

New care standards for microtia

Vicki Kirwin, Ken Stewart and Ruth Henderson look at the new care standards for services working with children and adults who have microtia and/or atresia

Microtia is the absence or underdevelopment of the outer ear and affects around 1 baby in every 6,000 births. For 90% of children their microtia (or 'little ear') is unilateral with twice as many on the right side compared to the left. Microtia affects boys in 65 percent of cases and girls in 35 percent. Aural atresia describes failure of development of the external auditory canal and is present in 80% of children with microtia. The atresia ranges in severity from a patent auditory meatus with a 'blind-ending' auditory canal, to complete absence of development of the meatus and canal with associated abnormal development, or absence of the middle ear structures.

Microtia and atresia are frequently associated with other complex craniofacial conditions such as hemifacial microsomia and Treacher Collins syndrome, and may impact on all aspects of the child's life.

Options and choices for families are complex and ongoing. We have long appreciated the impact of bilateral deafness but evidence is emerging of the impact of unilateral deafness for a significant proportion of the children. For many families, no surgical intervention is wanted but for others new implantable devices give options for improving hearing function if conventional hearing aids cannot be worn. Reconstructive techniques have improved enormously in recent years so that older children have the choice to have new ears built from their own rib cartilage, reconstruction with a subcutaneous prosthesis or an external moulded prosthesis if they wish. Providing information and support, together with monitoring the child's development, audiological, psychological and surgical care requires close collaboration between the family and the multidisciplinary team working together to offer a package of care in which one intervention does not compromise another.

Key points from the standards include:

- Children with congenital microtia and atresia should be referred at the earliest opportunity to clinicians with appropriate professional expertise and knowledge of these conditions.
- Complex aspects of microtia and atresia care should be addressed by specialised multidisciplinary teams.
- The specialist team should work in close collaboration with local teams and professionals supporting families.
- Regular review within a multidisciplinary setting offers the patient and family holistic assessment and management.
- The multidisciplinary team should consider audiological, psychological and reconstructive aspects of care in an individualised manner.
- Information about support groups and organisations should be provided.
- Patients should be offered a point of contact for ease of access to the service. This may be a specialist nurse or other appropriately trained individual.
- It should be recognised that unilateral atresia and associated hearing loss may have an impact on a child's development, and that the child's progress and hearing should be closely monitored.
- For hearing restoration, options may include: educational support, conventional hearing aids, bone conduction hearing aids, bone anchored hearing aids and implantable hearing devices.
- Patients should be offered all appropriate reconstructive options for both the external ear and auditory restoration.
- Patients and families should be supported in an unbiased manner in making informed decisions about which, if any, treatments are most appropriate for them.
- Patients and families should be able to access services at any age. For example, if a decision is made not to intervene as a child this should not preclude the same patient being offered intervention as an adult.

The new care standards were published in March 2015 and were developed by a collaboration of professionals with stakeholder organisations including patient, parent and carer groups.

The standards along with an information booklet written for families on microtia and atresia can be downloaded from the NDCS website: http://www.ndcs.org.uk/family_support/audiology/types_and_causes_of_deafness/microtia.html

Mrs Vicki Kirwin is the Development Manager (Audiology and Health), National Deaf Children's Society, Mr Ken Stewart is a Plastic Surgeon at the Royal Hospital for Sick Children, Edinburgh and Dr Ruth Henderson is an Associate Specialist, Community Child Health, NHS Lothian.

Refereence:

Henderson R, Moffat C, Stewart K and Clapperton K (March 2015). *UK Care Standards for the Management of Patients with Microtia and Atresia.*

Scientific concepts

Jenny Wilkins discusses her MA critical study on the challenges of Science Education for deaf students with a focus on learning scientific vocabulary and concepts

The aims of my MA critical study were to try to establish the reasons why deaf students tend to find science learning challenging; to identify any useful evidence-based approaches beneficial for demonstrating scientific concepts to deaf students in order to develop their scientific knowledge and comprehension; and to support deaf students in developing and retaining their scientific vocabulary. There is limited research on deaf students' science learning and attainment. A focus on learning scientific vocabulary and concepts was selected because my personal experience supported the research findings that deaf students tend to struggle to develop and retain their scientific vocabulary, and face challenges in their scientific conceptual understanding development (Spencer and Marschark, 2010).

A small scale empirical research study was devised to glean evidence-based data that could be applied to inform practice. The research tools used were a mixture of a semi-structured staff interview, a structured student interview and an observation checklist, all devised with the aim of obtaining data to try to identify the challenges relating to deaf students' science learning and the teaching approaches used. The data was collected from observations at five different settings, plus interviews with staff and deaf students, to give a broader overview of the different communication methods and teaching approaches that deaf students may experience while learning science.

Issues

Research has identified that if students are expected to participate in scientific investigations, discussions and arguments, they first need to have an understanding of science language and how to use it. However, from research, experience and observations, deaf students

Table 1 outlines the useful teaching approaches from interviews and observations for teaching scientific concepts

Method of approach	The perceived usefulness of the approach
Visual resources	The importance of the use of visual resources with scaffolding to give a richer context, such as linking the concept to their everyday lives to reinforce science conceptual understanding.
Use of technology such as iPads and the interactive whiteboard (IWB)	The student demonstrated understanding supported by the instant access to visual images of difficult scientific concepts on the iPad.
Video clips	The importance of giving an interpretation of the clip in BSL as appropriate and SSE, and supporting this by writing down the key words. However, staff do mention time constraints and the faster pace in mainstream classes affecting student understanding, and often the deaf student needs to review the clip as they have to divert their attention between the clip and the BSL input. Also the subtitles are often inaccurate or difficult to understand.
Science practicals	Most mentioned was that it was helpful to introduce the practical early in the lesson to support deaf students' conceptual development to give context, meaning and visual representation for the text or verbal explanations.
Using concrete items	Concrete items were used to prompt discussions on scientific concepts. The students engaged in the discussions and had the confidence to contribute their ideas and seemed to develop their conceptual understanding further while doing this.
Group discussions in the class	The occasional need for modelling, by the Teacher of the Deaf and another adult, how to ask questions and answer them or contribute in discussions so that the deaf students could develop an idea of what was expected from them and focus on the activity.
Communication mode	The usefulness of each mode (BSL or SSE or spoken English) should depend on the individual deaf students' language and communication needs and the level of BSL skills.
Use of role play	Science concepts can be introduced in a fun way for very young deaf children (for example 'making an umbrella for teddy', 'having a tea party' or 'creating a telescope for a pirate').

Table 2 lists the approaches identified from interviews and observations to support scientific vocabulary development.

Method of approach	The perceived usefulness of the approach
Use of flashcards (or post-its with the keyword stuck to the object)	Students commented on the usefulness of matching key word flashcards to images or objects in helping them to retain the scientific vocabulary. In the schools for the deaf this was done during the starter activity prior to any instruction or practicals.
Use of technology such as iPads and the IWB	The usefulness of technology was highlighted in its versatility as a resource to support deaf students' scientific vocabulary development, such as the use of images, websites, games, and video clips to reinforce scientific vocabulary learning.
'Word Wall' displays	Displays with images and text of various scientific vocabulary in a designated area in the classroom that students could refer to at any time promotes independent learning.
Use of everyday objects to demonstrate key vocabulary	All the hands-on demonstrations enabled students to grasp the meaning of the key vocabulary and retain it as they could link it to their experiences and observations.
Use of group discussions	Practice in discussing key vocabulary and the meaning in their preferred language, practising recall and use of key vocabulary and linking it to the topic being discussed supporting writing using scientific vocabulary.
Multimodal way of introducing science vocabulary – via BSL, finger spelling, text and the spoken word	This multi-modal way of introducing key words, often called 'chaining', was observed frequently in science lessons and was used to reinforce meaning and support memory retention.
Use of language best suited to the deaf student's own language and communication needs	This adjustment of language and communication during explanations and discussions of scientific vocabulary enabled deaf students to engage in the lesson.
Use of a set proforma guide	The guide supported deaf students with their science writing; for example, in science report writing. The deaf students developed an understanding of what was expected in a 'report'.
GCSE Revision guide with clear summaries and keywords emboldened	Quick method to identify and refer to key words, and to revise for exams and practise answering questions.

tend to struggle to converse effectively among themselves either in English or BSL due to their limited language levels, and with others in the mainstream setting who are not able to converse effectively with them. The ability to participate in science discussions in either BSL or spoken English, the use of appropriate BSL and the clarity in translations and explanations and difficulties with science literacy can create barriers.

Issues in deaf students' science learning identified from literature ranged from difficulties in metacognition such as in processing and recall, having limited incidental exposure to science information, difficulties in understanding science vocabulary and concepts, having a language and vocabulary delay and making the link to their everyday lives, as well as the challenges in language and communication used in the science classroom.

Challenges

From the observations and interviews, the common challenges for deaf students' science learning were identified as:

- *Insufficient visual resources* – in mainstream classes to support understanding.
- *Pace* – the fast pace used in secondary mainstream classes, and the pressure to keep up means that deaf students tend to struggle to grasp the concept, and having to divert their attention between the visual resource, text and input could affect their conceptual understanding of a topic.
- *Timing of science practicals* – in mainstream classes the practical tends to be introduced much later after a discussion about the theory and the information has to be repeated for the deaf students during the practical to give context.
- *Focus* – deaf students' ability to focus over a long period of time, and their tendency to become easily distracted.
- *Peer discussions* – it can be challenging to encourage deaf students to participate in peer discussions and contribute their ideas linked to a science topic.
- *Communication* – variability of the communication method and fluency of BSL used to explain scientific terminology to deaf students, and the lack of a standardised BSL science sign to use. The need to allow time for deaf students to take in new information in multi-modal ways and for repetition.

▶ *Continued at base of next page*

Better outcomes and better plans

Ian Noon provides an update on the National Sensory Impairment Partnership's work to support professionals in developing good Education, Health and Care plans

It is now nearly a year since the Children and Families Act 2014 came into force, beginning the formal process of converting statements of special educational needs (SEN) into Education, Health and Care (EHC) plans. This remains an ongoing process, with local authorities having until April 2018 to convert all remaining statements. This article highlights the support available to services in this area, some of the challenges that local authorities have been facing in creating EHC plans and the next steps for the National Sensory Impairment Partnership (NatSIP).

Resources

The NatSIP resource *Better Assessments, Better Plans, Better Outcomes* provides a multi-disciplinary framework for EHC needs assessments. It seeks to help answer the questions: What information do we need about a deaf child or young person to ensure that:

- plans for education, health and care support are based on a full and thorough assessment and understanding of that person's needs and their implications?
- any barriers to their development and achievement are identified and measures, regularly monitored and reviewed, are put in place to address them?

Accompanying the resource is a proforma to support professionals in information gathering.

NatSIP has also developed a series of model exemplar EHC plans to illustrate what we see as the good features of a plan. Three of the exemplar plans – 'Kirsty', 'Robert' and 'Ruby' – are based on actual cases involving deaf children (names have been changed).

Setting good outcomes

One aspect of EHC plans that some areas seem to be struggling with is around setting outcomes and the difference between outcomes, steps and targets.

The SEN and Disability Code of Practice (paragraph 9.66) offers the following definition of an outcome:

"An outcome can be defined as the benefit or difference made to an individual as a result of an intervention.

▶ Continued opposite

▶ Scientific concepts – continued from bottom of previous page

- *Writing activities* – it can be very challenging to encourage deaf students to write about topics linked to science in detail in their own words.

Teaching Approaches

From the literature, effective teaching approaches used in science classes were identified, such as teaching explicitly and directly in the students' first language, introducing new vocabulary via the multimodal method of 'chaining' (Spencer and Marschark 2010), in which a word is introduced using all modes, by giving the BSL sign then fingerspelling it, accompanied by the spoken word and writing it down. The use of scaffolding of a topic, using visual prompts and activities to give a 'richer' context along with concept maps, and writing activities with frequent reinforcement and recapping of scientific vocabulary and concepts were also identified as being effective.

Another aspect of deaf students' science education identified was the importance of the teacher's knowledge of science and ability to communicate effectively with the deaf students directly.

Conclusions

Although there was little research found on the topic of deaf students' science learning, scientific conceptual understanding and scientific vocabulary development, this small scale study found many similarities in the approaches identified (Table 1 and Table 2) with those in the literature. However, this is an area that needs more in-depth research as science is a core subject.

To enable deaf students to have meaningful access to science learning which meets their diverse language, communication and cognitive needs the approaches identified in Tables 1 and 2 need to be proactively considered and incorporated into the science classroom containing deaf students using a combination of visual hands-on resources and engaging discussions and explanations at an appropriate pace. Guidelines could be created collaboratively in-house recommending strategies to use when deaf children are part of mainstream science classes. However, in practice this may not be always possible due to time constraints, curriculum pressures and staffing issues.

Jenny Wilkins is a deaf Teacher of the Deaf working in a Deaf Resource Base in a mainstream secondary school. This research was part of her MA in Deaf Education (Teacher of the Deaf Qualification) at the University of Leeds.

Reference

Spencer PE and Marschark M (2010). Evidence-Based Practice in Educating Deaf and Hard-of-Hearing Students. New York: Oxford University Press.

It should be personal and not expressed from a service perspective; it should be something that those involved have control and influence over, and while it does not always have to be formal or accredited, it should be specific, measurable, achievable, realistic and time bound" (SMART).

It is important to remember that outcomes are not a description of the service being provided – for example, the provision of weekly support from a Teacher of the Deaf is not an outcome. In this case, the outcome is what the Teacher of the Deaf intends to do to help the individual achieve what they cannot achieve presently and determine when this will be accomplished.

To develop outcomes, it will be important to consider and list

- the **aspirations** of the pupil and those of their parents
- the challenges for the pupil identified from a thorough **assessment**.

Together, these will provide the areas of focus, which can then be turned into SMART outcomes.

- The **shorter term steps** and **targets** to achieve those outcomes.
- The **provision** and **adjustments** required to achieve the outcomes.

For example
Jack is in Year 7 with a severe hearing impairment:

- ***Aspiration****: Jack wants to get a good job and parents want him to achieve his potential.*
- ***Assessments*** *indicate Jack is two years behind the average for his peers in English and maths, but has above average non-verbal ability.*

A sensible outcome for Jack might therefore be:
By the end of year 11, Jack will gain the necessary qualifications to go on to his chosen post-16 destination.

An example of a step towards achieving this outcome could be:
He will make measurable year-on-year accelerated progress in English and Maths so that he will be working at the level appropriate for his ability by the end of year 9.

The detailed short term teaching targets (e.g. work on parts of speech in English or percentages in Maths) would be set by the relevant teachers based on the assessment.

The model exemplar EHC plans developed by NatSIP include more examples of how steps towards meeting outcomes, and the special educational provision needed to achieve this, can be set out.

Outcomes being set will always be individual to a child or young person. However, we know that many deaf children will experience challenges around the development of language, communication, literacy, confidence and social skills, and so any outcomes and support strategies should address those needs.

Though developing EHC plans often falls to SEN officers, Teachers of the Deaf obviously have a clear role to play throughout the process by interrogating achievement data, completing specialised assessments and providing for and supporting technology needs. They will also discuss with SEN officers any concerns over the outcomes set as well as advise on appropriate support strategies.

Another key role for the Teacher of the Deaf is monitoring and reviewing the progress made by a deaf child. Being clear in the EHC plan on steps, targets and outcomes can support the review process. If the expected progress is not being made, a clear plan will make it easier to identify why that might be and outline the alternative steps that might be taken to address this.

What next?

NatSIP will be continuing its work in this area, as part of its new grant with the Department for Education. NatSIP plans to:

- review a sample of EHC plans to identify areas where new guidance is most needed
- build on the *Better Assessments* resource by providing advice on how information gathered should be used to write an effective EHC plan
- develop a resource for audiologists on contributing to EHC plans.

Can you help? We are looking for examples of EHC plans to review that can be shared with us in confidence. Examples can be anonymised before being given to us. We are also keen to hear from Teachers of the Deaf on their own experiences of their involvement in developing EHC plans and any issues they have encountered.

Contact us at ndcsprofessionals@ndcs.org.uk if you are able to help.

All of the above NatSIP resources are available to download from their website at:
www.natsip.org.uk/index.php/send-reforms/ehc-plans

The National Deaf Children's Society has also developed a factsheet for parents on EHC needs assessments and plans, which can be downloaded from their website via www.ndcs.org.uk/sen or ordered from the NDCS Freephone Helpline at 0808 800 8880 or email helpline@ndcs.org.uk

Ian Noon is the Head of Policy and Research at the National Deaf Children's Society and coordinator for NatSIP workstreams on assessments improving outcomes. He is a member of the NatSIP Project Board and planning team for the annual HoSS conference.

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Developing Theory of Mind

Keith Poole describes interventions to develop secondary-aged deaf children's theory of mind

There are many strategies and interventions used by our school to improve pupil progress and access to the curriculum. Two of the most effective have been thinking skills (Leading in Learning) and daily language and listening lessons, which test collaborative work and metacognition, and give a different perspective of pupils' abilities beyond the curriculum. Evaluations of these lessons have highlighted that many of our pupils struggle to have an understanding of their own needs and the needs of others. The same pupils often have problems with friendships and the increasingly complex and ubiquitous world of social media.

This ability to understand the thoughts and motivations of others is called theory of mind. Most children develop some form of theory of mind by the age of four or five; however, in children with autism, attention deficit or non-verbal learning disorders this can be delayed or not develop at all. Studies have also shown that many deaf children have a delay in developing theory of mind. They are able to identify the emotions of others from facial expressions, but find it difficult to predict the possible causes of these feelings.

A working group was set up to assess if any of our pupils had delays in this area, using three tests adapted from Kristina Ordetx's 'Teaching Theory of Mind'. The first two tests used picture cards, one set showing just facial expressions and the other more complex situations often with a number of environmental cues. Most pupils were able to identify emotions; however, they struggled to predict causes from the situation cards. For example, pupils were shown a picture of a girl looking angrily at a woman with both of them standing in a teenager's bedroom. Many were able to comment on the girl's emotion, but only some could speculate on why she was upset.

The final test was the first and second order false belief tasks. The first order false belief task tests the ability to understand that others have incorrect ideas based on incomplete or inaccurate information. In order to reduce the language content we decided to act this out instead of presenting it just as a text. For the first order false belief task a teacher was asked to leave the room. Pupils were shown a crayon box containing batteries. After the box was sealed, the teacher returned to the room and asked what was in the box. Pupils had to guess what the teacher would say.

In contrast, the second order task tests the understanding that people have incorrect beliefs about the beliefs of others. Most children reach this stage between six to eight years old. The story acted out involved a mother secretly buying an iPad for her son's birthday, but telling him that he would be getting a book. The son then finds the iPad without his mother knowing. Pupils were asked what the mother believes that her

son thinks he is getting for his birthday. Clearly, this can be quite confusing and benefited from staff acting out this scenario.

Results showed that eleven out of sixteen pupils failed second order false belief tasks, with seven of these pupils also failing both tasks. Although there were some exceptions, the picture card results matched those from the false belief tasks. Other tests showed that many of these pupils also had lower than average non-verbal intelligence, and delays in reading and language.

Language is a key factor in the development of theory of mind; more specifically, early exposure to language related to emotions and other mental states. Encouraging metacognitive discussion of different perspectives with peers and adults is one proven way of helping children achieve theory of mind. Therefore our working group decided to focus on the pupils failing the false belief tasks to see if we could influence the development of theory of mind.

Pupils were given two lessons a week over a term. In the first six weeks they worked on demonstrating, identifying and linking emotions and thoughts of other people through discussions. Pupils then produced a feelings scrapbook, taking photographs of themselves and others in the school. In another activity, small groups were asked to act out photographs of situations. This proved very successful and many groups showed very imaginative interpretations of the situation cards.

The second six weeks involved a simplified version of Lego Therapy. Lego Therapy is a barrier game where one pupil has to give instructions (the architect) to another (the builder) in order for them to construct a Lego model. The builder cannot see the instructions and the architect cannot touch the Lego bricks. After each model has been built the pupils swap roles. The role of the teacher is to suggest that a problem exists and help pupils find a solution.

These activities have been shown to develop reasoning, social communication, listening and language skills, and potentially theory of mind. The key to progress in Lego Therapy is self-evaluation and problem solving. Pupils were asked to do this at the end of every lesson, either in their pairs or as a class. We filmed small clips of them working together and showed it to the class at the beginning of the next lesson. Through assessing their own pair work and the work of others, most pupils were able to set themselves targets and became faster at giving and receiving instructions.

Pupils were very engaged and enthusiastic about this activity throughout. Another benefit of using Lego was its versatility. Once we understood the constraints of the lesson, staff were able to devise their own models and instructions by taking a series of pictures with iPads. Pupils who mastered several models were also able to produce their own versions.

At the end of the twelve weeks the pupils were retested. Five out of seven passed the first order false belief task (with one pupil also passing the second order false belief task) and two pupils made significant progress in the feelings and thoughts picture card tests.

Results and observations suggested that these interventions were effective over a short period of time; therefore it was decided to extend Lego Therapy to include more complex models and a greater level of challenge. Year 7 pupils have started to study facial expressions and inferencing situations from photographs. Other ideas we are beginning to explore include games that involve some form of deception and magic tricks, which require the performer to have an understanding of the audience's perspective. Working on the magic tricks has been a real challenge for most of the pupils as they require a number of different cognitive processes to run concurrently.

To reflect the changes in the new Code of Practice, the work will be adapted to address the social, emotional and mental health needs of the pupils, as well as issues with e-safety. Teachers will also begin to evaluate whether these activities are having any impact on the pupils' academic progress.

Keith Poole is the Additional Needs Coordinator and humanities teacher at Knightsfield School in Welwyn Garden City in Hertfordshire.

Cued Speech – research and evidence 40 years on

Anne Worsfold reports on how Cued Speech has developed over four decades to help children with hearing loss understand spoken language more easily

In 2016 Cued Speech (CS) celebrates its 40 year anniversary with a conference in America which will be attended by academics and researchers from around the world. In the past 39 years a wide range of evidence has grown which demonstrates its effectiveness and yet there's still confusion in the minds of many people in the UK as to what exactly CS is. The name 'Cued Speech' probably doesn't help matters. Many people believe that the French name Langage Parlé Complété (LPC) or 'completed spoken language' paints a clearer picture and has helped to bring about the situation where every deaf child is offered the option of visual access to French through LPC.

CS is a visual version of the spoken **language** in which it is used. Why then, the name Cued Speech? For hearing children the speech of parents/carers is both how they develop language and the first expression of language. For deaf children, CS does the job of speech; it is your speech made visible. When you use the eight handshapes and four positions which are the 'cues' of CS, you turn the 44 phonemes of your speech into visible units which can, like sounds, be combined into words, sentences and, as a result, full language. Just as hearing children learn a full language through listening to speech, so deaf children can learn a full language through watching speech which is 'cued'.

International research

There is now a wide range of international research on CS. The essential findings (with space constraints forcing me to reference just a few of the scores of relevant papers) are:

- **Understanding English** – Without CS, about 35% of what is said can be lip-read; with CS this rises to 96%[1] making it easy for deaf children to learn and understand English. New research tells us that CS is not lip-reading with an additional cue; the cue is received first, disambiguating the following lip-pattern.[2]
- **Access to early language** – Babies and children can absorb their family's spoken language without delay[3], just as hearing children do. Cued Speech is 'just' the English language so once the system has been learnt parents and teachers can make the whole of the English language fully visible.
- **Second generation cuers** – (deaf children of deaf parents brought up with CS) are reaching the same linguistic milestones in English as hearing children of hearing parents.[4]
- **Belonging and self-esteem** – an American study of 32 adults who grew up with Cued Speech found 'high levels of self-esteem and self-confidence, which they credit to their parents' choice of Cued Speech, their early childhood experiences of feeling included in family activities and conversations and in peer groups, and positive feelings of competence and success in school'.[5]
- **Literacy** – international research demonstrates that deaf children brought up with CS achieve reading scores equivalent to hearing children[6 & 7]and that cueing deaf children acquire phonological abilities better than non-cueing deaf children and comparable to hearing peers[8]. A recent English case study looking at the perception of phonemes in regular non-words found 50% accuracy in spelling non-words (e.g. 'drump') when listening and lip-reading, and 100% accuracy once CS was added.[9]
- **Speech production** – speech intelligibility was better in CS-using implanted children than non-CS-using[10].
- **Cued Speech is inclusive** – it helps deaf children get the best from their hearing aids and cochlear implants[11]. On the other hand, whilst CS was intended by its inventor to be accompanied by an audible spoken message, CS gives full access in the absence of any hearing[12] and works well when used bilingually with a signed language.

Additional points:

- CS is used by professionals around the world to give deaf children full access at school, college and university; France and the USA lead the way in qualifications (degree level in France) for Cued Speech Transliterators.
- Most deaf children who learn language through CS communicate with speech (although their diction may be poor, especially in the early years). All deaf children who learn English through CS, regardless of how they communicate, are able to reap the benefits that full understanding of English will bring.
- CS has been adapted into 63 different languages and dialects, so can be used in the home by families for whom English is a second language and to give access to modern foreign languages.

For busy Teachers of the Deaf who are looking for more general evidence about CS use, I would recommend four additional sources of information:

1. For a quick summary, go to the Cued Speech Association UK website www.cuedspeech.co.uk 'research' section or for personal accounts of CS use look at our 'cuetube' section.

2. For a comprehensive overview obtain the book 'Cued Speech and Cued Language for Deaf and Hard of

Hearing Children' (2010). This edited volume draws on the years of international research to demonstrate the effectiveness of CS and shows that the uses of CS and understanding of it have evolved over time. The six sections look at the background and linguistics of cueing; describe the effectiveness of the system for: (a) phonological perception, (b) natural language acquisition, (c) the development of reading, and (d) atypical populations, and finally report on technological initiatives.

For practitioners with limited time I especially recommend the chapter(s) on:

- literacy (chapters 11- 14)
- early language development of deaf twins of deaf parents who are native cuers of English (chapter 8)
- the Minnesota bilingual programme (chapter 10) which reports 95% of pupils making one year's progress in English in one year of time
- Auditory Neuropathy/Auditory Dys-synchrony (chapter 15) by American AN/AD specialist Dr Charles Berlin, Research Professor, University of South Florida.

3. New this year is an invited paper in the American Annals of the Deaf (Volume 159, Number 5, Winter 2015 pp. 447-467): *Reading for Deaf and Hearing Readers: Qualitatively and/or Quantitatively Similar or Different? A Nature versus Nurture Issue* by Carol J Lasasso and Kelly L Crain. The authors quote from a wide range of research to back up their assertion that: 'In our view, the child's hearing status (deaf, hearing) is less important in learning to read than are environmental factors, including: 1) the richness of the child's early linguistic environment leading to an age-appropriate L1 prior to formal reading instruction, and 2) clear, complete visual access to the instructional language (eg English, Spanish, ASL) used to deliver the school curriculum via conventional or English Language Learner (ELL) methods.' 'Of the available communication systems to convey English conversationally (oral-aural methods, MCE sign systems, Cued Speech), only Cued Speech is structurally capable of affording clear, complete visual access to English.'

4. Also new in 2015 is a revised edition of the *Oxford Handbook of Deaf Studies in Language*, edited by M. Marschark & P. Spencer (Oxford University Press), with an additional chapter by Jacqueline Leybaert, Clémence Bayard, Cécile Colin (ULB) and Carol LaSasso (Gallaudet University) on: *'Cued Speech and Cochlear Implants – a powerful combination for natural spoken language acquisition and the development of reading.'* The authors say that in the chapter: 'we review the available literature showing that CS enhances speech perception in CI children, and it also favors the appropriate development of the three R's (reading, rhyming, and remembering).'

Nationally there is increased focus on deaf children's outcomes and, as the research demonstrates, CS will deliver access to English and greatly improved literacy. Also the new SEN Code of Practice ('From birth to two – early identification' para 5.16) says that parents of some SEN children, including deaf children, must receive support, which may include 'training for parents in using early learning programmes to promote play, communication and language development'. CS is a very effective **and** cost effective way of providing that support. See our charity's Local Offer page on our website for an overview of how we can help parents and teachers, or give us a call to chat about options, or the practical use of CS.

Anne Worsfold is the Executive Director of Cued Speech Association UK.

www.cuedspeech.co.uk ☎ 01803 83 27 84

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Audiology updates

This page features innovations and discussions of what is happening in real-world educational audiology and gives readers the opportunity to highlight issues that they encounter in the workplace

Update:
Following the BATOD South spring event many delegates said they enjoyed being able to take time to discuss and explore issues with the various workshop leaders. Pupils may be issued with equipment with little information passed on to a Teacher of the Deaf about additional optional programmes, why particular settings have been selected or intended outcomes, while soundfield systems, induction loops and a range of IT equipment may be installed during school holidays. Yet the ToD will be the first port of call for colleagues, children and families seeking advice on usage, problems or compatibility.

It is clear from both this event and the BTEC Audiology Technicians' course that sitting down with manufacturers, suppliers and clinicians is invaluable for all concerned; yet is rarely pursued outside of occasional formal training sessions.

Manufacturers want to know that their products are being used and working optimally, so welcome queries and observations from those in the field. A phone call, email or site visit can allow issues to be identified and addressed and for trends to be identified. Exploring their websites can provide opportunities to improve product knowledge and gain training.

Similarly, developing relationships with clinicians benefits everyone. Some clinical staff are reluctant to provide detailed information to schools because they believe it wouldn't be understood, while ToDs feel that clinicians don't appreciate the issues everyday listening conditions present. Face-to-face discussions can identify the type of information both parties need to share for children and families to receive optimal support.

Keeping up to date is not an optional extra to be squeezed into rare free moments – it's the job. So build up your database, get to know your local reps and make sure your senior managers recognise the value of your attending clinics and Children's Hearing Services Working Groups.

A reader asked:

- A child with hearing aids with full earmoulds has recurring bouts of glue ear and there's some debate amongst our team as to whether he will be able to have grommets. Are there any special precautions or routines that need to be observed if the surgery goes ahead? Are there any risks?

You say:

- There should be no problem at all. If anything, he may be more comfortable not having the pressure of glue ear. The only problem is if he gets an infection, but parents will be told what to look out for post-operatively.
- If the hearing aids were adjusted to account for glue ear adding to hearing loss they need to be re-adjusted so they are not over-amplifying.

The experts* say:
Whether to proceed with grommets will always be an ENT surgical decision; other options may be considered such as prescribing long-term antibiotics to try and eliminate the infection and stop it recurring. For children with permanent childhood hearing impairment additional factors need to be considered, including possible further detriment to language, literacy and learning potential; difficulty in managing appropriate amplification when hearing levels fluctuate over time; feedback being aggravated due to stiffening of the tympanic membrane, and potential longer-term damage.

Ask for advice from the ENT team (possibly through the family). Some hearing aid wearers experience no difficulties; for others, the presence of the earmould – preventing natural ventilation in the ear canal – seems to provoke infections around the site of the grommet and can lead to increased use of antibiotics and decreased use of hearing aids until the infection clears. Close monitoring of the ear canal for any signs (smell/discharge) of infection is important, along with regular monitoring of the outer and middle ear by medical professionals and/or audiologists; obviously, hygiene routines in school and at home need to be as rigorous as possible.

There are some strategies worth considering to keep the ear 'open' and reduce the risk of problems:

1) would a soft band BCHI be an option?
2) could the earmould be vented?
3) sterilising the earmould, particularly while the ear is infected
4) providing two sets of earmoulds so they can be cleaned and swapped
5) regular re-tubing so infections are not re-introduced
6) not wearing the earmould if the ear is weeping
7) having periods of time without the aid to allow the ear to breathe.

A reader asks:
Do resource bases normally purchase and issue consumables such as batteries, tubing etc or would you expect these to be provided by families?

If you can suggest a solution, or would like to pose a question for our readers and experts, please contact Stevie Mayhook: steviem@ewing-foundation.org.uk

* Information provided by members of the Ewing Foundation: www.ewing-foundation.org.uk in consultation with Educational Audiologists.

ICT news and Down's Syndrome

Louie Ruck interviews the mother of a child with Down's Syndrome and the struggle she has had to access the right technology for her daughter

For this issue I have taken the opportunity to help a friend raise awareness about an issue very dear to her, and now to me – the technological and human support available for children with Down's Syndrome and their families. So I conducted an interview with her (over a coffee and a general mummy-mummy catch-up) and asked her what her experiences have been and if she can offer any words of advice to other parents of children with Down's Syndrome or, dare I say, any faux pas that we as professionals should absolutely avoid! She (we'll call her Ruby and her daughter Clara for the sake of anonymity) had an awful lot to say, most of which I think you'll agree is eye-opening and something our profession should be taking serious note of.

So, tell me about Clara's diagnosis. How and when did you find out that she has a hearing loss?

"It wasn't that early on – it wasn't part of the new Newborn Screening Programme, but was picked up as part of a routine check-up and hearing test when she was about nine months old. This apparently is quite a normal procedure for babies with DS, because it's quite common. So they just said to us 'Yep, she has a moderate hearing loss'. At that point I didn't really understand what that meant. So I had to go away and look this up myself. I've since found out that it's due to differences in their ear structures – the Eustachian tube is often smaller and at a slightly shallower inclination, making it more susceptible to blockages. This then, coupled with the fact that people with Down's Syndrome produce thicker mucus, often results in their conductive hearing loss lasting a lot longer than normal. I think really, it was kind of expected."

I know that you've had a real fight to get Clara her softband; so why was there a delay?

"Well, this is the ridiculous thing. If you had an otherwise typically developing child and they were identified with glue ear and had a speech delay, the guidelines (issued by NICE) say 'wait and see'. But with children with Down's Syndrome, that's so wrong! Research indicates that if children with Down's Syndrome develop a speech delay, unlike the majority of 'typically developing children', our children's speech will not catch up later. They continue to have a delay. So, they need aiding immediately to prevent that delay developing in the first place. But this is not what NICE says. I had to do hours, and I mean hours, of research from the Down's Syndrome Association and NDCS to build an argument to get her the softband. I ended up saying "Give Clara a hearing aid, now!". And, to be really fair, they did. They listened to what I had to say, and what I had found, and they did as I (quite firmly) requested. I was the first parent to get a softband for a child with DS at our clinic. But the point is, I shouldn't have to do that. I shouldn't have to do the research and pass it to the professionals – they should be keeping up with current research themselves. What's more, the articles and papers I found are not hard to find. The biggest piece of information for us was an article in an NDCS publication [Down's Syndrome and Childhood Deafness, 2011] that clearly stated that in the case of Down's syndrome, the 'wait and see' policy is not recommended."

So your clinic decided on the conduction hearing aid (softband) for her, but they've only given her one. She has a bilateral loss, so what was their reason for only unilaterally aiding?

"They told me that firstly it was down to cost, but also that with a conductive hearing aid she only needed it on one side because the ear on the other side will pick up the signal. I didn't agree with that and some of the research I did previously supported that. I am worried that she needs to be aided on both sides so that she can hear from both sides. This is a basic safety need; I mean think of crossing the road. So we've agreed now that she can have a second one when she starts walking – that hopefully won't be too long."

What other technology have you been advised about to support her development?
"None really from the professionals, but I've found a lot out myself. What I have found is that the ICT toys are great for stimulation. Clara is stimulated much more through a multisensory approach because she has a condition called SPD (Sensory Processing Disorder), so lights, colours, textures, temperatures and noise are a great stimulus for her. But making sure she can access these is really important – especially sound. I really want her to be able to speak. The thought of her not being aural terrifies me. I want her to be able to listen to what's going on around her."

Are you aware of the NDCS test-drive service?
"Nope."

It's a really useful service (although there's a waiting list) that allows you to borrow equipment before you decide to buy. Thinking about Clara's age, she'll be potty training soon, so things like a bed wetting alarm are supposed to be quite good. They've got a list of things you can borrow on their site, it's worth a look.

What about the future, do you think her hearing loss is permanent? If so, do you think you'll consider a bone conduction implant?
"We're hoping that actually her loss isn't permanent, in which case we'll just stick with the soft band. But if it's not, I'd like to get her the magnet one – I just don't like the idea of something sticking out of your head!"

That's understandable. The newer processors also offer lots of features now such as TV streaming, blue tooth to your mobile etc. Of course that's a long way off at the moment! But wireless streaming might be really useful as she starts school – that will allow her to hear her teacher's voice more clearly – or whoever is holding the microphone, so a friend maybe.
"You see, it's things like this that we just aren't aware of. But it takes such a long time to find all this information, but also to register it – to understand it. We, as parents need help with all this. We need services to be giving us information for things that are going to present themselves as possible issues soon, not now, as they are happening. You see to get this equipment can be really complicated and time consuming, and expensive. We need to know in advance what we're likely to need, not when we need it."

So would you say that there is a lot of technology out there to help?
"Probably! But I'm just not that aware of it yet – I wish I was!"

What has been your biggest barrier to getting the help you need?
"Well I know you mean in terms of tech, but actually this is more important – this is what we've found. We would just like Clara to be considered as any other child, and receive care appropriate to her needs. What really hurts me and hurts us as a family is the continued questioning about whether I had the amniocentesis or not. The fact that people even need to ask me that is insulting – especially when it has absolutely nothing to do with the conversation. One consultant (not an audiologist) even said to me "Well next time, we'll get you tested nice and early because, you know, as lovely as Clara is, we wouldn't want another one". I left that appointment in tears. She didn't understand the significance of what she'd just said. I've since told her. But the thing is it leaves you wondering why Clara hasn't always received all the things she needs. We're given excuses about funds and stuff, but when you're constantly told that 'she could have been avoided', you begin to wonder if eugenics really is at work, if culturally, our society is actually trying to get rid of people with Down's Syndrome, and if she is being discriminated against. I'd like to think not, but these sorts of comments are so common among the medical professionals, and I mean to my face, it really knocks your confidence in them. Even terms such as 'Down's children' are highly offensive! She is a child – she happens to have Down's Syndrome – she isn't defined by her condition! Professionals need to be so much more careful about how they explain themselves and their thoughts, as so often they just don't think about how it's being interpreted by the people to whom they're speaking."

That's awful. What's the biggest piece of advice you could give to parents of children with disabilities and hearing loss?
"Read. Read, and read more. Understand what it is you want, and then go talk to the professionals with all your evidence there to give them. They do their job because they care, but they're still human, and they have faults. Be prepared to fight for what you want, fight for your child's right to hear."

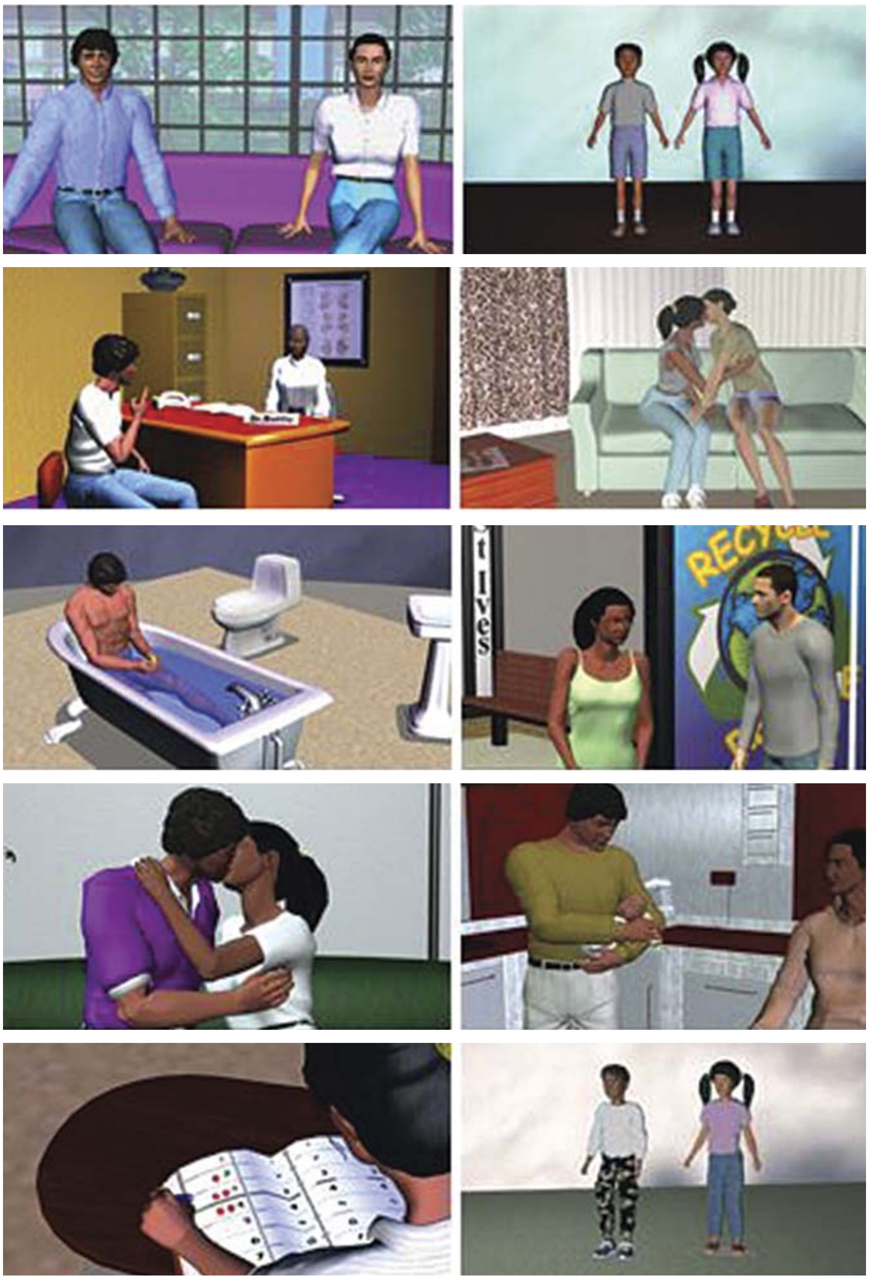
Reviews

Tell it like it is!

DVD	Life Support Productions
ISBN	978-0-9551735-7-8
Reviewer	Corinda M. Carnelley, Teacher of the Deaf, London Borough of Croydon

Before I trained as a ToD, I spent a term working in a school for the deaf. As the newbie, I was given several unenviable tasks, one of which was to teach sex education to the fifth form. My teaching resources comprised a large blob of blu-tack (to represent an ovary) and two balloons (no, really, it's true!)

I wish I had been offered a copy of this DVD!



The DVD is divided into five chapters; Growing up; Looking after yourself; Sex; Pregnancy; and Help and Advice. Each chapter is sub-divided further with the smaller sections lasting around three or four minutes. It's presented by two rather androgynous, cartoon-type characters, which actually made the 'naked' scenes much more bearable – much less squeamish. The only disadvantage of this is that there is no lip reading possible. The characters' mouths move, but not in any identifiable way.

The DVD is quite clear about what is and is not acceptable behaviour and re-iterates several times that this is what will happen, this is what is normal, this is private etc. and suggests talking to a teacher, parent, carer or doctor if the young person is unhappy about anything. It also offers clear guidelines about saying, 'No' and that it's OK to say 'No' in many circumstances. 'Your body is yours' is the over-riding message.

There are several helpful inclusions such as a wide range of 'slang' for different body parts; homosexual and lesbian relationships, contraception – although only condoms are mentioned; caesarean sections, and breastfeeding. There is also a very clear message about sex being illegal under the age of 16. The actual mechanics of the sexual act are included on the section on pregnancy – which may confuse initially.

This DVD would be helpful to use with junior aged children, or the lower end of secondary school. It uses accessible language, and provides clear subtitles, but is not signed.

I occasionally wonder if my ill-conceived (no pun intended) attempts to teach a group of teenage boys about sex and relationships was successful – or whether they all went on to have large, unplanned families. This DVD would have helped me to be more sure that they knew and understood the consequences of what I was trying to teach them, and were aware that there are choices to be made, both by them and by their partners.


Redcat Access
lightspeed

What went on at NEC

Sandy Goler reports from the NEC meeting in London on 13th June

Usually the June NEC meeting is on one of the hottest days of the year – fortunately not so this year. Several delegates were delayed because of transport difficulties, but the meeting started only a little late with Stuart Whyte as President Elect initially taking the chair. All were warmly welcomed, especially new members Helen Cooper and Teresa Quail.

The meeting split into three groups to discuss and then feed back on:

- Conference 2016. This has the working title 'Working with Technology' and will be in Cardiff on March 12th. Topics for workshops were decided – look out for further information on the website.
- CPD. The group has started work on reinstating the BATOD CPD log. The work will be at two levels:
  - strategic – having the necessity for CPD recognised as essential by authorities
  - practical – that a log should be useful and manageable.

This work will be continued at future meetings.

- Sharing good practice. After some discussion, this working group suggested opening a Facebook page where ToDs could share good practice by posting links to sites and networking. The idea will be discussed further at Steering Group.

The meeting continued with a discussion of the main problems and concerns delegates are finding at work. The main issues raised were:

- staff not being replaced and the cumulative effect on the workload of others
- the effects of repeated restructuring
- lack of or poor service level agreements and no set staffing quotas
- demoralised workforce
- recruitment difficulties – getting qualified ToDs, CSWs, use of agency staff
- pupils with CIs having to wait longer for upgrades, spares not being left with schools and families having to buy non-essential items
- EHC Plans – either not appearing at all or not being specific enough. Yr 11 in particular are likely to be losing funding without appropriate plans. There is a schedule of transfers which should be followed and staff working with more than one LA felt a common EHCP form would be useful
- influx of populations with hereditary hearing loss leading to large numbers of deaf children in particular in mainstream schools resulting in staffing issues. It was made clear that children with a disability do not have to wait 3 months before accessing services – there should be immediate support through a Section 17 assessment
- only children with statements being seen – thus ruling out many pre-school children
- the position of deaf children and staff in Academies including:
  - deaf children are being supported by Graduate Coaches with little or no training
  - staff being withdrawn to work in other areas.

If you are having any problems in these or other areas, please contact the BATOD Consultant – it would be helpful to build up a national picture.

A lengthy discussion on the position of Academies followed. There are concerns over:

- the effect of central budgets reducing – though the High Needs Block should not be reduced
- how services are commissioned.

The business section of the agenda included:

- the Action Sheet – most items were completed, though some, such as putting new resources on the website, are ongoing.
- reports from Officers:
  - The National Executive Officer reported on an international meeting in Romania and the important role BATOD has in spreading information to countries where there has been less progress in the education of deaf children.
  - The Treasurer reported that funds are much healthier than they have been, though there is no room for complacency. The next budget will be set at the Steering Group in September.
  - The Consultant reported that there has been a change in criteria for access to work funding which has caused problems. There has been an appeal which should have resolved this. If payments are often late being made, deaf staff should do the claims themselves. It was also pointed out that there is a new NatSIP eligibility framework which can be a useful tool in helping ToDs to argue staffing levels.

Reports from Regions and Nations followed. Most areas are holding successful day or twilight sessions which are increasingly well attended. There are, however, many concerns about restructuring and budget cuts.

After an informative and worthwhile day, the meeting closed just after 5.00pm. The next NEC will be in Birmingham in September.

Why not follow us on Twitter?
@BATOD_UK

BATOD South event

Debbie Staneva and other members of the committee write about a recent BATOD South event

Earlier in the year, in an effort to galvanise the membership, the BATOD South committee sent out an online survey to ascertain their needs and interests. From this we devised a half-day INSET entitled ‘Accessing Audiology in Action’. To encourage larger attendance we charged a flat rate of £5 and switched the timing from twilight to afternoon.

There was an encouraging turnout of 17 delegates and seven committee members. They rotated in small groups around the four workstations in the carousel. These stations were facilitated by:

- Jolanda Scourfield from St George’s Audiology Department who discussed the importance of sharing information between clinicians and Teachers of the Deaf
- Richard Vaughan from Connevans who shared information on technology to enhance the listening experience
- Andy Taylor from FrontRow who demonstrated the Juno Soundfield System and its various features
- Adam Chell from Phonak who offered information and advice on the Roger System.

The consensus was that the content was relevant to their work, the atmosphere was positive and the event provided good value for money. The views of the presenters were also sought and their feedback was again positive. The Committee had provided sufficient information prior to the event for them to prepare their presentation, they were able to share good practice, discuss issues of interest to the delegates and they felt valued. They were able to meet with potential customers!

The atmosphere during the event was vibrant; everyone was able to acquire something by the end of the event that they could take away with them to their workplace.

Debbie Staneva is BATOD South Membership Secretary and a ToD at Willow Hearing Support Centre, Sellincourt Primary School.

This and that...

Email news to this-n-that@batod.org.uk

Connevans 2015 Catalogue

Connevans has published its latest catalogue with 260 pages of equipment and solutions to help people who are deaf or hard of hearing.

The re-designed catalogue has a fresh new look and clearly defines solutions for **School & Education**, for **Home & Leisure** and for **Work & Business**.

The new Connevans **Swift Digital** with **SwiftConnect** SoundField system is included as well as the complete range of Phonak Roger equipment.

Full of technical information and helpful advice, the catalogue gives many situation-specific solutions and is great for both professionals and for giving out to families. If you haven't received your copy, just email info@connevans.com and they will send you one or many!

Like us on Facebook
British Association of Teachers of the Deaf

First Sight Media

First Sight Media is a professional production company capturing video in High Definition and streaming live interactive events over the internet and producing video for websites and social media. **iPresenter** offers synchronised video and PowerPoint, **First Sight Media's** solution for delivering online presentations creating the opportunity for tangible distance e-learning materials which are engaging, creative and interactive for students of all abilities.
For more information call **0800 072 8753** or visit www.firstsightmedia.co.uk

Correction and Clarification

The workshop at which Greenwich deaf children wrote 'What the Jackdaw Saw' with Julia Donaldson was not held by The Booktrust/Inclusive Minds, as stated in the last edition, but by Life & Deaf (www.lifeanddeaf.co.uk). The book is on sale in book shops and online. Please see gu.com/p/49vc2/stw for articles by Julia and a deaf author about the process.

Acronyms & abbreviations
Due to extra articles this issue, please see website for up-to-date listing of abbreviations.

BATOD was there representing you...

Between the NEC meetings, members of BATOD attend various meetings that are of particular interest to Teachers of the Deaf. This list is not exhaustive. Your representatives at the meetings listed included: Andrea Baker, David Couch, Sue Denny and Paul Simpson.

Date	External participants	Purpose of meeting	Venue
May			
13	FLSE	SEND Forum	Engine Rooms, London
18	HIPEN	Visit representing FEAPDA and BATOD	Romania
19	Communication Trust	Regular meeting	The Lift, Islington
22	DESF	Regular meeting	NDCS
June			
4	NatSIP	Working Day	Hamilton House, London
9	CRIDE	Survey meeting	NDCS, London
11	DCAL	Research conference	City University
16	Ofqual	Access Consultation Forum	Coventry
19	NatSIP	Project and reference groups	SENSE
22	NDCS	Liaison meeting	NDCS, London
30	NatSIP	HOSS conference	Birmingham
July			
5	ICED	International Congress on Deaf Education	Athens
8	FLSE	SEND Forum	Engine Rooms, London
16	NatSIP	Meeting about exam access arrangements publication	RNIB, Birmingham

Please inform the National Executive Officer, Paul Simpson, if you know of any meetings where you feel representation on behalf of Teachers of the Deaf would be of benefit. Although there is no guarantee that BATOD would be able to attend every meeting, situations could be monitored and the interests of ToDs represented.

BATOD membership

BATOD activities are funded from your membership fee and some advertising income.

Colleagues who share your Magazine and Journal also benefit from BATOD negotiations with government and other influential bodies – but they are not contributing!

Persuade your colleagues to join BATOD and you will receive 10% of their membership fee as an ‘introduction fee’.

Full details of membership plus membership form are available at
www.batod.org.uk ▸ The Association ▸ BATOD Membership

ToDs in training will be entitled to a £20 reduction in annual membership fee when the Course Tutor countersigns the membership application form for those paying by Direct Debit (applies for up to 2 years; payable at the end of the year).

The BATOD Membership Secretary may be contacted via **membership@batod.org.uk**
The BATOD Treasurer may be contacted via **treasurer@batod.org.uk**

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Articles, information and contributions for the **Association Magazine** should be sent to:

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Tel/fax: 0845 6435181 Email: magazine@batod.org.uk
...as should Association information and general queries.

Advertisements for the **Association Magazine** should be sent to:
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Meetings and training Calendar

This page is an extract from the Calendar to be found on the BATOD website. Please note that it is not exhaustive. Items noted on this Calendar may have been advertised within the Magazine or the information reported by telephone. BATOD is not necessarily the organising body.

Please contact the organising body (column 2) for details of conferences, not the Editor of this Magazine.

Date	Organisation	Meeting topic	Venue
September			
15	Phonak	Focus Day	Scotland
15	Seashell Trust and Sense	Learning and Interactions – a conference with Jan Van Dijk	Manchester
16	DCAL	Early communication and language development	DCAL (Deafness, Cognition and Language) Research Centre, University College London, 49 Gordon Square, London WC1H 0PD
16	NDCS	Workshops on assessing and monitoring the progress of deaf children and young people	NDCS office, Belfast
16	NDCS	Workshops on assessing and monitoring the progress of deaf children and young people	NDCS office, Belfast
19	BATOD NEC	Association Business	Birmingham
22	Phonak	Focus Day	Leeds
25	The Ear Foundation	Supporting people with cochlear implants for Communication Support Workers	The Ear Foundation, Nottingham, UK
29	The Ear Foundation	Babies & toddlers with cochlear implants: A sound start	The Ear Foundation, Nottingham, UK
30	Phonak	Focus Day	North West
October			
1	Phonak	Focus Day	Birmingham
6	Phonak	Focus Day	Bristol
7	NDCS	Workshops on assessing and monitoring the progress of deaf children and young people	Ear Foundation, Nottingham, UK
8	The Ear Foundation	Complex children with cochlear implants for Teaching Assistants	The Ear Foundation, Nottingham, UK
8	Phonak	Focus Day	London
9	The Ear Foundation	CMV: Cytomegalovirus	The Ear Foundation, Nottingham, UK
15	The Ear Foundation	Children with cochlear implants: Slow to progress	The Ear Foundation, Nottingham, UK
19	NDCS	Workshops on assessing and monitoring the progress of deaf children and young people	Action on Hearing Loss office, Cardiff
20	The Ear Foundation	Sound to words: The brilliance of babies in one year	Bristol Sensory Support Service, Elmfield House, Greystoke Avenue, Bristol. BS10 6AY
21	The Ear Foundation	Radio aids & wireless technology workshop: Understanding the potential & building confidence	The Ear Foundation, Nottingham, UK
21	DCAL	Later language development and Theory of Mind	DCAL Research Centre, London WC1H 0PD
21	The Ear Foundation	Radio aids & wireless technology workshop: Understanding the potential & building confidence	The Ear Foundation, Nottingham, UK
November			
4	NDCS	Workshops on assessing and monitoring the progress of deaf children and young people	NDCS office, London
4	The Ear Foundation	Developing listening & language through primary classroom routines	The Ear Foundation, Nottingham, UK
6	The Ear Foundation	Language development & goal setting the SMART way Day 1 of a two day course	The Ear Foundation, Nottingham, UK
7	BATOD Steering Group	Association Business	London

The Calendar on the BATOD website is edited as soon as we know about meetings.
Additional information about courses and registration forms may also be linked to the calendar entries.

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(Feedback from recent courses)

TRAINING IS OFFERED IN:

Audiology

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  - Pure Tone Audiometry and Tympanometry
  - Otoscopy and Impression taking for service users over age 5
- Non-certificated courses and refreshers
  - Audiometric procedures
  - Masking
  - Speech-in-noise testing

Language development:

- Assessment & target setting: including training in the use of specific language tests
- Analysis of speech & grammar
- Deafness and additional speech and language difficulties
- Speech acoustics

Educational issues:

- Successful inclusion strategies
- Curriculum differentiation
- Supporting children who are deaf and have complex needs
- Social and emotional development.

If your team is small, why not join up with another service for a joint day of training?

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COURSES

HAMILTON LODGE

School & College

Education and Care for Deaf Students from Primary to FE

OFSTED CARE REPORT 2015 –

GOOD WITH OUTSTANDING OUTCOMES FOR RESIDENTIAL PUPILS

“The care offered to young people is very supportive and nurturing.”

“The variety of activities in which residential pupils partake enables them to develop social skills, friendship groups and confidence. The school actively promotes the presence of the residential pupils in the wider community and this enables them to feel valued and not isolated. Examples of activities have included completion of Duke of Edinburgh Awards with pupils from mainstream schools and who are able to hear.”

“They benefit from having their needs met in an individualised manner which enables them to make significant progress. Being part of the residential group means that many of the residential pupils are not isolated and that they can enjoy meaningful and enjoyable relationships with their peers. ‘If I wasn’t here, I would be lonely, it’s my second home’ is a comment from a residential pupil.”

“Residential pupils have a number of activities available to them. These include activities arranged by the school as well as an opportunity to attend clubs and other interests delivered by other organisations, such as Brownies and Scouts. As a result, they are able to widen their interests and circles of friends.”

Ofsted
reports.ofsted.gov.uk

If you are wondering about the benefits of a specialist deaf education for your child and would like to come and see us please contact the Principal, David Couch on 01273 682362 (voice and minicom) or email david.couch@hamiltonlsc.co.uk

HAMILTON LODGE, WALPOLE ROAD, BRIGHTON, EAST SUSSEX BN2 0LS
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Early CaLL: Early Cognitive and Listening Links

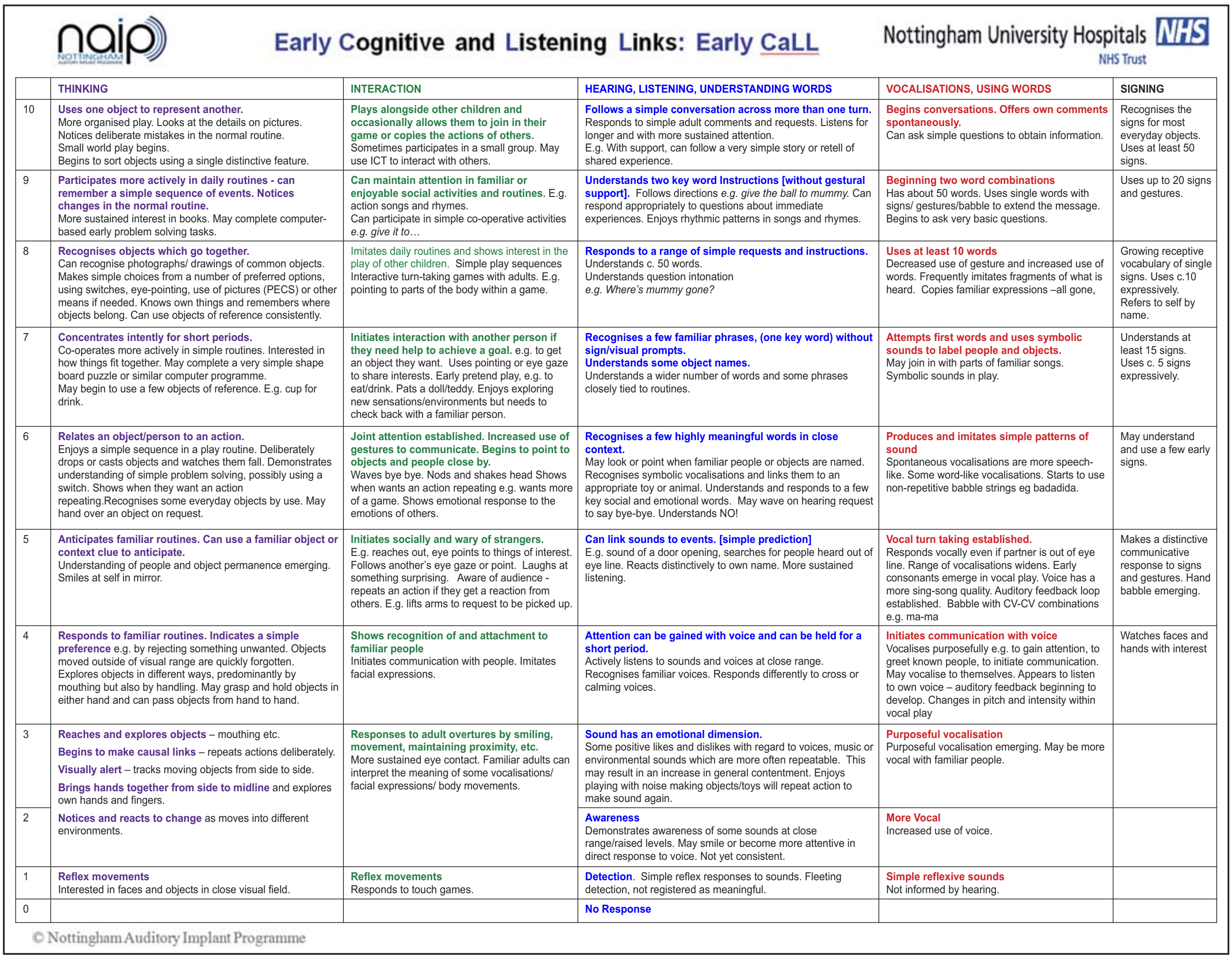
Karen Durbin describes the development and use of a profile for children with cochlear implants who have cognitive difficulties

Early CaLL is a population-specific profile to record the long term progress following cochlear implantation of children with severe to profound and multiple learning difficulties. It was developed by a multi-professional group from the Nottingham Auditory Implant Programme comprising Gill Datta, Chris Bones and Karen Durbin, Teachers of the Deaf; Amanda Odell, Speech and Language Therapist; and Cathy Grant, Clinical Psychologist.

Meeting challenges

In our 25 years of experience of cochlear implantation at the Nottingham Auditory Implant Programme we have provided cochlear implants to many children who have difficulties in addition to deafness. An audit by Jayne Ramirez Inscoe and Chris Bones in 2012 indicated that 47% of our paediatric population, as reported by their families, had at least one additional difficulty and 11% had three or more. Many deaf children with additional difficulties achieve listening and language outcomes in line with the general population of implanted children and we have materials such as the Nottingham Auditory Milestones (NAMES) which help us in their assessment and monitoring. However, we were aware of the need to develop materials for use with children who have more complex needs.

We designed the Early CaLL profile specifically for deaf children whose primary difficulty (in addition to deafness) is with cognitive development. This specific group of children either present with severe-profound learning difficulties in the assessment phase or subsequently receive this diagnosis. Many have additional physical and medical needs and a proportion have a diagnosis of autism. It is a heterogeneous group of individuals with a range of difficulties which form a



Early Cognitive and Listening Links: Early CaLL

Nottingham University Hospitals NHS Trust

	THINKING	INTERACTION	HEARING, LISTENING, UNDERSTANDING WORDS	VOCALISATIONS, USING WORDS	SIGNING
10	**Uses one object to represent another.** More organised play. Looks at the details on pictures. Notices deliberate mistakes in the normal routine. Small world play begins. Begins to sort objects using a single distinctive feature.	**Plays alongside other children and occasionally allows them to join in their game or copies the actions of others.** Sometimes participates in a small group. May use ICT to interact with others.	**Follows a simple conversation across more than one turn.** Responds to simple adult comments and requests. Listens for longer and with more sustained attention. E.g. With support, can follow a very simple story or retell of shared experience.	**Begins conversations. Offers own comments spontaneously.** Can ask simple questions to obtain information.	Recognises the signs for most everyday objects. Uses at least 50 signs.
9	**Participates more actively in daily routines - can remember a simple sequence of events. Notices changes in the normal routine.** More sustained interest in books. May complete computer-based early problem solving tasks.	**Can maintain attention in familiar or enjoyable social activities and routines.** E.g. action songs and rhymes. Can participate in simple co-operative activities *e.g. give it to…*	**Understands two key word Instructions [without gestural support].** Follows directions *e.g. give the ball to mummy.* Can respond appropriately to questions about immediate experiences. Enjoys rhythmic patterns in songs and rhymes.	**Beginning two word combinations** Has about 50 words. Uses single words with signs/ gestures/babble to extend the message. Begins to ask very basic questions.	Uses up to 20 signs and gestures.
8	**Recognises objects which go together.** Can recognise photographs/ drawings of common objects. Makes simple choices from a number of preferred options, using switches, eye-pointing, use of pictures (PECS) or other means if needed. Knows own things and remembers where objects belong. Can use objects of reference consistently.	Imitates daily routines and shows interest in the play of other children. Simple play sequences Interactive turn-taking games with adults. E.g. pointing to parts of the body within a game.	**Responds to a range of simple requests and instructions.** Understands c. 50 words. Understands question intonation *e.g. Where's mummy gone?*	**Uses at least 10 words** Decreased use of gesture and increased use of words. Frequently imitates fragments of what is heard. Copies familiar expressions –all gone,	Growing receptive vocabulary of single signs. Uses c.10 expressively. Refers to self by name.
7	**Concentrates intently for short periods.** Co-operates more actively in simple routines. Interested in how things fit together. May complete a very simple shape board puzzle or similar computer programme. May begin to use a few objects of reference. E.g. cup for drink.	**Initiates interaction with another person if they need help to achieve a goal.** e.g. to get an object they want. Uses pointing or eye gaze to share interests. Early pretend play, e.g. to eat/drink. Pats a doll/teddy. Enjoys exploring new sensations/environments but needs to check back with a familiar person.	**Recognises a few familiar phrases, (one key word) without sign/visual prompts.** **Understands some object names.** Understands a wider number of words and some phrases closely tied to routines.	**Attempts first words and uses symbolic sounds to label people and objects.** May join in with parts of familiar songs. Symbolic sounds in play.	Understands at least 15 signs. Uses c. 5 signs expressively.
6	**Relates an object/person to an action.** Enjoys a simple sequence in a play routine. Deliberately drops or casts objects and watches them fall. Demonstrates understanding of simple problem solving, possibly using a switch. Shows when they want an action repeating.Recognises some everyday objects by use. May hand over an object on request.	**Joint attention established. Increased use of gestures to communicate. Begins to point to objects and people close by.** Waves bye bye. Nods and shakes head Shows when wants an action repeating e.g. wants more of a game. Shows emotional response to the emotions of others.	**Recognises a few highly meaningful words in close context.** May look or point when familiar people or objects are named. Recognises symbolic vocalisations and links them to an appropriate toy or animal. Understands and responds to a few key social and emotional words. May wave on hearing request to say bye-bye. Understands NO!	**Produces and imitates simple patterns of sound** Spontaneous vocalisations are more speech-like. Some word-like vocalisations. Starts to use non-repetitive babble strings eg badadida.	May understand and use a few early signs.
5	**Anticipates familiar routines. Can use a familiar object or context clue to anticipate.** Understanding of people and object permanence emerging. Smiles at self in mirror.	**Initiates socially and wary of strangers.** E.g. reaches out, eye points to things of interest. Follows another's eye gaze or point. Laughs at something surprising. Aware of audience - repeats an action if they get a reaction from others. E.g. lifts arms to request to be picked up.	**Can link sounds to events. [simple prediction]** E.g. sound of a door opening, searches for people heard out of eye line. Reacts distinctively to own name. More sustained listening.	**Vocal turn taking established.** Responds vocally even if partner is out of eye line. Range of vocalisations widens. Early consonants emerge in vocal play. Voice has a more sing-song quality. Auditory feedback loop established. Babble with CV-CV combinations e.g. ma-ma	Makes a distinctive communicative response to signs and gestures. Hand babble emerging.
4	**Responds to familiar routines. Indicates a simple preference** e.g. by rejecting something unwanted. Objects moved outside of visual range are quickly forgotten. Explores objects in different ways, predominantly by mouthing but also by handling. May grasp and hold objects in either hand and can pass objects from hand to hand.	**Shows recognition of and attachment to familiar people** Initiates communication with people. Imitates facial expressions.	**Attention can be gained with voice and can be held for a short period.** Actively listens to sounds and voices at close range. Recognises familiar voices. Responds differently to cross or calming voices.	**Initiates communication with voice** Vocalises purposefully e.g. to gain attention, to greet known people, to initiate communication. May vocalise to themselves. Appears to listen to own voice – auditory feedback beginning to develop. Changes in pitch and intensity within vocal play	Watches faces and hands with interest
3	**Reaches and explores objects** – mouthing etc. **Begins to make causal links** – repeats actions deliberately. **Visually alert** – tracks moving objects from side to side. **Brings hands together from side to midline** and explores own hands and fingers.	**Responses to adult overtures by smiling, movement, maintaining proximity, etc.** More sustained eye contact. Familiar adults can interpret the meaning of some vocalisations/ facial expressions/ body movements.	**Sound has an emotional dimension.** Some positive likes and dislikes with regard to voices, music or environmental sounds which are more often repeatable. This may result in an increase in general contentment. Enjoys playing with noise making objects/toys will repeat action to make sound again.	**Purposeful vocalisation** Purposeful vocalisation emerging. May be more vocal with familiar people.	
2	**Notices and reacts to change** as moves into different environments.		**Awareness** Demonstrates awareness of some sounds at close range/raised levels. May smile or become more attentive in direct response to voice. Not yet consistent.	**More Vocal** Increased use of voice.	
1	**Reflex movements** Interested in faces and objects in close visual field.	**Reflex movements** Responds to touch games.	**Detection**. Simple reflex responses to sounds. Fleeting detection, not registered as meaningful.	**Simple reflexive sounds** Not informed by hearing.	
0			**No Response**		

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Fig. 1

continuum of increasing need. We wanted the profile to assist us with the challenges of assessment (during the **assessment** phase and during monitoring if they are implanted), **decision making** and **expectation counselling** for this group of children.

Family Views

The work by Manchester University (2011) and the interviews conducted by the Ear Foundation (2011) supported the need to devise a population-specific profile. Families wanted recognition of the impact of their child's deafness, alongside an understanding of their individual abilities and needs. In the assessment phase, families identified the need for counselling about realistic outcomes tailored to an understanding of what would constitute auditory benefit for their child and how this could contribute to an improved quality of life. Post implant, they wanted information on progress informed by evidence which was relevant, clear and accessible.

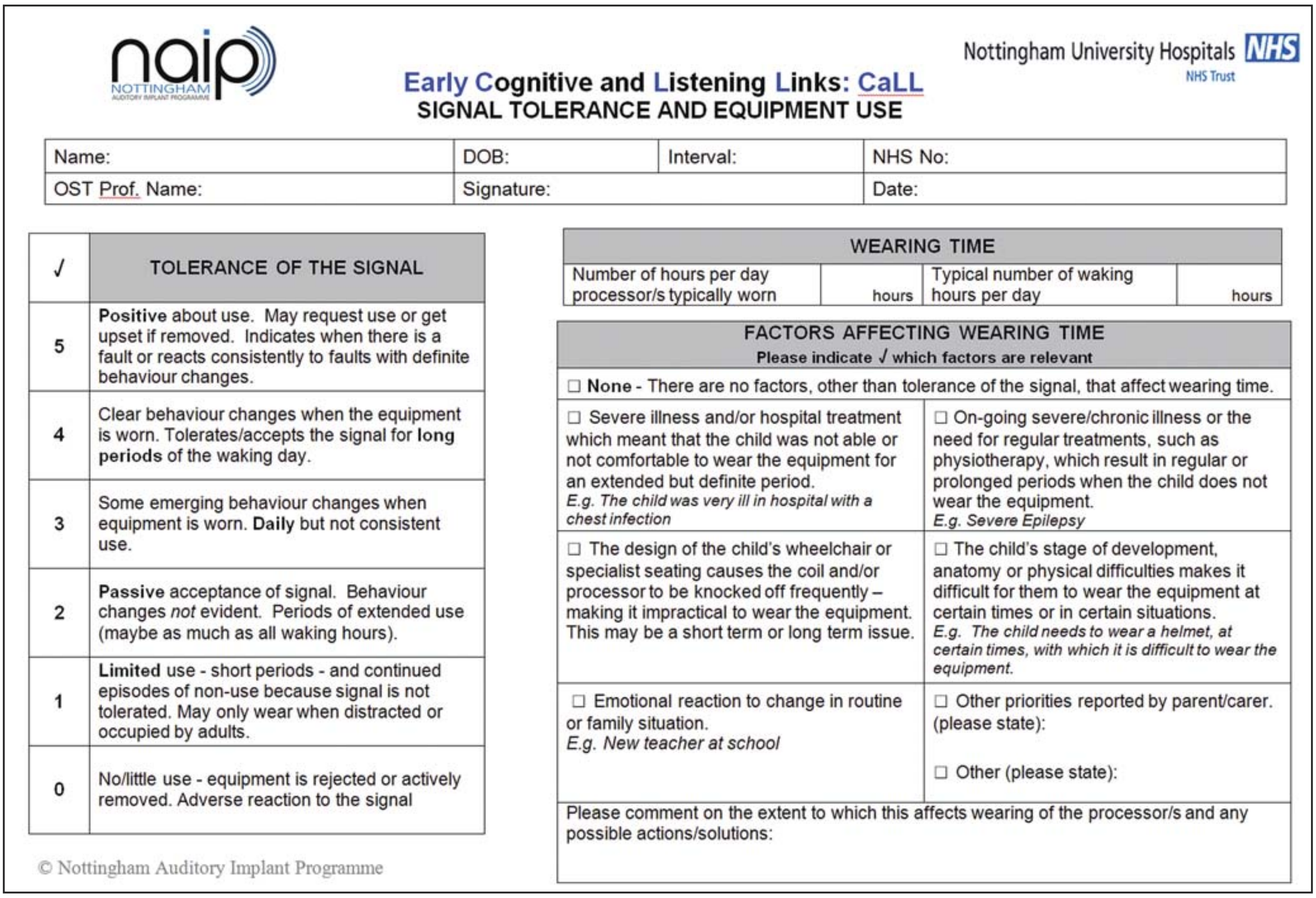
A framework to share expectations about outcomes

The families of children with significant additional difficulties enter the cochlear implant assessment process, like all others, with their central focus on the desire to address their child's deafness. They are unlikely to have a clear idea of expectations post implant, as the vast majority of information currently available focuses on the typically developing population. This can create a misleading picture of a direct link between the provision of hearing via the equipment, leading automatically to listening, understanding and talking. Families are often aware of the potential additional complications presented by their child's additional needs. However, a clearer framework was needed in order to facilitate a more informed discussion about the potential benefits of cochlear implants.

A key aim of the Early CaLL profile is to explain to families, in an accessible, positive but realistic way, the fundamental inter-relationship between their child's likely level of benefit from cochlear implantation and their current cognitive and communicative abilities. The profile demonstrates to care-givers and non-specialists that the development of listening and understanding depends very much on the child's thinking skills and ability to process the signal. It can help with difficult discussions. For example, a child who is at stage one in terms of their 'Thinking and Interaction' can only make basic reflex responses to sensory stimulation. These limited responses make the provision and programming of cochlear implants very challenging. It can also help to explain why a cochlear implant may be able to improve a child's detection of sound, but that this may not develop into the ability to understand and use spoken language.

Profile design and organisation

The profile consists of two sections: A developmental profile and a record of signal tolerance and equipment use.



naip NOTTINGHAM AUDITORY IMPLANT PROGRAMME

Nottingham University Hospitals NHS
NHS Trust

Early Cognitive and Listening Links: CaLL
SIGNAL TOLERANCE AND EQUIPMENT USE

Name:	DOB:	Interval:	NHS No:
OST Prof. Name:	Signature:		Date:

√	TOLERANCE OF THE SIGNAL
5	**Positive** about use. May request use or get upset if removed. Indicates when there is a fault or reacts consistently to faults with definite behaviour changes.
4	Clear behaviour changes when the equipment is worn. Tolerates/accepts the signal for **long periods** of the waking day.
3	Some emerging behaviour changes when equipment is worn. **Daily** but not consistent use.
2	**Passive** acceptance of signal. Behaviour changes *not* evident. Periods of extended use (maybe as much as all waking hours).
1	**Limited** use - short periods - and continued episodes of non-use because signal is not tolerated. May only wear when distracted or occupied by adults.
0	No/little use - equipment is rejected or actively removed. Adverse reaction to the signal

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WEARING TIME			
Number of hours per day processor/s typically worn	hours	Typical number of waking hours per day	hours

FACTORS AFFECTING WEARING TIME Please indicate √ which factors are relevant	
☐ **None** - There are no factors, other than tolerance of the signal, that affect wearing time.	
☐ Severe illness and/or hospital treatment which meant that the child was not able or not comfortable to wear the equipment for an extended but definite period. *E.g. The child was very ill in hospital with a chest infection*	☐ On-going severe/chronic illness or the need for regular treatments, such as physiotherapy, which result in regular or prolonged periods when the child does not wear the equipment. *E.g. Severe Epilepsy*
☐ The design of the child's wheelchair or specialist seating causes the coil and/or processor to be knocked off frequently – making it impractical to wear the equipment. This may be a short term or long term issue.	☐ The child's stage of development, anatomy or physical difficulties makes it difficult for them to wear the equipment at certain times or in certain situations. *E.g. The child needs to wear a helmet, at certain times, with which it is difficult to wear the equipment.*
☐ Emotional reaction to change in routine or family situation. *E.g. New teacher at school*	☐ Other priorities reported by parent/carer. (please state): ☐ Other (please state):
Please comment on the extent to which this affects wearing of the processor/s and any possible actions/solutions:	

Fig. 2

Patience, consistency and resilience

Sarah Norris considers some of the challenges in working with deaf children with complex needs and who have cochlear implants

Working with children and young people requires patience, consistency and resilience. Working with children with complex needs requires more patience, more consistency and more resilience. There needs to be a clear understanding that you may not be following the same path that children and young people without complex needs may be following. We all know it is not an easy decision for any family to make about whether or not they should pursue a cochlear implant for their child but for a child or young person with complex needs it is just much more… complex. As with all implants no outcomes are guaranteed but with complex children and implants what does the future hold? So with this in mind one family decided to say yes.

Sam (not his real name) was born at the start of 2003 and was diagnosed with Down syndrome a few days after his birth, he has Hirschsprung's disease, and he failed his Newborn Hearing Screening. He was issued with bilateral hearing aids and after a long period of testing, retesting and increasing the gain on his hearing aids he was diagnosed with a bilateral profound sensori-neural hearing loss towards the end of his fourth year confirmed by ABR. Additionally he has a visual impairment and has been prescribed glasses.

After much discussion with medical and educational professionals, many appointments and thorough investigations, a unilateral cochlear implant was agreed and carried out. No one said it was going to be easy but this young man has had a couple of set backs with regards to his implant: his magnet dropped and had to be surgically removed and then reinserted. Then after his second switch on a severe ear infection just two months later further delayed the consistency needed for wearing his speech processor.

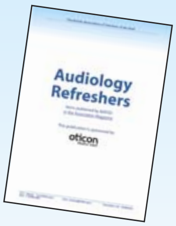
Up until June of 2012 (four years post implant) he was wearing his speech processor for short periods of time throughout each day. Then something happened – he refused it and would become extremely distressed and upset even seeing it. We don't know why he stopped using it – he can't tell us. He is non-verbal. He has a few Makaton signs but is not a consistent communicator. Through a recommendation from his Auditory Implant Program (AIP) Teacher of the Deaf his local Teacher of the Deaf followed a desensitisation programme which enabled him to tolerate looking at it, even putting it on but not switching it on. Now three years from that point he is using his speech processor for half a day at school!

There is not just one thing that has supported his regular use of his speech processor but quite a few; not least of all a full time intervenor (due to his dual sensory loss it has been included in his Statement from January 2013) which has made a tremendous difference; she supports him completely throughout his day at school. She is able to make adaptations to his support based on his needs alone. For example, she has recently made what appears to be a minor adaptation but it has had a major impact on his ability to use his processor for longer periods of time. He uses a body worn processor and often his decision to not wear his processor involved taking it off and throwing it across the room. His intervenor has attached his body worn processor to a retractable key chain. This allows him to remove it but doesn't allow him to throw it across the room. This minor adjustment has had a major impact. He now no longer has the interest in removing it as frequently as before.

He is responding to some amazing things through audition alone! His eye contact has improved tremendously! He now looks quite intently at adults when they are speaking. He is responding to his name more regularly, he is following simple instructions through listening alone, he is playing turn taking games where he is copying and attempting to imitate sounds. He has begun to vocalise initial consonant sounds for example, m-m for more and b-b for bird when being read one of his preferred stories at school.

So it may surprise some to hear having just reached half of day of usage of his speech processor seven years post switch on is a success – but it is! Look how far he has come and what he has managed to overcome. Yes these beginning steps of success have come from working closely with many people: his class teacher, intervenor, AIP Teacher of the Deaf, and his family, but mostly because all of these people have been patient, consistent and resilient.

Sarah Norris is a Teacher of the Deaf with the Wandsworth Hearing Support Service.



We can help anyone who has suffered from meningitis/meningococcal septicaemia, including family, friends and carers and any professionals working with them.

Home visits: We have Community Support Officers (CSOs) in all the UK regions who are committed to supporting sufferers, whatever their experience and whenever it was. A home visit can provide vital support and a chance to discuss how we can help.

Educational needs: Many families feel that the educational needs of their child following meningitis are not fully understood and can be overlooked. Some benefit from arranging for a CSO to visit their school to discuss meningitis, its impact and resources available to help children after meningitis.

Counselling and emotional support: Counselling can be helpful if you have had meningitis yourself, or if you are close to someone who has had the disease, and can be used by adults, couples together, young people and children. All the counsellors are members of professional bodies and have appropriate skills, experience and insurance. Sessions are available throughout the whole of the UK, are fully funded by Meningitis Now and there are no waiting lists.

Creative and complementary services: Following an experience of meningitis, many children will not want to talk about what has happened to them, but changes in their behaviour, sleeping, eating and interaction with others will suggest that they are experiencing some form of emotional distress. Access to a creative therapy can help children express their feelings in a gentle, supportive environment. We can make a referral to a professional therapist who can use art, play, drama or music to help a child make sense of what has happened. This can also be very helpful for siblings, who may be experiencing the impact of the disease on their own lives.

Family Days: Family Days happen in various locations throughout the UK and throughout the year, and are an opportunity for families with children up to the age of 12 who have been affected by the disease to meet one another in a fun and relaxed environment.

Believe and Achieve weekends: Our popular regional Believe and Achieve weekends are action-packed events for young people aged 11 to 18-years-old who have had meningitis or meningococcal disease.

Financial Support Grants: Perhaps one of the most significant impacts of meningitis can be financial. To counter this we have set up our Financial Support Grants system to provide practical help with things including:

- Therapeutic and re-training activities: such as speech and language therapy, physiotherapy, sign language classes and driving lessons.
- Special aids and equipment: including special beds, wheelchairs, and sensory equipment.
- Computer equipment; including specialist software such as touch screen and special needs educational software.
- Education: if a child has identified special educational needs, and is waiting for an SEN assessment, short-term educational support may be possible.
- Home adaptations: for example, stairlifts and bathroom adaptations.
- Respite care: for those who care for a family member with disabilities caused by meningitis.

Meningitis now

For more on how we support families fighting back from meningitis, call our helpline on 0808 80 10 388 or visit www.MeningitisNow.org

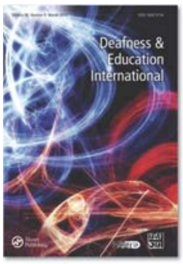
Ffion Haf is Community Support Officer for Meningitis Now in Wales. Cathy Hill is Community Support Officer in the South West region, covering Cornwall, Devon, Somerset, Dorset, Bristol, Bath and North East Somerset and the Scilly Isles.

References:

1. UK estimated average annual number of cases 2001 – 2012
2. MOSAIC study
   http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(12)70180-1/fulltext

Deafness & Education International

Online access available for BATOD members



Did you know that as a member of BATOD, you are entitled to free online access to Deafness & Education International?

Editors: **Linda Watson**
(University of Birmingham, UK)
& **P Margaret Brown**
(University of Melbourne, Australia)

To access the latest journal articles, just follow these simple instructions:

1. Go to **www.batod.org.uk**
2. **Log in** as a member with your email address and BATOD password
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BATOD


A revolution in signal to noise ratios


ReSound

DELTA. Interpreters were available for all the talks and around the stands in the hall to ensure everything was accessible to all.

What was the result?
A great day was had by all. Over 500 people attended and 100% said how valuable and informative the day was and wanted to know when the next event would be held!

What families found valuable about the event:

There were many positive comments from parents including:

"An amazing amount of information is here; nobody should feel they haven't been given all the facts."

"A very informative day, we stayed all day."

One comment from a parent of a recently diagnosed profoundly deaf baby made everything worthwhile, *"It was so good seeing deaf children running around doing normal activities like other children"*.

Comments from professionals included: *"Good networking opportunity and to learn about the difficulties deaf people have,"* and *"Met lots of families and young people"*.

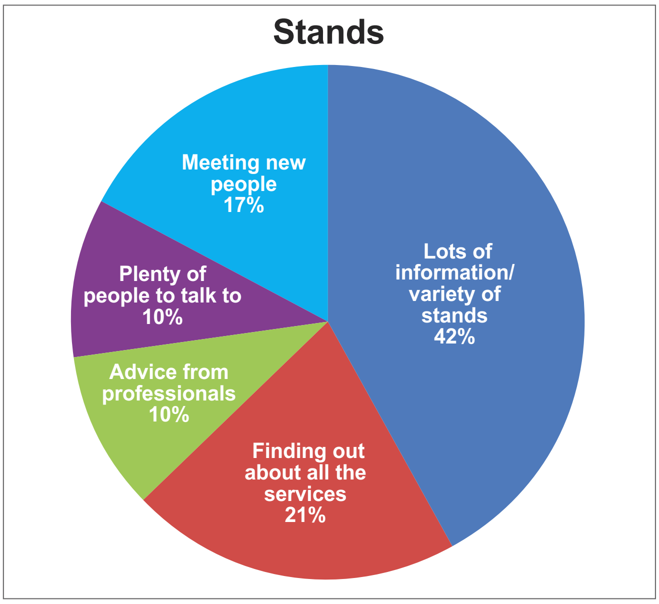
Since DEAFEXPO some children in mainstream schools who were reluctant to use amplification have changed their attitude and are now wearing hearing aids. Some children have requested an FM system as a result of seeing other HI children and talking to manufacturers.

What would we do differently?
This was the third DEAFEXPO in the last seven years and each one has got bigger and better as we learnt from our experiences. Next time, we would develop a working group of young people who would be involved in generating ideas for DEAFEXPO and would also play a role in promoting and the running of the event. This would promote independence, confidence and social skills and may increase the attendance of young people at the event.

Would we plan another DEAFEXPO? The short answer is yes! From the feedback it is clear that the aims originally set were well met. Seeing the children and their families enjoying themselves and hearing their positive feedback outweighed the additional work and sleepless nights. What became clear from this event is that hearing-impaired children and young people, parents, professionals, charities, organisations and companies are all able to gain from opportunities to network in this way.

If you are interested in organising a similar event in your area, please do not hesitate to contact us: Ann.vickers2@kent.gov.uk

Ann Vickers is the County Co-ordinator for HI in Kent and Lisa Durrant is a Specialist Teacher for HI.



The main issues which arose were:

- The terms ‘mild’ and ‘moderate’ used to describe the hearing loss do not describe the impact described by parents and professionals at home and school.
- There is a bigger impact of mild/moderate hearing loss on family and education than generally recognised by others. *“Massive (impact). He is underachieving academically and socially in the school environment.” (Parent Survey)*
- Children and young people with mild/moderate hearing losses in school have to use greater levels of effort than generally realised.
- Mild/moderate hearing loss frequently has a social and emotional impact on the child or young person.
- Family adjustments are often required to meet the needs of the child or young person with mild/moderate hearing loss.
- 60% of parents felt that they wanted more support for their child: they most commonly wanted more individual 1-1 support in education.
- When asked about information, 66% of parents considered that the child’s teacher or form tutor had sufficient information about hearing loss.
- There is a major lack of deaf awareness in mainstream schools for children and young people with mild/moderate hearing loss in particular. *“Phonics a nightmare but no flexibility in teaching.” (Parent Survey)*
- Children with mild/moderate hearing loss experience diagnosis and fitting of aids later than in other groups, with an apparent lack of care pathway and liaison between professionals:

  “From birth my son never passed newborn screening, after repeated screening and my husband and I getting angry, it was confirmed.” (Parent Survey)

  “I would say you have to push and push and inform yourself unfortunately. You have to do all the reading and you have to advocate for your child. It is unlikely that any one else will do it. You will be lucky if you find someone who does.” (Parent Interview)
- There is a need for parents of children and young people with mild/moderate hearing loss to be particularly pro-active: parents were unaware of the roles of Teachers of the Deaf and teaching assistants.
- There is an increasing use of technology, including bone conducting hearing implants, for children and young people with mild/moderate hearing loss and there is a need for up to date information and training for those working with them, including audiologists.
- While hearing technologies are very effective in this group, they may appear not to need them, and appear to ‘hear’ without them. This can lead to confusion for them and their parents and teachers and possible non-use in later years. *“I would say embrace hearing aids – they are your friends.” (Parent Interview)*
- The impact of fluctuating, conductive losses and unilateral losses is often not recognised.
- Parents and young people valued support groups for families and young people with mild/moderate hearing losses; their needs may be different from those of the profoundly deaf.
- With financial and service cutbacks and prioritisation of services, there appears to be a particular impact on support for children and young people with mild/moderate hearing loss. *“No support as need is not recognised...” (Teacher)*

The findings of this study are revealing and thought provoking about this group of often overlooked children. For Teachers of the Deaf, one of the most important points to take away is how few parents knew about Teachers of the Deaf or specialist classroom assistants. This report can inform parents, teachers and other professionals about the impact of mild to moderate hearing loss on the lives of children or young people with mild to moderate hearing loss.

- *“It is important to stand up for children with mild and moderate losses”. (Teacher)*

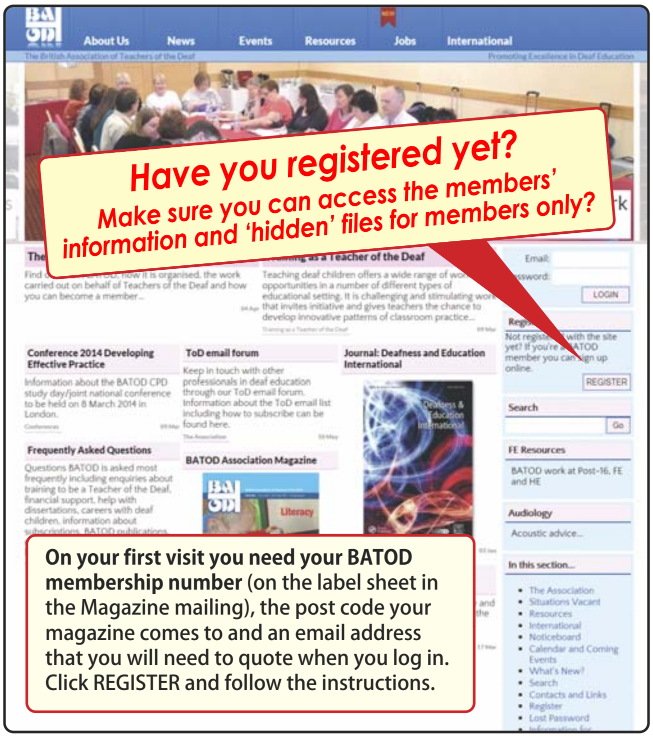
With thanks to all the parents and teachers who helped with this study.

The full report is available to download from the NDCS website at www.ndcs.org.uk/research

Information for families about mild/moderate hearing loss is also available from the NDCS website at www.ndcs.org.uk/mildmoderate

The research was carried out by: Sue Archbold, Sue Gregory, Zheng Ng, Suzanne Harrigan, Tina Wakefield and Lynda Holland.

Sue Archbold is the Chief Executive Officer of the Ear Foundation.



Information about the BATOD CPD study day/joint national conference to be held on 8 March 2014 in London.

Keep in touch with other professionals in deaf education through our ToD email forum. Information about the ToD email list including how to subscribe can be found here.

Have you registered yet?

Make sure you can access the members’ information and ‘hidden’ files for members only?

On your first visit you need your BATOD membership number (on the label sheet in the Magazine mailing), the post code your magazine comes to and an email address that you will need to quote when you log in. Click REGISTER and follow the instructions.

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What went on at NEC

Sandy Goler reports from the NEC meeting in London on 13th June

Usually the June NEC meeting is on one of the hottest days of the year – fortunately not so this year. Several delegates were delayed because of transport difficulties, but the meeting started only a little late with Stuart Whyte as President Elect initially taking the chair. All were warmly welcomed, especially new members Helen Cooper and Teresa Quail.

The meeting split into three groups to discuss and then feed back on:

- Conference 2016. This has the working title 'Working with Technology' and will be in Cardiff on March 12th. Topics for workshops were decided – look out for further information on the website.
- CPD. The group has started work on reinstating the BATOD CPD log. The work will be at two levels:
  - strategic – having the necessity for CPD recognised as essential by authorities
  - practical – that a log should be useful and manageable.

This work will be continued at future meetings.

- Sharing good practice. After some discussion, this working group suggested opening a Facebook page where ToDs could share good practice by posting links to sites and networking. The idea will be discussed further at Steering Group.

The meeting continued with a discussion of the main problems and concerns delegates are finding at work. The main issues raised were:

- staff not being replaced and the cumulative effect on the workload of others
- the effects of repeated restructuring
- lack of or poor service level agreements and no set staffing quotas
- demoralised workforce
- recruitment difficulties – getting qualified ToDs, CSWs, use of agency staff
- pupils with CIs having to wait longer for upgrades, spares not being left with schools and families having to buy non-essential items
- EHC Plans – either not appearing at all or not being specific enough. Yr 11 in particular are likely to be losing funding without appropriate plans. There is a schedule of transfers which should be followed and staff working with more than one LA felt a common EHCP form would be useful
- influx of populations with hereditary hearing loss leading to large numbers of deaf children in particular in mainstream schools resulting in staffing issues. It was made clear that children with a disability do not have to wait 3 months before accessing services – there should be immediate support through a Section 17 assessment
- only children with statements being seen – thus ruling out many pre-school children
- the position of deaf children and staff in Academies including:
  - deaf children are being supported by Graduate Coaches with little or no training
  - staff being withdrawn to work in other areas.

If you are having any problems in these or other areas, please contact the BATOD Consultant – it would be helpful to build up a national picture.

A lengthy discussion on the position of Academies followed. There are concerns over:

- the effect of central budgets reducing – though the High Needs Block should not be reduced
- how services are commissioned.

The business section of the agenda included:

- the Action Sheet – most items were completed, though some, such as putting new resources on the website, are ongoing.
- reports from Officers:
  - The National Executive Officer reported on an international meeting in Romania and the important role BATOD has in spreading information to countries where there has been less progress in the education of deaf children.
  - The Treasurer reported that funds are much healthier than they have been, though there is no room for complacency. The next budget will be set at the Steering Group in September.
  - The Consultant reported that there has been a change in criteria for access to work funding which has caused problems. There has been an appeal which should have resolved this. If payments are often late being made, deaf staff should do the claims themselves. It was also pointed out that there is a new NatSIP eligibility framework which can be a useful tool in helping ToDs to argue staffing levels.

Reports from Regions and Nations followed. Most areas are holding successful day or twilight sessions which are increasingly well attended. There are, however, many concerns about restructuring and budget cuts.

After an informative and worthwhile day, the meeting closed just after 5.00pm. The next NEC will be in Birmingham in September.

Why not follow us on Twitter?
@BATOD_UK

BATOD membership

BATOD activities are funded from your membership fee and some advertising income.

Colleagues who share your Magazine and Journal also benefit from BATOD negotiations with government and other influential bodies – but they are not contributing!

Persuade your colleagues to join BATOD and you will receive 10% of their membership fee as an 'introduction fee'.

Full details of membership plus membership form are available at
www.batod.org.uk ▸ The Association ▸ BATOD Membership

ToDs in training will be entitled to a £20 reduction in annual membership fee when the Course Tutor countersigns the membership application form for those paying by Direct Debit (applies for up to 2 years; payable at the end of the year).

The BATOD Membership Secretary may be contacted via **membership@batod.org.uk**
The BATOD Treasurer may be contacted via **treasurer@batod.org.uk**

Officers of Nations and Regions

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Treasurer:	Clare Bateson
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Secretary:	Hazel Sutherland
Treasurer:	Post vacant

BATOD contacts and Magazine Distribution

Articles, information and contributions for the **Association Magazine** should be sent to:

BATOD National Executive Officer: Paul Simpson
Tel/fax: 0845 6435181 Email: magazine@batod.org.uk
...as should Association information and general queries.

Advertisements for the **Association Magazine** should be sent to:
Elizabeth Reed-Beadle, BATOD Advertising Manager
142 New Road, Hethersett, NR9 3HG
Tel: 01603 812111 Email: advertising@batod.org.uk

Full guidelines for submissions and abstracts of **papers published in the Journal 'Deafness & Education International'** are to be found at
www.maney.co.uk/instructions_for_authors/dei
Enquiries related to the Journal to:
Dr Linda Watson, email: l.m.watson@bham.ac.uk

Manuscripts should be submitted online at
www.editorialmanager.com/dei

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Meetings and training Calendar

This page is an extract from the Calendar to be found on the BATOD website. Please note that it is not exhaustive. Items noted on this Calendar may have been advertised within the Magazine or the information reported by telephone. BATOD is not necessarily the organising body.

Please contact the organising body (column 2) for details of conferences, not the Editor of this Magazine.

Date	Organisation	Meeting topic	Venue
September			
15	Phonak	Focus Day	Scotland
15	Seashell Trust and Sense	Learning and Interactions – a conference with Jan Van Dijk	Manchester
16	DCAL	Early communication and language development	DCAL (Deafness, Cognition and Language) Research Centre, University College London, 49 Gordon Square, London WC1H 0PD
16	NDCS	Workshops on assessing and monitoring the progress of deaf children and young people	NDCS office, Belfast
16	NDCS	Workshops on assessing and monitoring the progress of deaf children and young people	NDCS office, Belfast
19	BATOD NEC	Association Business	Birmingham
22	Phonak	Focus Day	Leeds
25	The Ear Foundation	Supporting people with cochlear implants for Communication Support Workers	The Ear Foundation, Nottingham, UK
29	The Ear Foundation	Babies & toddlers with cochlear implants: A sound start	The Ear Foundation, Nottingham, UK
30	Phonak	Focus Day	North West
October			
1	Phonak	Focus Day	Birmingham
6	Phonak	Focus Day	Bristol
7	NDCS	Workshops on assessing and monitoring the progress of deaf children and young people	Ear Foundation, Nottingham, UK
8	The Ear Foundation	Complex children with cochlear implants for Teaching Assistants	The Ear Foundation, Nottingham, UK
8	Phonak	Focus Day	London
9	The Ear Foundation	CMV: Cytomegalovirus	The Ear Foundation, Nottingham, UK
15	The Ear Foundation	Children with cochlear implants: Slow to progress	The Ear Foundation, Nottingham, UK
19	NDCS	Workshops on assessing and monitoring the progress of deaf children and young people	Action on Hearing Loss office, Cardiff
20	The Ear Foundation	Sound to words: The brilliance of babies in one year	Bristol Sensory Support Service, Elmfield House, Greystoke Avenue, Bristol. BS10 6AY
21	The Ear Foundation	Radio aids & wireless technology workshop: Understanding the potential & building confidence	The Ear Foundation, Nottingham, UK
21	DCAL	Later language development and Theory of Mind	DCAL Research Centre, London WC1H 0PD
21	The Ear Foundation	Radio aids & wireless technology workshop: Understanding the potential & building confidence	The Ear Foundation, Nottingham, UK
November			
4	NDCS	Workshops on assessing and monitoring the progress of deaf children and young people	NDCS office, London
4	The Ear Foundation	Developing listening & language through primary classroom routines	The Ear Foundation, Nottingham, UK
6	The Ear Foundation	Language development & goal setting the SMART way Day 1 of a two day course	The Ear Foundation, Nottingham, UK
7	BATOD Steering Group	Association Business	London

The Calendar on the BATOD website is edited as soon as we know about meetings.
Additional information about courses and registration forms may also be linked to the calendar entries.



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  - Otoscopy and Impression taking for service users over age 5
- Non-certificated courses and refreshers
  - Audiometric procedures
  - Masking
  - Speech-in-noise testing

Language development:

- Assessment & target setting: including training in the use of specific language tests
- Analysis of speech & grammar
- Deafness and additional speech and language difficulties
- Speech acoustics

Educational issues:

- Successful inclusion strategies
- Curriculum differentiation
- Supporting children who are deaf and have complex needs
- Social and emotional development.

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More detailed information about our courses can be found on our website at:

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“The care offered to young people is very supportive and nurturing.”

“The variety of activities in which residential pupils partake enables them to develop social skills, friendship groups and confidence. The school actively promotes the presence of the residential pupils in the wider community and this enables them to feel valued and not isolated. Examples of activities have included completion of Duke of Edinburgh Awards with pupils from mainstream schools and who are able to hear.”

“They benefit from having their needs met in an individualised manner which enables them to make significant progress. Being part of the residential group means that many of the residential pupils are not isolated and that they can enjoy meaningful and enjoyable relationships with their peers. ‘If I wasn’t here, I would be lonely, it’s my second home’ is a comment from a residential pupil.”

“Residential pupils have a number of activities available to them. These include activities arranged by the school as well as an opportunity to attend clubs and other interests delivered by other organisations, such as Brownies and Scouts. As a result, they are able to widen their interests and circles of friends.”

Ofsted

reports.ofsted.gov.uk

If you are wondering about the benefits of a specialist deaf education for your child and would like to come and see us please contact the Principal, David Couch on 01273 682362 (voice and minicom) or email david.couch@hamiltonlsc.co.uk

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