NHS Newborn Hearing Screening

Programme Centre

Annual Report 2006/07
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This report is available in an interactive format with additional videos and audio commentary from Sir Muir Gray, Professor Adrian Davis OBE and Professor John Bamford at hearing.screening.nhs.uk/annual_report_2006-07
1. **ACKNOWLEDGEMENTS**

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*This work was undertaken by the NHSP Programme Centre who received funding from the Department of Health; the views expressed in this publication are those of the authors and not necessarily those of the Department of Health.*
2. **FOREWORD**

I admire the way in which the Programme Centre as taken a poorly performing screening test and through management has effectively implemented a new scientifically proven screening programme.

Some people believe that change and transformation are the same thing, however change does not necessarily lead to reform or transformation. In the past the health service has been constantly changing but transformation has not happened. However I believe NHSP has transformed hearing screening and hearing services.

There is only one thing that is guaranteed in service provision and that is constant need for improvement. It is unacceptable for progress in terms of technology, experience and policy not to evolve with evidence or technological advances.

I see the future of the NHSP Programme Centre as that of delivering continuous quality improvement in services and systems in relation to NHSP and the wider support and follow-up services.

The programme has been excellent in providing systems or as I like to think of them a nervous system, something that can guide, respond and adapt, that embraces evolution and seeks to constantly improve on current standards, with the ability to evolve with evidence and best practice. Information and systems give meaning to everything that we do, there is no point in going through the motions and providing a service if there are no systems on which to support, record or monitor the process or outcomes.

The national database is a fantastic resource that allows standardised care across the country, enhances research and understanding but not only that helps to fully utilise the unique resource the UK has in its NHS.

So congratulations’ and well done to everyone involved in this wonderful programme.

**Sir Muir Gray**

Director of Clinical Knowledge, Process and Safety for NHS Connecting for Health

*Adapted from the Podcast recorded by Sir Muir Gray for the interactive annual report which can be found at hearing.screening.nhs.uk/annual report 2006-07*
2.1. Welcome from the Director

Thanks to the hard work of local NHSP staff, private and voluntary sector partners and the Programme Centre team, 2006/07 was the first year in which newborn hearing screening was offered universally in England (and around the UK).

Recently NHSP announced (Aug 07) that 2,000,000 babies have been offered a hearing screen (English programme). I am able to include the recognition of this huge milestone in the annual report for 2006/7, as I have been very slow to write my welcome. But it was worth the wait to be able to include it!

The Programme Centre and the Department of Health have entered into a new Service Level Agreement for the Programme Centre to continue to 2010, so that it can continue to bring innovation, quality management and risk management to newborn hearing screening and associated services for deaf children and their families. We are extremely pleased to be continuing the work with all stakeholders to deliver the original vision for NHSP: all children should be able to develop high quality interaction with their parents and family at the earliest opportunity.

There has been major investment in screening and healthcare, with palpable results. The age at which severely and profoundly deaf children are identified has been hugely reduced. Even larger reductions have been made for those children who have moderate hearing impairment. This is fantastic and I really do want to thank all those who make this possible on a day to day basis. Keep up this excellent work!

We have shown that NHSP has made a difference, so we want to begin to look to the future sustainability and the need to benchmark and improve services. It is necessary for there to be equity in screening, assessment, hearing aid fitting and availability of communication support options, of cochlear implants, and of specialist support such as Teachers of the Deaf, Speech and Language Therapists or Social Care professionals.

NHSP began the implementation of the Quality Improvement (QI) programme in November 2006. To date (Sept 07), there have been 66 quality assurance visits to sites. The findings for 2006/07 (24 visits) are discussed later in the report. The major emphasis in this round of visits (Nov 06 – Mar 08) is to rapidly discover 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. We hope to commission new software in the very near future to improve the project management of the QI programme and to manage the recommendations that come out of the reports. This should reduce the burden, both on services and on the QI team.

The Programme Centre firmly believes in continuous improvement and with this principle in mind continues to consult with service users and providers regarding their opinions, wants and needs. The latest in the series is a consultation with deaf children about their thoughts on hearing services (to be continued into 2007/08). A DVD from the first of these is available on request from the Programme Centre and further details appear later in the report.

Over the course of the year the team has achieved successes in many areas:

- Worked with the NSC & other Antenatal and Newborn Programmes to develop and deliver new information packages for parents.
- NHSP was the first screening programme to launch its care pathways in the Map of Medicine; these are now operational in the tool for practitioners and clinicians.
- Successfully launched the first in a series of elearning modules for screeners, which along with the Observed Structure Clinical Exam make up Screener training. The new NHSP Screener training programme has been approved by the British Academy of Audiology (BAA) Board and Education Committee.
- Introduced a new and improved website for the sharing of knowledge and information see hearing.screening.nhs.uk

As many of the local NHSP services are aware, especially those in London and in the Manchester area, we have been assessing the advantages and disadvantages of moving towards managed networks of care. ‘A Guide to Promote a Shared Understanding of the Benefits of Managed Local Networks’ (DH Gateway ref: 4968) highlights the benefits to working within a local network(s) for certain services. The major benefits are seen in terms of the stability of the organisation and the ability to offer all children and their parents quality, not postcode options, for their support. This work is ongoing.

I am particularly interested in the quality of the data that is recorded from maternity through newborn hearing screening and into hearing assessment (often in audiology departments). Currently there are anomalies in the data collected for the 634, 320 babies
that were offered a hearing screen in 2006/7. Some of these anomalies require better systems in place to feedback and ensure that they don’t continue to happen. We are working towards enabling this. More training may be necessary in some cases and a bit more effort from everyone to ensure that good data is recorded. The NHSP information system (eSP 4.2 sourced through our contract with Northgate IS Ltd) is ‘probably the best in the world’. But if the data in the system is incorrect or is inadvertently not updated then individuals’ care can and will suffer. Ultimately the programme, locally and nationally won’t benefit from the large public investment in the system.

However the eSP system has now been given the go-ahead to become ‘spine – compliant’ (Aug 07). This means that it will be accepted as a mainstream NHS IT service and that it will communicate with the major new systems coming along from Connecting for Health once work is complete. It may also enable us to let individual programmes and staff compare their performance year on year, or with neighbouring areas. A key element of this work is knowledge and information about the children who are identified with a hearing loss or deafness.

Whilst looking at the data from eSP, several issues have been raised: the major one being that, if we cannot specify how many deaf babies are identified by NHSP then it is difficult to justify the huge investment in staff and money to deliver the services. Presently there are 21 local NHSP programmes where the number of deaf and hearing impaired children identified is significantly below the expected value. It is difficult to say if this is due to the fact that the data are not entered, not updated or that babies have been missed by the screen. We are focused on working with local programmes through the QA process and through the training events we host to overcome this situation. For further details on training opportunities visit our website hearing.screening.nhs.uk/nhsptrainingandconsultancy.

Recently, the very real need to update the data was highlighted in an incident where referral from the screen was not appropriately logged by the department responsible for the hearing assessments. As a result as many as 40 referrals may have gone astray. If these were typical referrals (on average 1.92% referrals with about 0.50% being bilateral no clear responses), the data in eSP shows that there may be 10 children referred who had no clear responses on both ears among those 40. One in five of these children will have raised hearing thresholds (from all causes) with about 13% having bilateral permanent deafness of 40 dB HL (average) or more. We encourage all NHSP programmes to agree assessment appointments and enter them into eSP at the time of the screen.
However to support the care pathway and to provide good quality information on each local programme there is also a need to know if the baby attended and what the outcome of the assessment was for each baby referred. Over the coming months, we will consult with you about how we can work together to assess and benchmark these technical outcomes as well as making an assessment of what standard data and information on child health outcomes can be collected routinely, without imposing any additional burden of data collection. I would be very keen to receive any ideas about how this can be best done.

The programme has revolutionised a system of care nationwide through the implementation of the Screening Management System. This tool, linked to the Performance Management System, has the potential to substantially increase our knowledge base: England is in a unique position compared to the rest of the world in that it runs a state funded National Health Service which has huge potential to inform future care and eSP is very well placed to help us achieve this for deaf and hearing impaired children. One of the key weaknesses in our knowledge and information base highlighted above is data on hearing assessment and outcomes. Without this 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.

To realise this vision there is much work to be done not just by the Programme Centre but by everyone who has responsibility for child development and welfare. In order to ensure better governance and family friendly practice we need every individual on a nationwide scale contributing their bit to the national picture. Only with cohesive and collaborative ways of working can we get the job done and ensure deaf and hearing impaired children reach their potential. We need to build on the critical mass and strengthen areas of weakness. This can be achieved.

Finally, over the summer Dr Anne Mackie has been appointed to be Head of Screening Programmes (in England). Anne has been chair of the Foetal, Maternal and Child Health Committee for a few years and is very familiar with NHSP. We welcome her appointment and really look forward to working with her over the coming years.

Thank you

Professor Adrian Davis OBE
Director NHS Newborn Hearing Screening Programme
2.2. Highlights for 2006/07

- Professor Adrian Davis was invited and attended a dinner with PM Tony Blair (pictured).

- The Queen’s Birthday Honours list included an OBE for services to Healthcare for Professor Adrian Davis.

- The programme was asked to showcase its work and achievements to PM Tony Blair in February 2007, which was well received by the PM and Patricia Hewitt, Secretary for Health.

- The Department of Health and University of Manchester have entered into a Service Level Agreement via Central Manchester and Manchester Children’s University Hospitals NHS Trust to continue to fund the NHSP Programme Centre to 2010.


- NHSP became the first screening programme in England to publish care pathways in the Map of Medicine, enabling knowledge and information transfer at the point of care delivery.

- The new screener elearning module was launched; ensuring levels of competence are maintained and achieved in the local screening teams and making training more affordable and accessible nationwide. For a demonstration please visit hearing.screening.nhs.uk/elearning

- NHSP established a new and improved website hearing.screening.nhs.uk to enable information to be accessed by patients, the public and professionals alike.

- An innovative consultation with deaf children was held to establish their opinions and thoughts on hearing services, a DVD is available on request via the Programme Centre.
2.3. Programme Performance & Statistics

At the moment, the prevalence of bilateral permanent deafness, (using data from April – November 2006) is about 0.8 per 1000 with 0.4 per 1000 being unilateral deafness. This breaks down to 5.3% for NICU babies and 0.5 per 1000 for non NICU babies for bilateral deafness. These prevalence rates are lower than we might expect from previous research, but are likely due to the lack of appropriate data in eSP or the difficulty in carrying out assessments in challenging situations.

The following programme statistics were compiled on the 22nd June 2007 for babies born within the last financial year; 01/04/2006 – 31/03/2007.

Coverage and screen take-up

- New birth records 641,976 recorded in the year (recorded in eSP via Babies birth notification feed NN4B)

Of these births

- Screens offered 98.8%
- Screens started 96%
- Screens complete 94%

Indicating that coverage is good, but screens completed requires more attention.

Screening Outcomes for the following date range Apr-Nov 2006 due to the time it can take some time to for some incomplete reasons or NICU tests to be collected. Using the data, For babies who completed the screen the outcomes set are as follows:

- Clear response – no follow-up required (89.77%)
- Clear response – targeted follow-up required (3.12%)
- Incomplete - in any way (5.19%)
- No clear response – Bilateral referral 0.50%
- No clear response – Unilateral referral 1.42%

The number of incomplete outcomes is concerning, but some of these are inevitable. The bilateral refer rate is low and the unilateral refer rate is good. The unilateral refer rate is lower in community sites than in hospital sites.

324 children have been identified with permanent bilateral moderate, severe or profound deafness (out of 428,020). This is a prevalence of 0.8 per thousand.

19 (6%) of these deaf children were identified via targeted follow up, a yield of 4 per thousand
children who took the targeted followed up (approximately 40% of children identified as requiring targeted follow up, have data recorded)

There were 37 children with auditory neuropathy in this time period.

The median age of first assessment of referrals was around 45 days, with confirmation of permanent hearing impairment (that are known now) at 66 days.

The median age of first hearing aid fitting, in those that chose this option was 91 days

There were 189 children identified with severe or profound bilateral deafness (out of the 324)

518 children identified with permanent unilateral or bilateral moderate, severe or profound deafness. This is a prevalence of 1.2 per thousand. Of these children 320 had severe or profound deafness.

316 additional children with bilateral moderate hearing loss, whose type is unknown, are being monitored by services.

Most of these children will have glue ear, but some may have underlying mild/moderate permanent hearing impairment.

There were 227 referrals with bilateral no clear responses (11%) for this period where the assessments have either not been carried out or where the results are not yet recorded.

There were 572 (9%) of unilateral referrals in a similar position.

About 2.3% of children who started the screen, who were due a further appointment did not attend that appointment.

We all need to ensure that the number of babies with clear response on first screen is maximised, that the number of referrals is kept as low as possible and that parents’ concerns are properly addressed where they are expressed.
3. ACHIEVEMENTS

3.1. Quality Assurance & Quality Improvement

The NHSP is governed within a risk management framework that encompasses a quality assurance programme and risk management activity. The framework supports services to enable the achievement of the highest possible standards of care for deaf children and their families. It does this by working in partnership with service managers in health, education and social care, local trusts, public health, commissioners, private and voluntary sector.

In 2006/7 the focus of the risk management framework was to implement a national peer-review programme and a governing body, the NHSP Quality Assurance Board. To continue the drive towards incident reduction and risk management in hearing screening.

Quality Assurance Programme

A national recruitment campaign in summer 2006 culminated in the appointment of 26 professionals from the fields of Screening, Audiology, Medicine and Education to form the QA team and a Quality Assurance Co-ordinator to provide full time administrative support for the QA programme. A training day was held in October for the entire team, including NHSP National Co-ordinators, and the first QA support visits began in November 2006. The remit of the QA team is to seek assurance that systems are in place to provide high quality services with effective error prevention and management. In particular, they will be looking at how robust the governance arrangements are locally, whether services have been commissioned with the capacity to meet demand, if service provision is in line with the quality standards and family friendly practice and if there is a quality improvement culture in place. In addition, the National Co-ordinators will assist in the quality assurance programme by helping sites prepare for the visit itself and supporting the development of improvement plans after QA visits.

By the end of March 2007, 24 visits had taken place. The report, written after each visit, is reviewed by the Quality Services Manager at the Programme Centre and then sent to service providers for comment on accuracy. It is then published and circulated in hard copy, along with an action planning tool, to trust managers,
managers of special education, social services, commissioners and public health.

To date feedback from service providers and public health indicates that the QA programme is being well received and is providing a positive impetus for quality improvement. Gaps have however been identified, both within the QA process and in the quality standards, these will be addressed in 2007/8. In particular, there is a need to incorporate parents’ views into the visits in a more systematic way. Currently the QA team only have access to the views of a limited number of parents who are selected to participate locally. Ensuring the content and judgements made at visits are consistent is also a challenge. The QA team focussed on this issue at their second training day in February 2007. There will be a rolling programme of training throughout the year and consistency will continue to be a core focus.

**Awareness of the QA Programme**

In September and October 2006 a series of 10 seminars were held one at every SHA. The seminars reached an audience of over 700 professionals from health, education, social care and public health and were designed to raise awareness of the QA programme, its political context, the process and local requirements for its successful delivery. Articles have also been written in site updates to keep service providers informed of the programme’s performance and invited presentations have been given at the British Association of Audiological Physicians conference in Southampton, The Annual Hearing Screening Workshop in London and the 2006 Hearing Screening conference in Como, Italy.

**Results summary, November 06-March 07**

Graph 1 summarises the QA support visit findings from the first 24 visits. For each standard (1-26, abscissa), the QA team judged whether the standard was met (score of 3), almost met (score of 2) or not met (score of 1). The bar chart shows the mean scores across visits for each standard (ordinate). In the screening part of the journey many services are meeting or almost meeting the standards around screen coverage (standards 5-7). Information in the antenatal period usually given out (standard 2) and there is usually some kind of interpreting services available (standard 1) but this is often over the telephone. The demand for interpreting services varies a great deal from site to site. The NHS numbering system is working well in almost all sites (Standard 3). The
quality of verbal information given to parents about the screen (Standard 4) is generally high quality, however, the need for continual screener training and competency assessments is a common theme (for details on how we will address this see section 3.4). It is clear, from the standards relating to the appropriate use of the IT system (Standards 10-12) around checking the accuracy of screening data that local screening services are taking data quality issues seriously and trying hard to mitigate the risk of giving parents the wrong screen outcome.

Of more concern is the time taken to assess babies in audiology following screen refer (Standard 15) and the capability and capacity of audiology services to identify permanent childhood hearing impairment by 6 months of age (Standard 16).

Fundamental audiological testing methods such as frequency specific ABR and bone conduction ABR is lacking in many services along with the expertise to fit the most up to date and appropriate digital hearing aids to young babies. The quality of audiology data in eSP is still inadequate and an area that requires much focus. There is no assessment data for up to half of referrals in some sites and there is often missing data around hearing thresholds, both of which prevent the true yield of the programme being accurately assessed.

The majority of standards around early support (Standard 21 onwards) for babies and families from education are being met. The social care functions are generally being met but often not through the input of dedicated social workers for the deaf. Instead they are...
being fulfilled through education services.

**The QA Board**
The QA board was convened in October 2006 and meets quarterly. The terms of reference have been agreed and the Board has started to receive and comment upon the reports from the QA support visits. The Board is overseen by Dr Graham McLean who is a parent of a deaf child (now adult) and former trustee of the National Deaf Children’s Society. Membership extends across health, education, social care, voluntary sector and public health.

**Engagement with Social Care**
To date the Programme Centre has largely focused on ensuring early identification of deafness through high quality screening and diagnosis and that early audiological management and education support is in place and appropriate. However in the light of the QA agenda there is a need to further our understanding of what families want and need in terms of social care and how the social care system might respond to meet these needs in line with both statutory and non-statutory duties and responsibilities.

To take this agenda forward the Newborn Hearing Screening Programme Centre has been working with Professor Alys Young, Professor of Social Work Education and Research at the University of Manchester. This resulted in a workshop to engage Social Care professionals in NHSP, Dec 2006. The workshop was designed to explore the role of social work and social care in the lives of newly identified deaf children and help shape the programme’s understanding of what constitutes a high quality Social Care service and what the NHSP QA programme should be focusing on. As a result of this workshop, two social workers will join the QA team and help develop strategies for further areas of development.

**Improved Commissioning Arrangements**
A baseline assessment of service provision across Greater Manchester was carried out collaboratively with the Association of Greater Manchester PCTs and the newly developed service specification for hearing screening was agreed and launched during National Knowledge Week for Hearing 2007. A workshop will be held in June 07 to facilitate the implementation of the service specification by providers and commissioners and promote improvement planning as a result of the baseline assessment.
3.2. Information Technology, eSP and Knowledge Base

Information Systems

NHSP has an ongoing commitment to providing robust, innovative, integrated and easy to use information systems to support screening services from start to finish. This is primarily delivered through the eSP national Screening Management System, and related interfaces with screening equipment, and through the NHSP website and Performance Management System.

Achievements 2006/07

After a thorough tender and evaluation process, led by the University of Manchester, a new contract was established (starting October 2006) with Northgate Information Solutions Ltd for the ongoing delivery and support of eSP, and related systems, until March 2010. The new contract offers even better value for money, improved governance and an ambitious programme of work to further develop the eSP product. The new contract has been the catalyst for many improvements to the eSP service over the past year. Table 1 overleaf shows that although the helpdesk is now dealing with a much higher volume of calls, the first time fix rate (issues resolved during initial call) is rising. All priority 1 incidents (resulting in the complete loss of service) were resolved quickly; overall Northgate have met their Service Level Agreement in terms of system.

The Helpdesk re-launch took place in December 2006. This included sending out a Helpdesk leaflet with contact details and hints/tips on eSP to all sites, making available a 2 page summary of the Service Level Agreement, creating a page on the NHSP website hearing.screening.nhs.uk/helpdesk and moving to a new local rate number. A new call system means all calls are now answered within 45 seconds.

eSP v4.0 was launched on 3 April 2006 and v4.1 on 8 November 2006, together introducing key new features to improve data quality, that allow easier patient management (for example by sharing records between sites when appropriate) and to facilitate information sharing with Child Health.
The NHSP website was re-launched, (after an extensive period of review and consultation) during National Knowledge Week for Hearing 2007. It has a completely revised user interface, with a better public/parent focus, pan-screening programme branding and easier to find information. The new address is hearing.screening.nhs.uk

The Performance Management System has been extensively used to investigate incidents and provide performance reports for local services, including new reports which allow services to easily see whether they are meeting the NHSP Quality Standards.

**Plans 2007/8**

As part of the new contract Northgate acquired the rights to the eSP application for the UK. This was to improve the delivery and quality of the eSP application and in future new releases will take place on a quarterly basis. The first release under this new arrangement will be v4.2 in August 2007. This is primarily geared towards improving the audiology pages making the system more user friendly for entering information. eSP will also become SNOMED compliant in this release following consultation with the Connecting for Health Clinical Terminology Team.

Release, v4.3 around Nov 2007, will provide a new interface between screening equipment and eSP, as well as a new workflow system for managing records. The changes will significantly improve data quality and make eSP both easier to use and more useful in terms of reporting and, information management.

Discussions with Connecting for Health about making eSP compliant with the National Care Records Service (NCRS) are ongoing. Unless work begins by the end of 2007 there is a major risk that NHSP might lose the current electronic birth notification feed, with catastrophic implications for the programme.

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**Table 1**

<table>
<thead>
<tr>
<th>Period</th>
<th>Calls logged</th>
<th>Priority 1</th>
<th>Priority 2</th>
<th>First time fix</th>
<th>Changes logged</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apr – Jun 06</td>
<td>536</td>
<td>1</td>
<td>2</td>
<td>unavailable</td>
<td>21</td>
</tr>
<tr>
<td>Jul – Sep 06</td>
<td>855</td>
<td>3</td>
<td>0</td>
<td>65%</td>
<td>29</td>
</tr>
<tr>
<td>Oct – Dec 06</td>
<td>757</td>
<td>2</td>
<td>10</td>
<td>56.30%</td>
<td>24</td>
</tr>
<tr>
<td>Jan – Mar 07</td>
<td>1264</td>
<td>5</td>
<td>2</td>
<td>81%</td>
<td>35</td>
</tr>
<tr>
<td><strong>Total for the year</strong></td>
<td><strong>3412</strong></td>
<td><strong>11</strong></td>
<td><strong>14</strong></td>
<td><strong>67.43%</strong></td>
<td><strong>109</strong></td>
</tr>
</tbody>
</table>
3.3. Operations Management

Site Issues

The first full year post implementation has seen many challenges for local screening programmes in England. The challenges faced were as a direct result of local recruitment freezes and inadequately resourced screening programmes. These problems were also mirrored in many Paediatric Audiology services. The Programme Centre has worked with specific sites to ensure the risks associated with staff not being replaced due to recruitment freezes were highlighted and escalated. Once notified of these problems the Programme Centre has been successfully able to complete and issue specific risk assessments regarding long standing vacant key posts. These risk assessments have been successfully escalated at a local level and resulted in these posts being released and subsequently filled.

As the end of central funding approached in March 2007, fixed term contracting of screeners was also a problem for some of the programmes that implemented during the fifth and final phase of roll-out. With some PCTs unable to commit to substantive contracts for the screening teams this led to the inability of local managers to retain their trained screening teams or recruit new members. This was demonstrated in a reduction in the number of completed outcomes for these individual sites. This is still a problem for some sites and the Programme Centre is continuing to work with those affected.

The Programme Centre is looking at different solutions to short term staffing problems in order that sites can continue to provide full screening coverage whilst vacant posts are advertised and filled.

Site support and development

The National Co-ordinators continued to play a pivotal role in site support and development. To highlight the clear move forward of the
Programme Centre from implementation to ongoing quality assurance the National Coordinator team were reallocated to support sites on a more regional basis.

As well as assisting sites to prepare for their QA visits and supporting the development of improvement plans after the QA visits, the National Coordinators have provided ongoing support and development for Local Coordinators throughout the year.

During 2006 the National Coordinators provided risk and incident management training to Local Coordinators across the country. These two day regional training events involved planning strategies for risk and incident mitigation with scenarios related to specific incidents. It also saw the introduction of the new best practice guidelines and provided valuable information leading up to the quality assurance visits.

Day one consisted of

- Reduction of errors and system failures
- Identification and management of errors and system failures
- Quality improvement – barriers and solutions

Day two focused on performance monitoring and reports

- Introduction to the quality assurance programme
- Introduction to the revised quality standards
- Introduction to the best practice guidelines
- Key performance indicators – national report 1
- Impact of data quality on reports
- New quality standard reports
- Discrepant and lost data
- Managing the screening journey
- National reports 2-7

The Programme Centre continues to develop the support it gives to local screening programmes and 2007/8 will see some exciting developments piloted.

We are planning to pilot a national helpdesk for sites to contact, which will enable one point of contact for operational support issue. If deemed successful by the team and local programmes this will become a permanent feature.
3.4. Equipment: Consumables, Calibration & Repair

Central funding was again available for the repair and calibration of screening equipment and the provision of consumables. The close monitoring and distribution of consumables will continue throughout 2007/08 and sites will once again be required to submit, in writing, requests for any increase to their allocation for the period of the financial year.

The Programme Centre continues to work closely with equipment manufacturers and suppliers with meetings held on a regular basis to review equipment and feedback user issues and concerns.

It is through the central procurement of equipment and consumables that the Programme Centre saves the NHS approximately £2,000,000 per annum. This is due to the framework agreements negotiated through NHS PASA (Purchasing & Supplies Agency) and through the sheer bulk buying power of NHSP on a national scale.
3.5. Risk & Incident Management

Table 1 gives a summary of incidents recorded for 2006. Incidents are reported to the Programme Centre in addition to the normal local reporting procedures. This allows the Programme Centre to identify trends and patterns and initiate appropriate mitigation and advice. Table 2 shows further details of the serious incidents recorded for 2006/07.

Table 1: Summary of incidents recorded for 2006/07

<table>
<thead>
<tr>
<th>Incident type</th>
<th>Error</th>
<th>Incident</th>
<th>Near miss</th>
<th>Serious incident</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appointment sent for deceased babies</td>
<td></td>
<td></td>
<td></td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Data loss</td>
<td>16</td>
<td>64</td>
<td></td>
<td></td>
<td>80</td>
</tr>
<tr>
<td>Discrepant data</td>
<td>30</td>
<td></td>
<td></td>
<td>1</td>
<td>31</td>
</tr>
<tr>
<td>Equipment fault</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Failure to follow equipment protocols</td>
<td>1</td>
<td></td>
<td>10</td>
<td></td>
<td>11</td>
</tr>
<tr>
<td>Failure to follow up referred babies</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Failure to follow up targeted babies</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Ongoing audiological management Issue</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
<td>1</td>
<td></td>
<td></td>
<td>14</td>
</tr>
<tr>
<td>Screening protocol failure</td>
<td>6</td>
<td></td>
<td>1</td>
<td></td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>68</strong></td>
<td><strong>65</strong></td>
<td><strong>11</strong></td>
<td><strong>15</strong></td>
<td><strong>159</strong></td>
</tr>
</tbody>
</table>

Table 2: Information about serious incidents for 2006/07

<table>
<thead>
<tr>
<th>Category</th>
<th>Identification method</th>
<th>Current controls</th>
<th>Suggested future controls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening appointment sent for deceased baby</td>
<td>Usually by parent reporting to the local screening programme</td>
<td>- Included in risk and incident training for local coordinators held in summer 06.</td>
<td>- Exploring links to patient demographic information in national care record.</td>
</tr>
</tbody>
</table>
| **Discrepant data** | Incorrect screening test results manually entered in eSP and consequently baby not offered appropriate follow up. Presented to Audiology service at age 2 years when bilateral hearing loss confirmed. | - All screening tests results in hospital sites now routinely uploaded electronically into eSP. Monthly exception reports provided to each site listing any manually entered test results or any results where the result in eSP differs from the result imported from the screening machine. Local coordinators check and sign off all such reports.  
- Community data checker tool developed and made available in community sites.  
- Revised equipment specification and screening equipment interface project will result in improved process for data transfer and storage in eSP. |  |
| **Equipment fault** | Audiologist observed artefact on an aabr trace in a referred baby. | - All sites informed, results checked to identify pass results that could be influenced by artefact, affected babies recalled.  
- Equipment replacement in progress; Visual inspection of pass results instituted in the interim. |  |
| **Failure to follow up a referred baby** | Local coordinator started to run routine checks on eSP following advice from national coordinator. | - New screen refer and yield report provided monthly by programme centre identifies all screen refers that are pending.  
- Use of eSP searches included in risk and incident training for local coordinators held in summer 06.  
Mandatory training for all local coordinators will focus on data quality and use of eSP to manage the screening and referral process. |  |
| **Poor quality assessment (Ongoing audiological management issue)** | Research assistant from Programme Centre visited the site to train local team in the use of audiology pages in eSP. | - Audiological assessment and processes are a focus for the QA visits.  
- Programme Centre continues to provide training in early assessment and habilitation.  
- Audiological assessment and processes are a focus for the QA visits.  
- Programme Centre continues to provide training in early assessment and habilitation. |  |
3.6. Information & Communication

Information Materials
In 2006-07 all five national antenatal and newborn screening programmes put together some of their information leaflets for parents, into one booklet, entitled ‘Screening tests for you and your baby’. The 64 page A5 booklet of leaflets was developed at the request of the UK National Screening Committee (NSC) and introduced on 1 March 2007. The booklet is designed to guide a woman through pregnancy and birth in terms of screens.

New ‘Modern’ Leaflets
Following a consultation with 60 parents in March 2006, we received constructive criticism about our leaflets. In response to this the newborn hearing component of the Screening tests for you and your baby booklet has been completely updated and revised in line with the suggestions parents made. The photography-led style was the unanimous choice over five others that were discussed at a consultation event with 14 mothers held in London in October 2006.

The NHSP part of booklet also combines the old leaflets 1 and 2 (Your Baby’s Hearing Screen and Your Baby’s Follow-Up Hearing Screen). We are currently working on publishing all our leaflets to parents in the new style – as well as updating the text - for publication in Autumn 2007.

Information in 15 Languages
NHSP is extending its translated materials to a total of 15 languages. We have always published in Gujarati, Hindi, Urdu, Punjabi and Bengali. However the results of a survey with Local Coordinators revealed the need for Chinese, Kurdish, Polish, Romanian, Somali, Spanish, French and Portuguese languages as a priority. These will be published in the new photographic style on our website in autumn 2007 for sites to download. High quality electronic versions will be made available so sites can print their own leaflets locally if required.

One-Stop-Shop
From March 2007, all information leaflets and the checklist will be available to order through Prolog. Meaning all your information needs will be met through one central point of contact.
3.7. Training & Development

NHSP eLearning

With ever-increasing demands on time and financial constraints within NHS training budgets, the Programme Centre has concentrated on developing eLearning opportunities in 2006/07 to overcome these barriers to access.

The NHSP eLearning screener module was piloted and evaluated by 15 NHSP sites. Outcomes from the evaluation concluded that the understanding and coverage was appropriate, with 77% of users indicating that they found the experience very enjoyable and 85% thought the aesthetics and layout was either good or excellent and found it easy or very easy to use. The module is now ‘Live’; it is supported by the NHSP website and is firmly embedded in an assessment and mentoring framework.

The modules aim is to provide training for newly recruited NHSP screeners and to provide an up-to-date resource for existing, trained, NHSP screeners. This approach enables us to assure screener competence and ensure a focused and up-to-date resource which will adapt with the evolution of new technology, evidence and clinical practice. For a demo please visit hearing.screening.nhs.uk/elearning

Further eLearning opportunities are being actively explored and developed including NHSP information modules for GPs, Health Visitors and Midwives. These will incorporate Early Support training materials for professionals involved with families at the time of confirmation and follow-up in the diagnostic period and early months of support.

Screener Competency

A new communication and clinical competence workshop has been developed for new NHSP screeners, to support the practical aspect of training that is provided locally. Incorporated into the workshop is an Observed Structured Clinical Examination (OSCE). The OSCE aims to examine all the essential screener skills such as communication, hand hygiene and
technical screening skills. The first workshops and OSCEs take place in June 2007.

A positive and productive Health Visitor Consultative Forum was held. This forum informed the Health Visitor elements of the NHSP Competency Framework and assessment toolkit.

**National Vocational Qualification (NVQ)**

To date 35 screeners have undertaken the Newborn Hearing Screening NVQ level 3 in Health; 13 of whom have successfully completed the qualification. Also 3 screeners are undertaking the NVQ assessor award; 1 has successfully completed. To support and encourage sites an NHSP NVQ guidance document is available plus details of successful candidates. The number is rather disappointing and is due to the fact that many NHSP sites are experiencing difficulties in registering screeners as funding is an issue and a number of PCTs have temporarily suspended all NVQ training.

**NHSP Awareness**

The NHSP was represented, together with the Antenatal, Newborn Blood Spot screening programmes, at the annual Primary Care conference in Birmingham. Activities to raise awareness amongst NHSP stakeholders are planned; we are actively collaborating with the Antenatal and Newborn screening programmes to produce eLearning and Training needs analysis for primary care.

**NHSP Training and Consulting Services**

The NHSP Training and Consulting Services became an accredited national Early Support training provider. A full programme of training courses is being prepared for 2007/2008. To include:

- New courses for parents
- Early support training for professionals in health, audiology and early years deaf education;
- Master classes in running effective children’s hearing services working groups
- Informed choice training
- The popular communication courses that are specifically aimed at professionals involved with families at the time of confirmation of deafness and early months of support.

The aim of these courses is to provide opportunities for local stakeholders to evaluate and develop their services.
3.8. Best Practice in Paediatric Audiology; MCHAS Findings

The Modernising Children's Hearing Aid Services programme is closely linked to the Newborn Hearing Screening Programme. In order to maximise the benefit of the early identification of a deaf baby it is vital that paediatric audiology services can provide effective amplification and early audiological management.

All audiology services in England received training through the Modernising Children's Hearing Aid Services programme (2001-05) with the introduction of digital signal processing hearing aids on the NHS. However not all services are fully compliant with all the MCHAS guidelines (reasons given included missing out on MCHAS training, lack of experience, confidence and underpinning knowledge, insufficient time to adhere to guidelines). This information was gathered by:

- Informal contacts
- Quality Assurance NHSP visits
- Enquiries received via the MCHAS website
- Polls taken at the training days from the attending delegates
- Training demand
- Data gathering in relevant research projects

Particular uncertainty is noted amongst audiologists regarding the audiological management and amplification of very small babies (less than 6 months) and the application of real ear measurements with this age group. This has a direct affect on the outcomes for babies and families.

MCHAS training initiatives for quality improvement over the past year have included:

- A master class in Real Ear Measurements at the BSA national conference 2006
The updated MCHAS website continues to be used as a resource for training and support materials (www.psych-sci.manchester.ac.uk/mchas).

Champions (experienced paediatric audiologists) have been identified to offer support and contact visits to other audiologists via the MCHAS website. This has resulted in a number of visits with benefits for both parties.

Training day in collaboration with NHSP on ‘Fitting Hearing Aids to Babies’. This course was oversubscribed and will be repeated.

Development of an e-Learning Masters-level module entitled ‘Effective Amplification for Infants and Children’. This will provide audiologists with convenient access to continuing professional development in this important area which has already been identified as a training need. The module will be piloted in September 07.

The response to these initiatives has been very positive and it is hoped that clinical practices are changing as a direct result as audiologists gain confidence in new technology and multi disciplinary working. The QA NHSP audiology visits indicate there is still a need for ongoing training in audiological management of babies and infants within audiology services. As the outcomes for the deaf babies and their families are directly affected by the quality of the audiological services they receive, it is necessary to continue to address the training needs of audiology services.
3.9. Audiology

**NHSP Clinical Group**

There is now a formal Clinical Group within NHSP to advise on clinical issues. Its remit is to develop and review clinical protocols and advise on clinical policy and practice issues relating to the programme.

The membership is currently Rachel Foley, Roger Green, Glynnis Parker, Clare Robertson, Tony Sirimanna, John Stevens, Graham Sutton (chairman), Kai Uus, and Sally Wood. Guy Lightfoot is also a regular advisor, and Adrian Davis has an open invitation. Please contact Sally.Wood@mrchear.man.ac.uk or Graham.sutton@mrchear.man.ac.uk if you have an issue you think we should discuss.

Part of the group’s work is to review the NHSP clinical protocol and guidelines. Usually we do this by asking a lead person to convene an expert working group, draw up (or revise) a document to come to the Clinical Group for comments, and approval.

To date we have approved the following:

- Guidelines for the early audiological assessment and management of babies referred from the newborn hearing screening programme (v1.1 March 2007, edited by John Stevens)

The following protocols are undergoing major revisions:

- Visual Response Audiometry (led by John Day)
- Auditory Brainstem Response testing by clicks, tone-pips and by bone conduction (led by John Stevens)
- Tympanometry in babies under 4m (led by Margaret Baldwin)
The document on screening using the distraction test has now been withdrawn.

We also consider calibration and equipment problems, and possible research collaborations using NHSP data.

The Surveillance document included a significant change to screening policy in that babies who have had bacterial meningitis should now not undergo screening but should be referred for audiological assessment.

Care Pathways
Care pathways produced under the Do Once and Share Programme [www.mrchear.info/projects/doas](http://www.mrchear.info/projects/doas) were published in January 2007 and are on the NHSP website. Relevant to this report are those for newborn screening, early assessment, habilitation, and cochlear implants. The screening and implant ones have been translated into the excellent map of medicine format, and there is hope that others will follow in due course.

Training Updates for Audiologists
We held several training days for audiologist/professionals involved in the early assessment and habilitation of infants identified by the screen. Two events focussed on early electrophysiological assessment and assessment and management of auditory dysynchrony/auditory neuropathy, one on early habilitation including hearing aid fitting and real ear measurement and two 2 day course on Aetiological investigation of deafness in newborns.

**The Map of Medicine Newborn Hearing Screening care pathway** available at: [www.mapofmedicine.com](http://www.mapofmedicine.com)

and on the NHSP website at [hearing.screening.nhs.uk/carepathways](http://hearing.screening.nhs.uk/carepathways)
3.10. **Children’s Consultation Event**

The Programme Centre aims to provide a first-rate, family friendly service. It is continually seeking to improve its service to families and to achieve excellence in its provision across the board from early identification of deafness through diagnosis to rehabilitation. It values the views of families and it has actively sought to involve parents in its work via a number of initiatives. For example, a Parents’ Consultation was commissioned in 2006 to establish parents’ views on consent and information issues in relation to the newborn hearing screen. Having consulted with parents, the Programme Centre wished to give primary users of paediatric audiology services, deaf children, the opportunity to have their say.

The NHSP commissioned a Children’s Consultation where 23 deaf children aged 7-13 years from 6 different London schools took part. The sample included a mix of oral speakers and British Sign Language (BSL) users. The event was designed along the lines of a public consultation where the children participated in facilitated discussion as a large group, as well as in smaller, moderated break-out groups. What distinguished this consultation from others of its kind was that signed support and BSL interpretation was provided throughout the day. It is believed to be the first consultation conducted with this audience.

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 prioritise for improvement.

The children were positive about a number of aspects of the service. They particularly liked the choice and range of ear mould colours and designs enabling them to effectively customise their hearing aids. Some enjoyed attending hospital settings with the opportunity to spend time with mum or dad and to meet new people. This was particularly the case where audiology clinics had been modernised or were located in new hospital buildings. Many had good things to
say about their audiologist in terms of the way they were treated and communicated with, though some children felt there was room for improvement (see below).

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

- dislike of old hospital environments

A full detailed report of the findings is available and a video of the day.
3.11. National Knowledge Week for Hearing

National Knowledge Week for Hearing 2007 was successful in bringing key issues to the forefront of clinicians’ & researchers’ minds. It has stimulated debate in important areas such as ASSR, ABR, diagnostics, aetiology, outcomes, Glue Ear, school screening and also highlighted children’s views on audiology services.

Roadshows & Seminars

The week was truly national with:

- A twilight seminar held at the Ear Foundation, Nottingham. This incorporated an introduction to the National Library for Health (NLH) & recent developments in Cochlear Implantation. Presentations were given by Sue Archbold, Dr Gerry O’Donoghue and Steve Sharp. For the presentations please visit hearing.screening.nhs.uk/nkwh2007 and click on external links (top right of page).

- A three hour session held at the University of Manchester which covered NLH, outcomes and case studies of deaf children’s progress, the Greater Manchester Service Specification for newborn hearing screening provision, and early previews of the e-learning module, Map of Medicine care pathway and new NHSP website.

- Over the course of the week Steve Sharp also delivered short workshops about the National Library for Health (NLH) in various locations throughout the UK including Nottingham, London, Exeter and Manchester. The sessions were intended to enable clinicians and researchers to find out more about the National Library for Health, its aims, uses and how to navigate this resource www.library.nhs.uk.

Exciting Information Developments Launched

During the week the NHS Newborn Hearing Screening Programme launched a series of new initiatives, which were available to view on the 22nd & 23rd March 2007:

- The new and improved website hearing.screening.nhs.uk which provides parents, professionals
and users better, quicker and easier access to information. It has increased functionality and is much more user friendly and intuitive.

- The first of a series of elearning modules, for new screeners starting work in NHSP. Screeners can sign up and **start the course from the 1st May 2007**. Other modules are planned for Health Visitors, Midwives and other key professionals involved in screening.

- **New care pathways.** NHSP is the first screening programme to map out and launch its care pathways in the Map of Medicine (MoM), the new tool for clinicians to provide clinical information at the point of care. We were very pleased that Neil Ferguson from Medic-to-Medic (developers of MoM) joined us at the workshop on Friday to launch the care pathway and answer questions.

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**Annual Conference on Hearing Screening in Children**

The week was brought to a close in London with the 20th Annual Workshop on Hearing Screening for Children, at the British Library. The day saw some excellent presentations given by leading professionals from the UK, Canada and USA.

The Keynotes were given by Christine Yoshinaga-Itano Professor of Audiology in the Department of Speech, Language and Hearing Sciences, University of Colorado.

Other speakers and contributors included:

- **Dr Sheila Shribman** National Clinical Director for Children, Department of Health, UK,
- **Dr Martyn Hyde** Professor at Departments of Otolaryngology, Public Health Sciences and Speech-Language Pathology at the University of Toronto & Director of Research & Development in the Hearing, Balance & Speech Department at Mount Sinai Hospital, Toronto
- **Professor Mark Haggard,** of the MRC Cambridge
- **Dr Catherine McMahon** Senior Lecturer and the Head of the Audiology Section at Macquarie University in NSW, Australia
- **Prof John Bamford** the Ellis Llwyd Jones Chair of Audiology and Deaf Education at the University of Manchester
- **Prof Adrian Davis** Director of NHS Newborn Hearing Screening Programme England and Head of MRC Hearing & Communication Group, plus many other contributors.

The day was informative and enjoyed by all who attended. All
presentations from the workshop can be found at hearing.screening.nhs.uk/nkwh2007

As the week was so well received & much follow-up work in many areas is needed we plan to host the week for the third time next year, in order to enable progress and updates on the key areas and issues raised, and to keep the flame burning in key issues related to Hearing.

Key speakers in 2008 will include:

Professor Richard Seewald, Ph.D.
Keynote Canada Research Chair in Childhood Hearing National Centre for Audiology, University of Western Ontario.

Professor Richard Tyler,
Department of Otolaryngology - Head & Neck Surgery and in the Department of Speech Pathology and Audiology at the University of Iowa.

Professor Richard Smith, Professor and Vice Chair: UI Department of Otolaryngology – Head and Neck Surgery, University of Iowa Hospitals.

Dr Judy Gravel PhD, Director of the Centre for Childhood Communication at the Children’s Hospital of Philadelphia and Visiting Professor of Otolaryngology and Paediatrics’ at the Albert Einstein College of Medicine, Bronx, New York.

For further information and a provisional programme visit hearing.screening.nhs.uk/annualconference2008. Registration for the conference will opened in September 2007. The conference carries CPD Points
3.12. London Moving Forward

Stakeholder Conference
A mapping report on newborn screening, paediatric audiology and education services for deaf children in London was submitted to the Department of Health in Spring 2006. The report highlighted:

- Very wide variation in service provision
- Very high Did Not Attend (DNA) rates for all appointment types
- Frequently very long waits for paediatric audiology services
- Patchy education support

To address the issues and develop a strategy to overcome the problems identified in the report, in June 2006, NHSP hosted a conference with 140 parents and professionals to consider how services in London might be improved for families with a child with hearing loss. The purpose of the day was to begin to create an integrated strategy that identifies priorities with realistic goals and timetables.

The day was characterised by a great deal of commitment and enthusiasm by participants. All were in agreement that it is a vital time for paediatric services in meeting the need of families and children with Permanent Childhood Hearing Impairment (PCHI).

The consensus priorities identified by participants led to the formation of project groups to take strands of work forward as follows:

- Recruitment and retention of staff; screening & audiology
- Developing a commissioning specification
- Early identification - maximising the number of babies screened in hospital
- Family support
- Developing London-wide networks

These initiatives are now grouped into an NHSP staff supported project entitled London Moving Forward.

London Moving Forward Outputs
The project groups listed above have been meeting regularly. Some of the outputs are as follows:
A draft service specification for London that will go out to full consultation in early Summer 2007

The mapping of existing family support to London’s deaf children as a first step towards reducing inequities and improving services generally

Proposals to develop a virtual parent-to-parent network, in partnership with NDCS

A standardised template family pack for Teachers of the Deaf

An “Ask the London Expert” function on the NHSP website where professionals can ask questions about issues in their professional practice - and have them answered within three days

A survey of London Local Coordinators which has led a better understanding of why screeners leave and the development of a strategy to address the problem of high turnover of screeners in many London sites

A study is underway in St. Helier Hospital to understand precisely why mothers leave hospital without their babies being screened.

About every two months, London Moving Forward issues a newsletter to all those who registered at the June 2006 conference to keep them abreast of developments and involved in the initiative.

NHSP will be hosting a second pan-London stakeholder conference on 19 October 2007 which will include parents, health services and support services'. The aim to consider progress so far and to and explore proposals to radically improve services to meet London’s challenges.
3.13. Education and Early Support

Education and early support services continue to be committed to development in the field of early intervention. Focus is on responding proactively to the government’s ‘Every Disabled Child Matters’ agendas.

The Early Support Programme is having an increasingly positive impact, particularly with influencing best practice in partnership working and in fostering family–centred practice and parent-led assessment and record-keeping. The NHSP Quality Assurance Support visits reveals however that there is still a significant ‘post-code’ lottery in terms of the frequency and the scope of support which early education services for deaf children can offer to families, and the level of resources vary considerably. That said, most services now offer a 52 week per year response to newly diagnosed families, and the quality of information given is much improved. Where services are under-resourced in terms of qualified Teachers of the Deaf (ToDs), there has been some innovative and effective partnership arrangements made with other professionals skilled in the area of early family support. Effective use of family liaison workers, also strengthen teams and increases access to services by families, some exemplary practice has been observed on QA visits. CHSWGs (Children’s Hearing Services Working Groups) are actively developing a wider and integrated agenda for families of deaf children. Evidence from the NHSP’s CHSWG course is that there is strong commitment from professionals in health, education and social care to make these even stronger at both strategic and management levels as well as being vehicles for enhancing practice and co-operation in front line service delivery.

Challenges still remain, with regard to the numbers of ToDs available, to support very young deaf children and their families. There needs to be a focus on collaborative working with social care services and for some, much closer involvement with health /audiology services around the time of diagnosis, so that early support can be offered to families without delay. Accessibility to the right information at the right time remains a national challenge, with regard to making the information available in the appropriate formats and languages, so that informed Choice’ can be supported.

Many professionals may be unclear about what is happening to Children's Social Services. Put simply, as a result of the Children Act 2004, Local Authorities (LAs) in England were directed to combine all their services for children into one body and form Children's Services. Children's Services were then to form local partnerships with health services and community and voluntary groups to form Children's Trusts. Children's Trusts were to consult widely with children themselves and their parents and carers.

The aim of these changes was to ensure that all children received integrated, holistic services that met their needs and helped them to achieve the five outcomes laid out in Every Child Matters:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic well being.

It was clear that a 'one size fits all' solution was not appropriate because each local area is different. As a result, not all Children's Trusts are organised in the same way. Indeed, some of them are not even called Children's Trusts! This is why the vision for Children's Trusts encourages local partners to be flexible and innovative in creating solutions to integrate all children's services.

The vision is that people will work in effective multi-disciplinary teams, be trained jointly to tackle cultural and professional divides, use a lead professional model where many disciplines are involved with one child or family, and may be co-located.

Primary Care Trusts (PCTs) and Strategic Health Authorities are named as key partners. It is crucial that PCTs be involved when drawing up arrangements for cooperation for all children's services in the local area. The Government expects that Children's Trusts will be led by local authorities as this is where responsibility for some key statutory duties relating to children lie. Each LA publishes a Children and Young Person's Plan (CYPP) annually on its website outlining how it will go about
achieving the 5 outcomes for children in the coming year.

Taking on board the Government imperative to work closely across professional and agency boundaries, NHSP has been proactive in contributing to this agenda of working together to promote the wellbeing of children. NHSP has in the past largely focused on education and audiology services, so a priority for this year was to work with those who provide social care services for deaf children and their families.

A consultation day was organised jointly between NHSP and the Social Work Department of the University of Manchester in December 2006. A mixture of deaf and hearing professionals took part including eight experienced social workers with deaf children along with two senior managers with a background in education and representatives from the NHSP team. The aim was to understand better how social care services for deaf children and their families are organised and delivered, to clarify the statutory and non statutory role that social workers have and contribute to the development of appropriate quality assurance standards in relation to deaf children and social care.
3.15. Positive Support in the lives of deaf children and their families

It is of crucial importance to families of deaf children, service providers and policy makers to understand the effectiveness of different types of support and intervention in helping children, families and society to improve outcomes and reduce the social and economic exclusion of deaf children. However, the evidence to make inferences about the effectiveness of the type, extent and quality of intervention is currently insufficient, with a lack of good quality data.

Service developments for deaf children and their families during the last five to ten years have been the most exciting and important for decades. Major developments include very early identification through newborn screening; more advanced digital signal processing hearing aids; early cochlear implantation for those parents wishing to take that option; development of the principles which should guide early support for families of deaf children (RNID/NDCS, 2000); detailed evidence-based practice guidelines and protocols from NHSP and MCHAS (the Modernisation of Children's Hearing Aid Services) for paediatric audiologists and teachers of the deaf supporting deaf children; training materials for early support workers; the publication of quality standards in paediatric audiology and in early family support for Education and Social Services; and the inter-agency Early Support Programme which used deafness as an exemplar (DfES/Department of Health, 2002). In these and other related initiatives, the major organisations representing deaf people have been closely involved, promoting a level of service-user consultation that is new to the field of childhood deafness.

The introduction of the NHSP has given rise to significantly earlier identification of deaf children than previously, with most now identified significantly below six months of age. Previous published research on outcomes in deaf children has indicated significant deficits in language, communication and literacy that impacts upon other activities and upon social inclusion.

The new service developments make this an extremely opportune time to carry out a longitudinal study of the first cohorts of children to be identified by the Newborn Hearing Screening Programme. A team from the
University of Manchester, in collaboration with colleagues from University College London, and supported by Deafness Research UK and NDCS, was funded by the Big Lottery Fund in 2005 to gather data on outcomes and on the variables likely to affect them, including detailed measures of intervention. 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. The project is called 'Positive Support in the lives of deaf children and their families' and is funded initially until 2008. Applications to extend the study towards school-entry age are now being made, which will enable further consolidation of findings to inform parents and service providers to help them get the best possible outcomes for deaf children and their families in the future.

We are looking for families to take part in our study into what best supports early identified deaf children to reach their full potential. We still need many more families to get involved, with babies born since 1st September 2005, and diagnosed as deaf within six months of birth with a permanent bilateral moderate or greater hearing loss.

It is very important that as many families as possible take part in the study. We currently have 63 families interested in taking part, many of which have filled in questionnaires about the support they receive from services, how they communicate with their child and what hopes they have for their child in the future, etc. The results will help families of deaf children in the future to make better informed choices, and will help services all over the UK to give the right support that families want and need.

There is much more information on the background to the study and how families and professionals can be involved on the Positive Support website, www.positivesupport.info and information is provided in many different languages, inc BSL.

All parents should be given the chance to join this unique study. Please support the study by encouraging parents to find out more by contacting Rebecca Lea on 0161 275 6924 or Rebecca.Lea@manchester.ac.uk or Tracey Keeble on 0161 275 5976 or Tracey.Keeble-2@manchester.ac.uk

Please also get in touch if you work with deaf children and their families and you would like any posters or postcards about the project to give to parents, to display, or for your own information.
Over the last year the NHS Newborn Hearing Screening Programme Centre has continued to improve its reporting to the Department of Health. The programme has delivered on the targets set for 2006/07 within its budget.

The financial process, procedures and expenditure under goes no less than three separate audits in line with the University of Manchester policies and the NHS guidelines. Improvements following these audits have been made and are being implemented, leading to greater accountability within the team and better processes overall.

The Programme Centre has recently entered into a Service Level Agreement with the Department of Health via the Central Manchester and Manchester Children’s University Hospitals NHS Trust and The University of Manchester to deliver and improve nation wide screening and paediatric audiology services until 2010. The programme has been allocated its budget for the financial year 2007/08.

Work has begun on delivering the milestones for 2007/08 in line with budget proposals.
3.17. Equality & Diversity

The NHS Newborn Hearing Screening Programme is committed to equality and diversity in all elements of its service provision for both staff and patients. We are dedicated to fostering an inclusive culture, and listening to the needs of service users and providers.

The following are some of the measures we have put in place in line with the Department of Health equality framework:

- The Screen is provided on a universal basis to all parents of newborns across England.
- Every effort is made to include and reach out to all sectors of society with particular emphasis placed on harder to reach minorities.
- We have always provided our information leaflets in translated editions and have recently expanded this from 5 languages to 15.
- Our information is also available in British Sign Language (BSL) and subtitled formats for the deaf community.
- Our information is disseminated in various formats DVD, Leaflets, via a new and improved website and verbally at various points of contact throughout the antenatal and newborn period.
- We encourage local sites to provide translators, link workers and interpreters wherever a requirement exists. Whilst some recent TV reports have suggested that the provision of translated materials and interpreting services act as a barrier to the integration into wider society of immigrant populations we believe in order for full informed consent to be achieved this is an essential requirement.
- We engage with the voluntary sector, both deaf specific and in the wider disability arena to ensure our programme takes into account diversity and equality issues as they arise.
- The team has started its peer review quality improvement visits. The aim of the visits is to ensure that services across
England are meeting the minimum national standards of care, to ensure that services are equitable.

The Programme Centre strongly advocates family friendly practices and informed choice and consent and strives to ensure that parents are equipped with appropriate information at every stage in the care pathways.

Training provided by the programme promotes equality and diversity and informs screeners and other professionals on how to remain culturally diverse and sensitive at all points of contact.

We have conducted several consultations with services users; both parents and deaf children have been focused. We have taken the messages from the consultations away and fed them into our practice or released the information to allow local service to take the messages on board as they see fit locally.
4. MILESTONES TO 2010

- Continue to manage the risk reduction and quality assurance programme currently underway. To visit each of the 122 England sites to carry out a peer review. Services will be assessed against key performance indicators and a report for each visit will be produced, highlighting good and bad practice and will focus on the following areas: commissioning, governance, performance and improvement of the hearing care pathway for children and their families. The Programme Centre will make strong suggestions for areas of improvement flagging problems up with Commissioners at PCT level where required. The team will also support local sites in implementing changes, offering development support and advice. The peer reviews will run on an 18 month cyclical basis with each site having had one visit by March 2008.

- Provide overall governance for the programme of work with DH, NSC, FMCH and the NHS to ensure that appropriate governance is in place.

- Maintain a small steering group to ensure that the future direction of the programme is evidence based and in line with NSC and NHS strategy.

- Maintain expert groups to provide support for risk management, clinical protocols (including equipment), family support, information and communications technology, training, patient information and financial management.

- Host, run and manage Quality Assurance board meetings in line with the terms of reference for the QA Board.

- Embed the NHSP risk management strategy within the programme as a whole by implementing risk management policies and procedures and provide Standard Operating Procedures (SOPs) for all elements of the screen and follow-on care for local programmes.
Continue to develop, promote and implement best practice in family friendly service and to work with family support, education and social care services to ensure that all families with deaf children get the support that they need.

Continue to support host and develop the nationally procured eSP IT System such that it supports local programmes to work to the screening, hearing assessment and habilitation pathways agreed in Do Once and Share: Hearing (Map of Medicine), to provide performance management information for the national programme, SHA, PCT and local programmes and to implement and manage the national register of deaf children, with sufficient information to relate to the health, education and social care needs of the children and their families.

Work towards ensuring that child outcome data, especially audiological data is entered by the sites onto the eSP system ensuring that data quality on the SMS & PMS is accurate, up to date and can yield sensible numbers. To continue to develop such systems that can routinely monitor deaf children’s outcomes.

Continue to provide PR to support sites including incident management and dissemination of lessons learned.

Review the population, demographic and geographic composition of NHSP sites with a view to reducing the number of NHSP local programmes from 122 to 30 by 2010. This reduction will improve governance, commissioning and accountability both locally and nationally.

Continue to consult with parents and patients about the services and the quality of service they would like to receive so that this can be reflected in service provision.

Develop, implement and manage e-learning courses for screeners and local co-ordinators, improving their career prospects through accreditation and helping to ensure quality assurance and quality improvement at local levels.

Continue to provide leadership and medical
courses for relevant professions, helping build the knowledge expertise and critical mass needed to deliver the program on a national scale to adequate quality controls.

- Deliver key training and host meetings for all sites to strengthen leadership, manage change across the programme, improve data management skills and foster a culture of risk management and quality improvement at the local level.

- Work with the National Library for Health and other key stakeholders to organise National Knowledge Week for Hearing on an annual basis.

- Continue to procure, manage and distribute screening consumables nationwide, resulting in a saving for the NHS of approx £1m overall.

- Continue to procure and renew old equipment and echochecks and to organise calibrations and repairs to ensure that equipment is fit for purpose on a national scale, again saving the NHS approx £1m pa.

- The audiology services in England are changing due to major innovations such as new hearing aid and implant technologies, the 18-week wait programme and NHSP. The Programme Centre is playing a major role in aiding these changes and providing the support so that they are successful.