Introduction: We Have the Technology!

In the UK we probably have the best audiology service in the world! It is free at the point of delivery for all people, for children, adults, new customers and existing patients. We have:

• innovations in technology that deliver best patient benefits
• systems and processes that deliver innovations in patient journeys with new technology
• a workforce and working practices that provide governance and competence
• the tightest specification of standard operating procedure in the world
• the most efficient services and the best procurement of hearing aids anywhere in the world.

Developing new technology is usually a costly, slow, step-by-step process. Getting the technology right for newborn screening has been a major achievement. It has taken a long time and has needed major investment in both resources and time. The screening procedures that were used since the 1960s, the Health Visitor Distraction Test (HVDT), involved different, less effective, technology. As a result, a child’s deafness was often undetected at a critical stage in their development, making it difficult to develop communication and language skills. By the 1980s, more robust screening technology had been developed (i.e., automated auditory brainstem response [AABR] and otoacoustic emissions [OAE]), which are capable of screening the hearing of newborn babies.

Brilliant technology with poor service implementation will not deliver good outcomes, so the task of developing good services to match the new technology needs equal time, skill and commitment. A multicenter trial using newborn screening technology began in 1988 in eight UK hospitals, with the results published in 1997 (Lutman, Davis, Fortnum and Wood 1997). This trial was targeted at newborn babies who were at risk from hearing impairment – a total of 7,500 babies had been tested by the end of 1995. The research concluded that targeted newborn hearing screening programmes can identify hearing impairment in a significant percentage of babies screened. The Wessex Hearing Assessment Project then tested all newborn babies, as opposed to a few targeted ones. The results of this indicated that more cases of significant hearing impairment could be identified and treated early, compared with when the test was not used (Wessex Universal Newborn Hearing Screening Trial Group 1998). A further review of newborn screening, taking into account the results of all the UK and US studies, concluded that, as well as being a specific and sensitive test, it was cost-effective. (Davis et al. 1997)

The Newborn Hearing Screening Programme (NHSP)

The universal NHSP (http://hearing.screening.nhs.uk) brought together the new technology and matched it with service changes. It was fully implemented in the National Health Service (NHS) in England in March 2006: each birthing hospital in the UK now offers the screen. Over 1,600 babies are screened every day. Recently (August 2007) the NHSP announced that 2,000,000 babies have been offered a hearing screen since implementation started (English programme).
The screen is also available in Wales, Northern Ireland and Scotland.

**Newborn Hearing Screening Method**

“Two simple screening methods are used to screen babies hearing – Automated Otoacoustic Emissions (AOAE) and Automated Auditory Brainstem Response (AABR). With the AOAE screen a small earpiece is placed in the baby's ear canal and a click stimulus is used to stimulate the cochlea. The haircells within the cochlea produce sound in response to this stimulus, which is picked up by the microphone in the earpiece and decoded. If we do not get clear responses from this first screen an AABR screen is done. An AABR screen again uses a click stimulus this time via ear muffs and sensors placed on the baby's head and neck detect the electrical response when the sound is transmitted from the inner ear along the auditory nerve to the brain. If both screens indicate a possible hearing loss, a referral is made to the appropriate Audiology Department for diagnostic testing.” (http://hearing.screening.nhs.uk/cms.php?folder=206)

This newborn technology has transformed the whole screening process. As a result the average age when children are identified as being deaf has been reduced from 20 months to three months.

Early identification of hearing impairment and deafness is incredibly important for deaf children, their families and for those that support them. The outcome is:
- on average, about two extra years of knowing child has a hearing loss
- about 22 months of extra aided audibility per hearing impaired child, for those families that accept hearing aids.

The two extra years and support in the early years means that children will have the chance of better tailored support, so that no long-term “catch up” in language and communication is needed. The 22-months extra-aided audibility results in greater access to sound, spoken language and communication when it is needed — in the first two years of life.

So we have “mastered the technology” and shown that services can deliver these interventions. Now our focus is on how we can maintain standards once the service becomes routine and the “halo effect” of innovation wears off. We have to continue to maintain and improve outcomes by regularly auditing and re-thinking hearing healthcare services: we are currently developing a national Quality Assurance Rating Tool for the NHSP Programme. England is in a unique position in that it runs a state-funded National Health Service which has huge potential to inform research and service delivery for deaf and hearing impaired children. The NHSP has revolutionized a system of care nationwide through the implementation of the Screening Management System and a rigorous quality assurance programme. The major emphasis in the current Quality Assurance Programme (Nov 06–Mar 08) is to discover rapidly if there are major system issues, especially around screening, and to start improvement plans where necessary. The next phase (Apr 08–Mar 10) will look more closely at interdisciplinary support for parents; this is where most parents find the greatest challenges. These tools, linked to the NHSP Performance Management System, have the potential to substantially increase our knowledge base and continue to improve services and outcomes.

**Does Early Identification Really Lead to Better Outcomes?**

The challenge now is to transform services we offer deaf children in a way that will:
- enable high quality parent – child interaction in first months of life for all children
- empower parents of hearing impaired children to make informed choices about early communication and support options
- maintain an evaluative culture of service provision, (e.g., through training, QA and evaluating outcomes):  
  - screening, assessment and diagnosis  
  - communication options  
  - early support and education  
  - social and family care.

To do this we must make outcomes integral to research, service planning and delivery.

Does early identification really lead to better outcomes for these children and better support for parents and families, in choices that they have to make for their children? Better outcomes for families? We must not be complacent because we have the technology — we need to be constantly pushing for outcomes that show the investment is paying off. One of the key weaknesses in our knowledge and information base is data on hearing assessment and outcomes. Without these data we cannot assess performance on a national or local scale and therefore cannot so readily make the arguments for improvements for services for families.

Early identification alone will not necessarily lead to:
- better outcomes for these children
- better outcomes for families
• better support for parents and families enabling them to make the choices that they have to make for their children.

Indeed, it may be that early identification and newborn screening are really neutral in respect to outcome, and that what the technology has done so far is to act as a catalyst for better services.

What Kind of Research do we Need on Outcomes?

A key element of this screening programme is improving our knowledge and information about the children who are identified with a hearing loss or deafness. We need to know a lot more about the factors that contribute to best outcomes: are these the same across all outcome domains? How much do they rely on newborn hearing screening per se? What outcomes should be monitored or researched, which are important or which a priority? What we need to do now is to show we are measuring outcomes that really matter. Yet how much do we really know about what matters to children and families? How might we measure that? What are the outcomes for children that improve audibility – repetition, imitation, development of listening skills and development of communicative competence?

Children are Rarely Consulted about the Services They Receive

It is extremely rare that children are consulted about any healthcare service – yet they are life-long users of hearing services. In 2007 the NHSP commissioned a Children’s Consultation where 23 deaf children aged 7–13 years from six different London schools took part. The sample included a mix of oral speakers and British Sign Language (BSL) users. The main purpose of the consultation was to find out how different aspects of hospital-based audiology clinics were received, and to discover what users themselves would prioritize for improvement. The key issues children raised about paediatric audiology services included the following:

• long waiting times
• lack of provision of suitable books/toys in the waiting area
• dull and drab-looking waiting areas
• lack of audiologists in general
• lack of audiologists who could sign
• better communication from audiologists – talk to them more, rather than only to mum or dad

• importance of continuity of audiologist
• length of time it took for new ear molds to come back
• difficulty parking at hospital
• dislike of old hospital environments.

Consultation events such as this provide a valuable starting point. However, if we are truly committed to researching, monitoring and auditing outcomes, then we need to maximize contributions to outcomes research from the children, parents and families. The time has come for parents and their children to have a bigger say and develop real ownership of these studies. We need to know more about the impact of hearing problems on children and families’ quality of life and the extent to which interventions work to enhance or even restore high quality hearing and communication.

How can we recognize and acknowledge the practice that contributes to good outcomes? How, why, when and for whom? And how do we measure that and improve it? How can we work together so that we regularly ask:

• How do I / we use evidence in my practice?
• How can I / we improve services and outcomes?

How can we recognize what these issues are, and move on from the “milestones” approach to practice which is so common in the target-driven culture of today’s health economies?

We feel we all know what good practice is – we certainly recognize it when we meet it, and we like to think we offer it. However, we need to move from the comfort zone of feeling we know what good professional practice is and having easily measured standards, to ways of capturing the “magic” of good practice so that we can understand it, reward it, teach it and refine it. We are the ones who need to do this: the funders of the services will always need simpler targets like waiting times, numbers seen and costs, but we are the ones who can move from mere measurement to magic. A magic service will be professionally and technically good, but it will also deliver the outcomes to children and parents in ways that matter. How do we set about the research that will help us develop these magic services?

This kind of research on what might be called softer outcomes has always needed champions – think of the long journey from feeling it was better for young children in hospital not to see their parents to our attitude to parents and children in hospitals today! Who will be the best champions for this kind of research and have greatest impact?
Measuring What Matters: The Challenges for Research

Clearly, answers to these questions and the development of good practice relies heavily on research, audit and also on case studies. Research on outcomes should influence policy. But is the research that is currently commissioned, carried out and reported the best research to inform us about all the questions raised above? This is “soft” research which is difficult to do and hard to get funding for. Good, unbiased recruitment is hard work at the best of times! Some current experiences suggest that there can be recruitment problems for such studies, as we have found in:

- Unilateral and mild hearing loss – RCT for amplification (www.mrchear.info)
- Positive Support – A UK Study about Deaf Children and their Families (http://www.positivesupport.info/). The aim of the research is to understand more clearly the link between outcomes and what happens with the deaf children and their families after identification of deafness.

Because of these difficulties, studies may be too small, too self-selective, and it is hard to get them published. They are too biased to be reliable indicators of population level outcome measures (e.g., language, speech, educational attainment) on which to develop a general approach and to apply to what you do for individual patients.

The Evidence Base for Complex Health Issues Needs a Whole System Approach

In addition to this, there is a more fundamental problem. For complex health issues, the “evidence base” may be different from the evidence base for simpler interventions (e.g., Does the drug reduce pain? Does the new hearing aid improve audibility?). In complex health issues one needs:

- different levels of evidence for different circumstances
- different evidence for different tasks
- different solutions for each local services
- to empower decision-making rather than imposing it.

Quantitative evidence is epitomized in healthcare by the methodology of the randomized controlled trial (RCT), made famous by Archie Cochrane (Cochrane 1972). The evidence base for complex health issues needs a whole system approach. In so many cases an RCT is not feasible for this kind of research, nor will it really show what to do in local services.

The multi-agency character of the hearing care journey also means that engagement with all relevant agencies, particularly education and social care, is vital. All this calls for a multi-agency, whole systems approach to research on outcomes, so the evidence comes from the whole patient care pathway rather than individual parts of their journey. The current gap lies in the lack of mechanisms and ability of these agencies jointly to measure, observe and optimize the whole process of the hearing care journey and reduce waiting times/inefficiencies. Particular challenges are the lack of agreed specification/standards across all agencies for what a “quality” service is, let alone what constitutes a good outcome. There is much still to be done here!

Evidence for policy is different from evidence for practice. Policy is necessarily developed at a general level. Implementing policy evidence needs to be considered carefully in each local service. So policy evidence needs to empower decisions rather than impose them – we can all think of examples where policy evidence applied without local adjustment has not worked. For complex health issues with long care pathways, multiple human interaction variables for staff, children and parents and multi-agency services, the definitive RCT approach won’t work. It can be argued that for this kind of service, the case study has a very high value AND enables us to help translate evidence and emerging technology into practice. The focus is “how does it work here?”, not “how did it work in centers of academic excellence likely to be used in the pilot studies which usually inform policy research?”

What do we Know About How to Transform Services?

Case studies are a way of improving services at a local level. But we would like to be able to do more, to transform rather than improve. Can we transform a health service like pediatric audiology? One way to start transforming a service is to introduce new technology, as we have seen, but most service transformation is not just about new technology.

The main thrust of this challenge in practice is changing people’s behavior. A recent NHS initiative “Thinking Differently” (http://www.institute.nhs.uk/images/documents/BuildingCapability/NewModels/ThinkingDifferently/) emphasizes that...

"...it is the extent to which we are willing to think differently that determines how great a difference we can really make. We can make incremental improvements,
which of course are good, but if we stand back and challenge more deeply how we do things, the gains could be much larger in terms of effectiveness and efficiency.”

(www.institute.nhs.uk/building_capability/new_model_for_transforming_the_nhs/thinking_differently.html, NHS Institute for Innovation and Improvement).

Thousands of words have been written about how to transform services, and we are all familiar with the theory:

- quality standards
- measure performance
- measure outcomes
- evaluate improvement in outcomes.

The UK National Institute for Health and Clinical Excellence has just produced a useful summary guide (Jan 08) How to change practice: understand, identify and overcome barriers to change. (www.nice.org.uk/media/AF1/73/HowToGuideChangePractice.pdf, NICE) It emphasizes that changing behavior is difficult without understanding, identifying and overcoming barriers to change. Doing this takes time: reflecting on practice, individually and collectively, is not common in services that are under pressure from targets which inherently involve time constraints. Sometimes people prefer to be busy rather than reflect on whether the ways they are being busy are the most effective.

How can hearing service transformation be achieved? In England there are about 180 local hearing services (pediatric and adult), each of which is, historically, organized in a somewhat different way and operating in a distinctive local professional, institutional and geographical environment. These are indeed complex health systems in complex environments.

“Compared with drug trials or trials of surgical procedures, the design and development of a health service intervention is highly complex. In practice such interventions are often defined pragmatically, according to local circumstance, rather than building on any specific theoretical approach. Even if an approach or technology can be clearly grounded in theory and evidence, it must still be operationalised and evaluated among specific practitioners and patients. There is thus a tension between evaluation of complex interventions and generalisability of results. Randomised trials alone can not tell us why an intervention was or was not successful, or whether the theory and evidence informing the intervention were appropriate or needed revision” (Bradley, Wiles, Kinmonth, Mant and Gantley 1999).

Evaluative Case Studies can be a “Powerful Persuader” in Changing Clinical Practice

It would be defeatist to say that because we cannot easily do RCTs we cannot design research methods which will help improve service outcomes – and sometimes transform them. The use of qualitative research methods, such as evaluative case studies, offers a way forward. Yin describes the scope of case studies:

“A case study is an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident” (Yin 2002).

The emphasis is on the real life setting in which these services are delivered and received. The focus is on how and why these interventions succeed or fail, and how the context in which they are delivered will influence the outcome. “Case study evaluations are valuable where broad, complex questions have to be addressed in complex circumstances. No one method is sufficient to capture all salient aspects of an intervention, and case studies typically use multiple methods” (Keen and Packwood 1995).

Case studies are not, of course, an easy option. But a service which regularly uses its own cases as study material, supported by audit information and benchmarking with other services and national standards and guidelines, will have a tool for reflecting on actual practice and improving it. Running a good case study system, discussion and action planning, is a skill we should be fostering as a way of making our service outcomes, both hard and soft, improve at a reasonable cost which respects the complexity of actual cases and local circumstances.

Case studies can be rigorously designed and will enable local managers and professionals to review their own practice, informed by an understanding of what it is and is not possible to achieve under their local conditions. A distinctive feature of case studies is the use of multiple methods and different sources of evidence: they often use “triangulation” (a method of establishing the accuracy of information by comparing three or more types of independent points of view on data sources) to ensure the findings are valid.

Case studies can also be particularly helpful in exploring the role of families and children, who often have had very little input into outcomes research. “Useful research will be directed not only at the issues that are identified as being of immediate concern by practitioners, but
also to those which the researcher can demonstrate ought to be of concern. It is often unhelpful to restrict research to those problems that are identified by practitioners or managers. We cannot always be sure that the problem presented by practitioners is in fact the one which needs to be addressed" (Murphy, Dingwall, Greatbatch, Parker and Watson 1998).

Techniques like discovery interviews can be used to support case studies so that children and family voices are heard.

At the same time this kind of research will give fair weighting to the perspectives of practitioners and managers:

“... The credibility and usefulness of a research report will be enhanced where the analyst conveys as much understanding of the powerful as of the powerless within the organization” (Murphy et al. 1998).

Data from case studies can often be a “more powerful persuader than scientific publication in changing clinical practice” (Green and Britten 1998). Transforming services is really an art – selecting from the range of methods the ones that are possible in a given situation and suit local circumstances and the level of motivation we are able to develop in our staff.

Case Studies Could Show Good Practice Along the Care Pathway

Case studies that work need to be grounded in quantitative evidence of what good practice looks like, where that is available from national studies/research, but also must be aligned with the core values and mission of the local services. Case studies could show good practice along the care pathway:

• screening
• follow-up
• improving local access for parents
• home assessment and diagnosis
• making good referral for otitis media
• providing wax removal services
• improving efficiency
• managing children with multiple pathologies
• integrating parent input or family support
• integrating audiology input with all other professional input
• outcome assessment.

It is crucial that everyone’s perspective is counted in, “triangulated”. Any research that seeks to go below the surface of routine data collection will only work if professionals, parents and children work in a climate which values telling it like it is. If professionals feel under pressure to be seen to be performing, the real picture will not emerge; if parents feel it’s better not to offend staff or if children feel overawed by their surroundings, the real picture will stay hidden. But it is that real picture which is the actual driver for service outcomes, so the task of designing ways of revealing it is a key management task, and contributing to it is a key staff responsibility. Evaluative case studies will only work if:

• professionals report their outcomes (e.g., it doesn’t help much, no difference for my patients)
• parents report their outcomes (e.g., it is ok, but Jack won’t wear them when he goes out)
• children report their outcomes (e.g., can I turn on the directional system when I want to overhear what my friend is saying about me?).

In the NHSP Quality Assurance Programme we have systematically documented eight major domains and derived standards: access, information provision and communication with individual patients; assessment; developing an individual management plan; implementing an individual management plan; outcome; professional competence; communication, support and collaborative working. Each one of these can have a different outcome measure for patients. We have devised and are improving a quality rating tool, which may be possible to use to monitor “compliance” and progress.

If staff can use these national standards for measuring services alongside local case studies to help implement and monitor their care pathways, we would have a balance between nationally agreed standards and locally understood services, which would be a powerful engine for service improvement and even transformation.

• what guidelines should we use to prepare the national standards?
• how should we review them?
• how do we moderate and learn from them?

Once we have introduced the agreed standards, how do we research how far case studies can provide adaptive learning, and are case studies best used in a local service or in a network? The advantage of using a network approach is that the cost of training and support for the skills and leadership needed for a robust use of the approach would be shared across several services. The downside might be a loss of local commitment. We need to compare the approaches to find out.

There are some studies that we have used in developing our national standards/local case studies approach. The literature is somewhat thin – because this is soft research, for which, as I said earlier, it is harder
to get funded. Palmer’s work (see Chapter 10 in this volume) shows how clinicians might go about answering specific clinical questions through:

- Clinical expertise
- Best evidence
- Patient values, circumstances

Another example is Bagatto, Seewald, Scollie and Moodie (2007); this case study illustrates the importance of implementing a comprehensive assessment protocol.

There are also a number of ways of involving children and parents so that they are a real part of the work. We have already mentioned discovery interviews; they are semi-structured with no formal direct questions. Discovery interviews can give children and parents the chance to tell the story of their illness or condition directly, using a framework that guides them through the key stages of their experience. Between 2002 and 2003 the NHSP Evaluation team undertook a qualitative interview study of 40 parents whose deaf children were identified through NHSP in Phase-One Pilot Sites (http://hearing.screening.nhs.uk/getdata.php?id=317). They used this technique because they wanted “more than asking service users their opinion…

- Evaluation through exploration of personal experience
- Parents’ set the definition and criteria for what counts as ‘meaningful’
- Allows for challenge to expert categories of interest, evaluation and analysis.”

Different Perspectives of Parents, Children and Professionals

Parents, children and professionals may have different views of what good practice is and what leads to good outcomes. You may think that you have good services (we all do), but are you and your staff really excited to get to work? Is good practice making Real Ear Measures (REM) work for an awkward patient, meeting someone’s need or ensuring that services always have crystal-clear information? The happy child may be the one for whom we know the target audibility has been met by conducting appropriate REM protocols. So, if we know the outcome, we can improve the services (http://www.library.nhs.uk/ent/ViewResource.aspx?resID=250767andtabID=289).

An important paper by Young et al. (2006) addresses the issues underlying the understanding and provision of informed choice for families with deaf children in terms of support and habilitation and the challenges to professionals (see Chapter 9 in this volume). Alberg’s paper on the “Beginnings” Early Intervention programme in North Carolina (a non-profit organization providing support and access to information to parents) outlines an Informed Choice approach in practice (Alberg 2006). The paper by King (2006) also explores the issues of complex choice-making for parents and highlights the importance of counselling in influencing future outcomes.

Building Communities of Practice

These case studies at a local level will not have great impact unless we use them to build what we call “communities of practice”, in hearing healthcare: that is, a culture in which professional guidelines, care pathways and best practice are adhered to by using mechanisms such as mentoring, shadowing, workshops (training), supervision, leadership and having champions both within and between departments/specialities. The NHSP national pilots established a community of practice, linked by the research and innovation focus. The challenge now, after national implementation, is to create communities of practice across the whole service.

The establishment of “collaboratives” and networks sharing knowledge and skills is a central element of the modernization programme of the NHS. The NHS has collaboratives in cancer, orthopedics and coronary heart disease. They have been shown to be effective in improving services because the staffs are committed to share best practice and implement it within a culture of continuous improvement and evaluation. Hearing healthcare in the UK could benefit from similar initiatives.

Development work to support the NHS Audiology Action Plan “Improving Access to Audiology Services in England” (2007) is encouraging sharing of good practice, and case studies are also being shared on the internet. The possibility of building “virtual” communities of practice may be new to older staff, but will be second nature to younger staff and many parents who have grown up with the internet as a key networking/communication tool: http://www.18weeks.nhs.uk/public/default.aspx?loadCaseStudyViewandID=71.

Services can look at these case studies of good practice and see what might work in their contexts. They can then share their learning and build up a community of practice in such a way as to validate their good practice, get feedback and find out if it is more widely applicable, and check that it isn’t off mainstream practice.
All this will help and embed an evaluative culture and quality assurance processes. We hope that the quality assurance measures will use a peer-review approach, which builds communities of practice. Staff need to share good practice such as that developed by the Modernising Children’s Hearing Aid Services (http://www.psych-sci.manchester.ac.uk/mchas/).

The culture needs to change to encourage staff to write up good practice and engage with supportive comment on other good practice case examples, to share and explain good practice. Other methods could be shadowing, on-elbow support, and role exchange, but in our model the use of national standards and a case study approach are the two key tools, which all staff would use.

The experience gained by the “world community of practice” in audiology and habilitation will of course be a driver for us in the UK. Our task as national leaders committed to improving and transforming services is to win the hearts as well as the minds of all involved! It needs our leadership and personal conviction. We must champion the values of research and case studies, as parents, professionals and politicians understand them. We must convince all in our organizations that this kind of “soft” research into the outcomes that really matter is vital in our communication-led society.

What we do Next: A Way Forward

The challenge for research into outcomes for deaf children is twofold. The first is in the design of research. We need:
- a cultural shift to place greater value on case studies
- to work with parents to include outcomes in routine services
- to promote good practice in “peer review” case studies
- to promote quality assessment (e.g., using a quality rating tool).

We need studies which look at not only the relevant clinical information, but all factors which affect their lives, such as family, cultural, demographic, and individual child characteristics.

The second challenge is ownership. We need to:
- explore new models of ownership
- work more closely with parents
- involve people outside deafness and hearing
- start a network for case studies.

We must make outcomes which matter integral to research, service planning and delivery – the main thrust of this challenge is changing people’s behaviour – in such a way that that they want this research done, are willing to be part of it, and will press for the research to be used to make changes in service delivery.

So Why Bother?

It took nine years to get newborn screening from pilot stage to a national programme benefiting all newborns. We can’t wait another nine years to find we haven’t answered the questions that really matter to children and parents. There is a tragic gap between what we know, what could be and what exists. If we can find ways of looking at and closing that gap together in communities of practice, world wide, national and local, I believe we can transform services and lives.

References


http://www.bmj.com/cgi/content/full/316/7139/1230#B6
http://www.bmj.com/cgi/content/full/311/7002/444


http://www.18weeks.nhs.uk/public/default.aspx?main=true&load=ArticleViewer&ArticleId=570#framework


**Website References**


www.mrchear.info

http://www.positivesupport.info/


http://www.institute.nhs.uk/building_capability/new_model_for_transforming_the_nhs/thinking_differently.html (NHS Institute for Innovation and Improvement)

http://www.nice.org.uk/media/AF1/73/HowToGuideChangePractice.pdf (NICE)