


Evidence based paediatric hearing services?

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Research led healthcare is challenging
but it does give us the chance
to get the best outcomes
for children and their families

How do we ?

- Obtain appropriate scientific knowledge
- Transfer that knowledge to benefit people
- Change services using that knowledge
- Implement change
 - National protocols and guidance?
- Quality assure services in the light of practice and new knowledge
 - Integrated knowledge and information systems across care systems?

Evidence based services

- One randomised control trial
- Gives more unbiased evidence than
- A hundred observational studies
- Archie Cochrane – Random reflections ..
- BUT all RCT should carry a health warning!!!

Partnership

- Scientists
- Clinicians
- Entrepreneurs (Eg include NDCS, RNID &)
- Systems of care – health, education, social, self
- People - parents, children

Some changes?

- Newborn hearing screening
- Transformation of opportunities for support
 - DSP hearing aids for children
 - Cochlear implants for children
 - or package of care in which ... ?
- Family friendly hearing services

How do we buy care?

- Procurement
- Evidence for components
- RCT based evidence
- Real system gain?

Evidence base

- Has informed policy
- Has informed elements of implementation
- Is useful in informing practice
- Can be used to formulate quality assurance

What evidence is needed?

- To inform practice ?
 - Protocols / guidance
- To provide good quality assurance?
 - Feedback
 - Quality improvement programme

Qualitative

Evidence

Quality Assurance

Training CPD
Site support I-term
Performance monitor
Quality reports

Operational

Rollout
Training
IT installation
IS support
Equipment
Financial services
Web information

Ad hoc workplan

Troubleshooting
Media
Critical Incidents
DRP
'big' meetings
Newsletters

IT functionality

Development
NHS NPfIT
PMS
Register
Communications

Strategy

Vision
Policy and guidance
Multi agency
Development
FP / Budget

Procurement

Equipment
IT
Consultancy
Training

Clinical and scientific

Screen equip & protocol
Assessment
Habilitation
Aetiology
Surveillance
Quality

Programme Informations

Design
Provision
Training

Education

Policy feed
Early Support
Development
Quality
Outcomes

Social care

Policy develop
Multi agency
Quality & critical mass

Evidence is not a substitute for

- Leadership
- Advocacy
- Vision

- Quality assurance
 - Training and guidance
 - Quality improvement programme
 - Information



Often we know what to do

- We can (just about - after 20 odd years)
 - Transfer some science into clinic
- Can we agree which method is best ?
- Implementation depends on many other issues
 - Eg training, robustness, governance

Vision of NHSP in England

- To enable high quality parent - child interaction in first months of life for all children
- To empower parents of hearing impaired children **to make informed choices** about early communication and support options so that interactions can be of high quality

Vision of NHSP in England

To establish an evaluative culture of service provision and partnership **through training and Quality Assurance in**

- Screening,
- Assessment,
- Diagnosis and
- Habilitation
 - Early support
 - Communication options
 - Education
 - Social & family care

What is the immediate impact of implementing an evidence based Newborn Hearing Screening Programme (NHSP)?

- Two stage screen introduced in 2002
- Full roll out 2005
- 4. Automated OtoAcoustic Emissions (AOAE)
- 5. Automated Auditory Brainstem (AABR)

Current status of Newborn Hearing Screening Programme (NHSP)

- More than 74% of all newborns are now screened, > 1100 per day
- All babies to be screened by end of 2005!
 - Ministerial commitment with pump-primed funding
- NHSP has commitment to meet timescales, but we will insist on meeting quality standards for services delivered

Newborn Hearing Screening Programme

- Evidence based screen?
 - Hospital and community based
 - Well baby and NICU baby protocol
 - 700,000 babies screened at April 2005
- Probably 90% of newborn deaf babies now being supported by 6 months of age in areas with NHSP
- Since the programme started
 - ~730 (1.05 per 1000) babies identified with bilateral deafness
 - ~460 (0.6 per 1000) babies identified with unilateral deafness

Yield

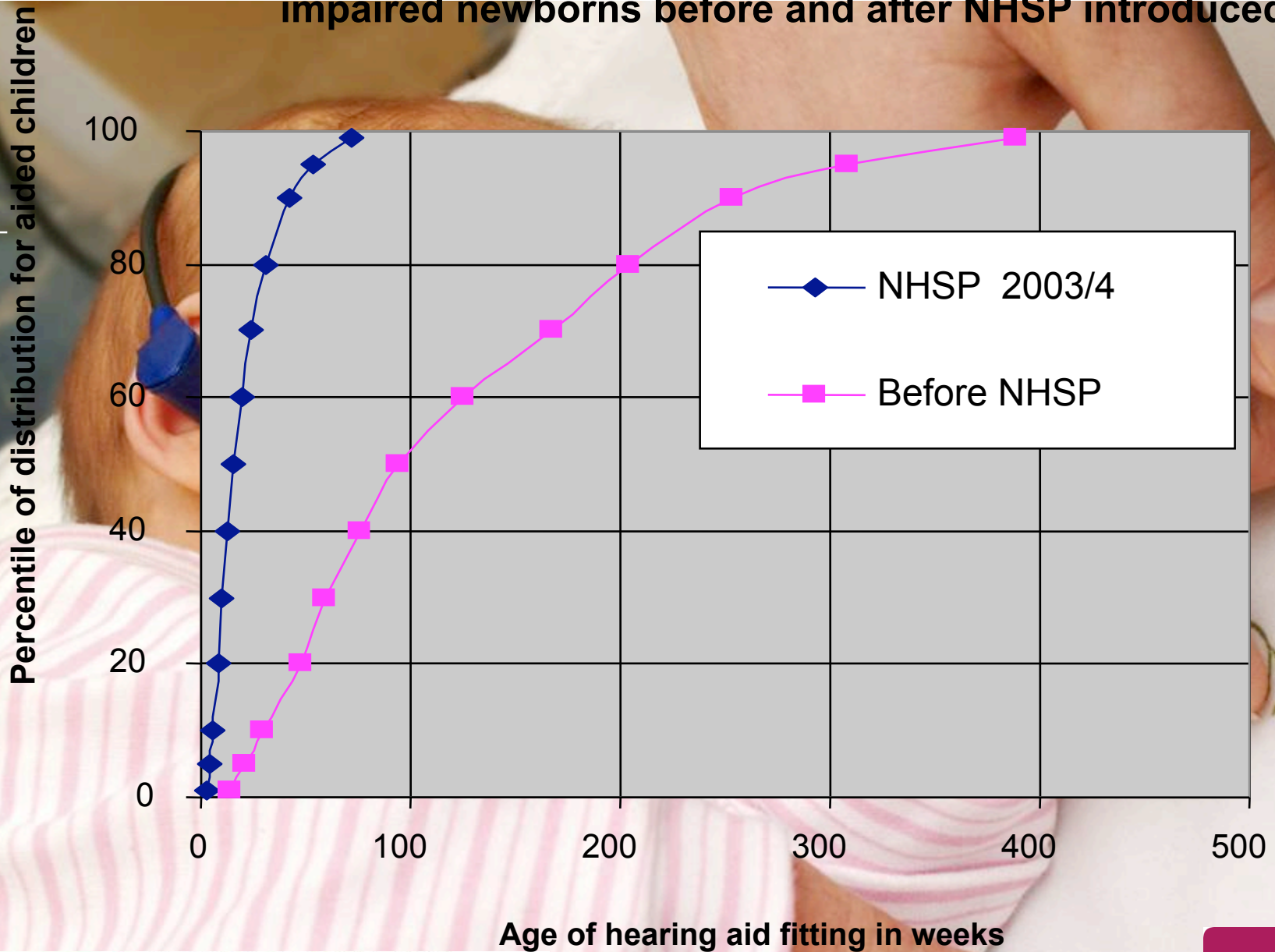
- 1.0 per thousand bilateral
- 0.7 per thousand unilateral
- 65% severe to profound so far
- 54% risk, major element NICU (> expect)
- 10% AN

Exemplars for comparison of the effectiveness and efficiency of NHSP compared with previous situation

- Assumption:
 - if yield is approximately equal then we can compare:
- Age of confirming hearing loss / deafness
- Age of intervention eg fit hearing aids, introduce communication support
- Health / Developmental gain eg years of appropriate communication gained
- Referrals for assessment

Distribution of age at hearing aid fitting for hearing impaired newborns before and after NHSP introduced

The University of Manchester



(NHSP data Feb 2005, n=228; Davis et al 1997 n=495)

Health and developmental gain (Before NHSP – After NHSP)

- Earlier identification enables better **personalisation** of services for parents and their deaf children
- If we assume equal yield the overall health / developmental gain per 100 children brought through earlier identification gives
 - **145 years** gained for Early Support from health, education and social care
 - **145 years** of parental lack of knowledge about child's deafness prevented
 - **257 added years** of benefit from amplification (where appropriate)

Note: this is a reasonable calculation as yield is comparable for NHSP as for earlier studies of IDT

What is NHSP about

- Babies developing communication
- Leadership
- Systemness
- Technology used by people for people

What have we learnt? where are the tensions?

- Serious untoward incidents happen
 - eg how do we decide whether to recall babies
- Keep it simple, refactor
- National guidance, personal preference
- Is national good
- Is guidance good
- Diversity can be the enemy of a good system?
- Can we provide better critical mass around paediatric audiology especially for children identified by NHSP

Need for critical mass

- For - Quality assurance and practice
- To use annual information appropriately there is a need for services to be aggregated to about 20, 000 births per year
- 20 bilateral permanent hearing impairment
- 15 unilateral
- 2 auditory dys-synchrony

Types of services

- Need for critical mass of professionals
 - Assessment of needs
 - Personal care plan
 - Information
 - Support for choices

Managed networks for paediatric audiology

- Evidence???
- How many?
- How would they work?
- What would they do?
- How could they be commissioned and
- Evaluated!

Impact of NHSP on demand for cochlear implants

- Newly identified children from NHSP
- At least 0.41 per thousand
- More profoundly deaf than we predict so far
- Old routes still providing children
- Hence next few years will see demand from many more families
- Earlier ! ??

Should all deaf and hearing impaired children (and their families) identified by NHSP be assessed to see if implantable devices might benefit them

- Depends on
 - Families views and wishes
 - Social inclusion and access
 - Information
- Different for?
 - Profound deafness
 - Children with potential multiple problems

Is it different for

- Profound bilateral deafness
- Do we need a fast track for much earlier, more in depth, assessment
- Hearing aids may be totally inappropriate?
- Other options need to be explored
 - Implants, early communication developing to sign
- Early implant (<6m) may enable natural development
 - We don't yet know – we need to collect evidence

Need for firm leadership

- NHSP has great potential benefits
- To convert into real benefits need good, firm, but innovative leadership
- Management of change in provision of implantable devices is important
- Controversy is not always best managed by maintaining the status quo

Safe environment for service development

- Early assessment of child and family for implantable device inevitably raises the emotional temperature
- Need to develop emotional intelligence within system to respond to those demands
- Very important that in the next phase this is handled in a safe and sensitive environment of service development and evaluation

Modernisation of children's hearing aid services

- Partnership
- NHS paediatric hearing aid services
- NDCS
- RNID
- MRC / University of Manchester

'Feasibility' studies in MCHAS...

- Enabled us to better understand the issues involved in switching children's services from analogue to DSP
- Provided the necessary link between evidence, policy and practice
- Enabled us to define service development targets and preferred practice guidelines and protocols
- Enabled us to design short-term training and influence on long-term training

Impact of MCHAS

- All children to be given option of DSP hearing aids
- New guidelines adopted
- National (short-term) training programme for paediatric audiologists and educators
- Varied range of high-quality branded DSP aids procured at reasonable prices for the National Health Service (nearly 100% of children managed by NHS—aids free to patients)

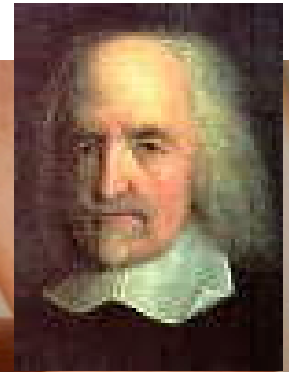
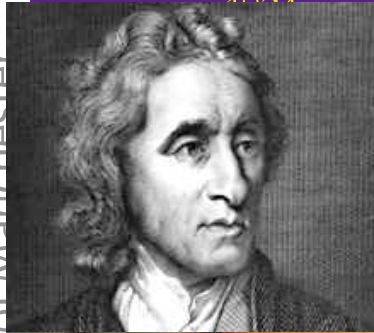
Modernised service (children)

- Use of published prescription procedures (DSL i/o generally) with REM/RECD to verify; not proprietary fitting rules
- Outcome questionnaires on aid benefit and on general development
- Six preferred practice guidelines
 1. Ear impressions and earmoulds for children
 2. Testing DSP aids 'in the field'
 3. Fitting, verification and evaluation of hearing aids for children
 4. How to optimise FM settings

Final report and executive summary

- Copies of the MCHAS report, preferred practice guidelines, and training materials can be viewed at:

www.mchas.man.ac.uk



Regulation?

- John Locke
(1632 - 1704)

- Thomas Hobbes
(1588 - 1679)

“People perform best if **trusted**, given resources and left to their own devices”

“People are inherently bad and need tight regulation to prevent them doing ill”

Family friendly hearing services

- May be the most important element of all
- Where is the evidence?
- Where are the parents?
- Can you all please really reflect on how we take this forward

Family friendly

- Do we need to think about a package of care
- Not just about
 - DSP hearing aids
 - Implants
 - FM systems
 - Ear moulds
 - Home support
 - Family to family support
 - Deaf role models
 - Social care, preventions, advice, support, action
- We need the evidence?
- We need trust to work together

Ultimately

- Not Locke or Hobbes
- Not you or me
- Stakeholders??
- It should be parents who help us connect the evidence to the benefit of their children and families
- Informed by best science and evidence
- In a language that is shared and enabling
- Maximise child's potential
- BUT needs leadership

Every child matters

Every child should count

- Early Support © DfES is vital
- Every Child Matters is important – consideration of all child's and family needs
- Developing evidence around Very early assessment, habilitation and offering parent's choice (or parents creating their own solutions) should only happen in an evaluative environment where we can learn about the benefits and risks should parent's accept

Need for research that leads to action!

- Europe has been very slow to develop capacity for safe and ethical service development
- In UK government reports has highlighted needs for scientists, clinicians and industry to work together
- In Europe there needs to be more 'concerted' action
- In UK we are working with DH and others to set up a clinical audiology research network to take these issues forward