

## Presentations at the BACDA Study Day “Choice for Parents”

### Abstracts

*Identification of functional needs from families with hearing-impaired children using the Family Needs Survey.*  
*Jane Dalzell*

How can professionals identify needs from families who have children with permanent hearing loss in a meaningful and practical way?

#### Identification of needs

- Health, education and social services
- Traditionally needs are identified by professionals and assessed from the professional perspective

*How do we identify the family's needs as they see them?*

**Definition of “need”** — ‘something required for a goal or purpose’

#### Why identify family needs?

##### Research

- Family-focused approach has benefits to child and family.
- Political backing:  
USA Public Law 99-457, 1986  
UK Court Report, 1976; Children Act, 1989;  
Patient's Charter, 1992; Supporting Families DoH 1998.

##### New paradigms

- Paternalism to partnership
- Family empowerment
- Family-Friendly Hearing Services, (Baguley et al., 1999)

*Identification of family need contributes to these approaches*

##### 21st Century Culture

- Climate of change
- New technology e.g. communications, information technology

Access to “information”

*Needs are a dynamic entity*

#### Identification of family need

- Unstructured or informal
- Structured e.g. using a measurement tool

#### Needs assessment tools

- Intervention programs : family assessment tools for Individualised Family Service Plan (IFSP)
- Review of needs assessment tools (McGrew et al, 1992)

*BACDA Newsletter October 2002*

- Content validity most important

#### FAMILY NEEDS SURVEY

- Designed by Bailey and Simeonsson (1988)
- Practical list of possible functional needs
- Rationale
- Field testing and measurement integrity (Sexton et al., 1999)

#### Family Needs Survey

- Six categories of need: information, support, explaining to others, community services, financial, family functioning
- 35 items of need: range 4-8 per category

#### Information needs

- 1 Child's condition/disability
- 2 How to handle child's behaviour
- 3 How to teach child
- 4 How to play/talk with child
- 5 Present services
- 6 Future services
- 7 How children grow and develop

#### Support needs

- 8 Someone in family to talk to
- 9 Friends to talk to
- 10 Meet other parents with a child with disability
- 11 Time to talk to child's teacher/therapist
- 12 Meet with a counsellor
- 13 Talk to a clergyman
- 14 Reading material about other parents with a similar child
- 15 More time for self

#### Explaining to others

- 16 Explain child's condition to sibling
- 17 To parents or in-laws
- 18 To spouse
- 19 To others/ strangers
- 20 To other children

#### Community services

- 21 Locating a doctor
- 22 Locating a dentist
- 23 Babysitters/respice care
- 24 Day care or preschool
- 25 Care during church services

#### Financial Needs

- 26 Expenses for housing/food/medical care/clothing/transport
- 27 Special equipment

# ADD9ENS

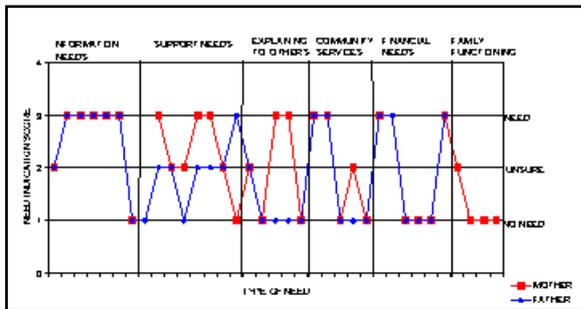
- 28 Therapy/daycare
- 29 Advice about employment
- 30 Babysitting/respice care
- 31 Toys

## Family functioning

- 32 Discussing problems and reaching solutions
- 33 Support each other
- 34 Household chores/childcare/family tasks
- 35 Recreational activities

## Example of format of survey

Item of need	Definitely do not need with this	Not sure	Definitely need help with this
I need more information re my child's condition/disability	Score 1	Score 2	Score 3

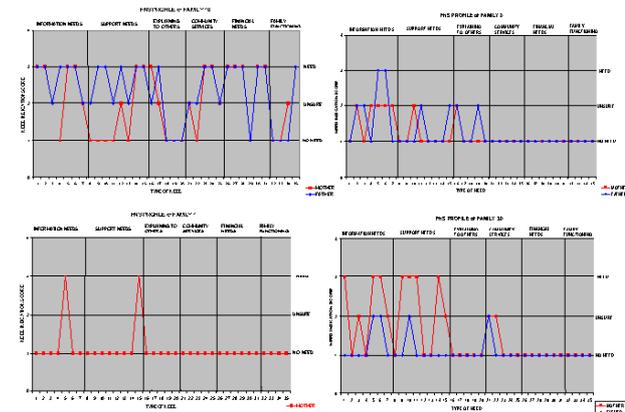


## Method

- Family Needs Survey delivered to families (additional section to list 5 greatest needs)
- Surveys collected and parents interviewed
- Data was coded, stored and handled using Microsoft Excel
- Statistical analysis for comparison of means using two-tailed t-tests (p = 0.05)

## To identify current functional needs from families (Part I)

- Needs of all parents
- Comparison between mothers and fathers
- Comparison between mothers with preschool and school aged children
- Comparison between mothers with children mild/moderate HL and sev/prof HL



## Needs Survey of Families With Hearing-Impaired Children. A pilot study.

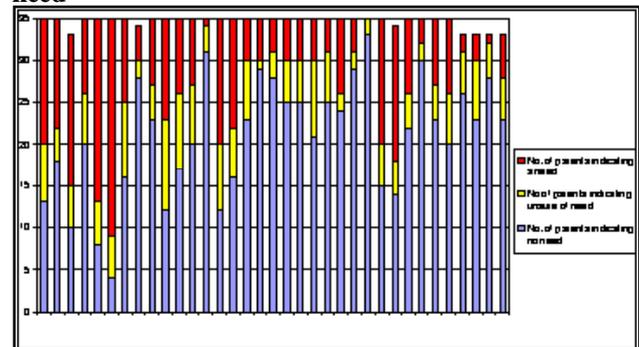
### Aims

- To identify current functional needs from families within a district (Chester and Ellesmere port)
- To consider the potential usefulness of the Family Needs Survey

### Family sample data

	20 mothers	20 surveys
<b>Families</b>		20 interviews
20 participated with children 0-11 yrs	15 fathers	15 surveys
<b>Age of child</b> (bilateral SNHL)	7 pre-school Children Mean age: 1y 9m (range 6m-43m)	8 interviews 5 + Dev. D
	13 School Children mean age: 8y 3m (range 5y-11y 1m)	2 + Dev.D
<b>Degree of HL</b> (ref. BATOD)	9 Mild / mod	2 + Dev. D
	11 sev / prof	5+ Dev. D

## The number of parents responding to each item of need



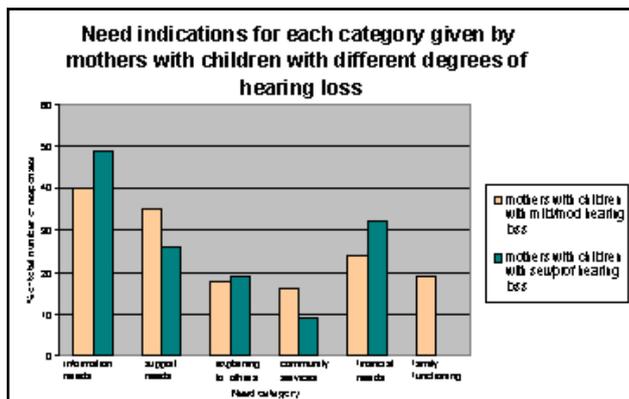
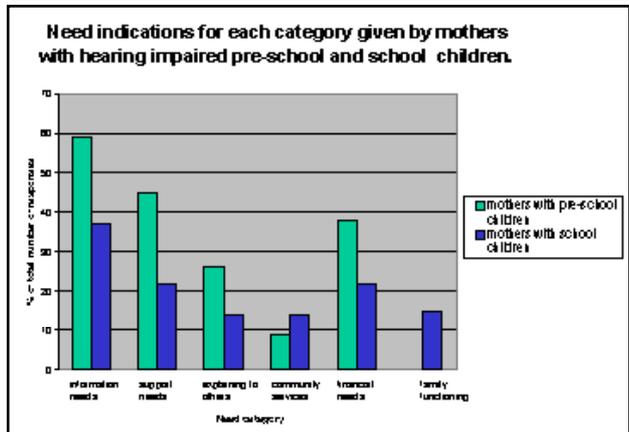
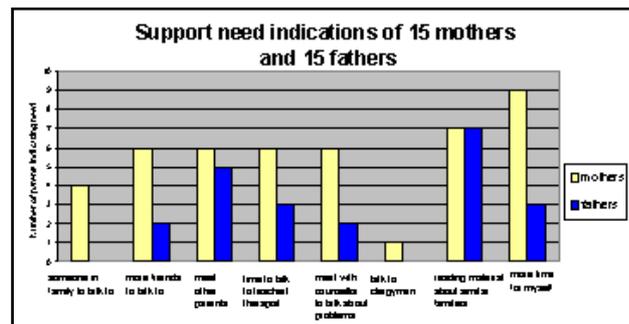
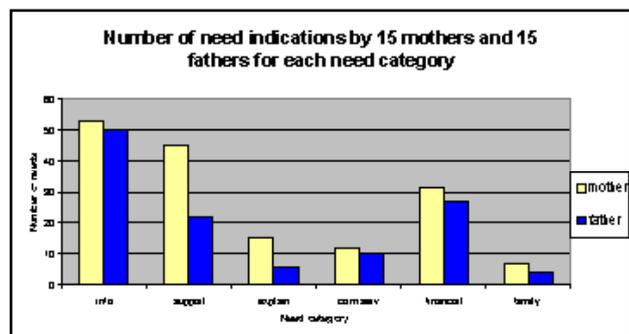
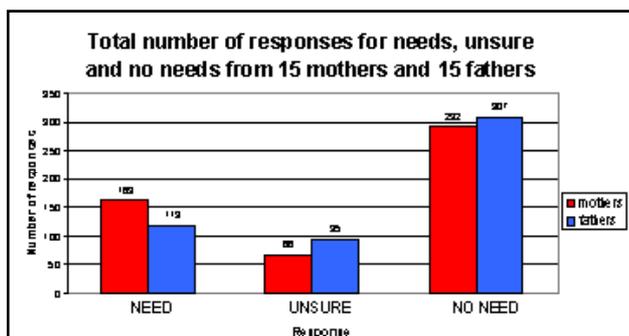
## Rank of needs from 35 parents

### The top five

#### % of parents indicating a definite need

- 74% future services (info)
- 63% present services (info)
- 51% how to teach child (info)
- 46% finance for special equipment
- 43% child's condition/disability (info)
- 43% reading material about other parents with similar condition (support)

# ADDRESSES



## Five greatest needs

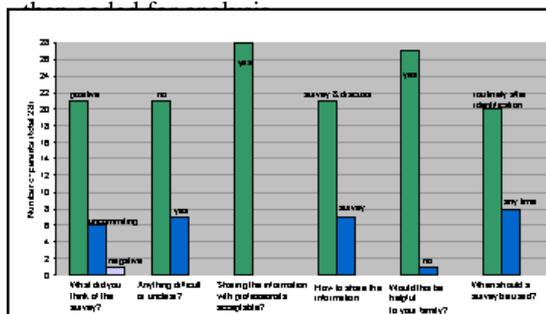
- 14 families completed this section
- Over 60% of these needs were listed in the Family Needs Survey
- Some related to hearing impairment
- Interpreter
- Information/financial/support

## Summary (Part I)

- Variety in number and type of need identified by parents
- 30/35 parents indicated at least 1 need.
- 74% of parents indicated a need for information about future services
- 40% of parents indicated needs from support and financial categories
- mothers indicated more support needs than fathers

## Parent views of the Family Needs Survey (Part 2)

- 28 parents interviewed
- Pre-determined questions which were structured, closed and open-ended
- All interview responses were recorded in writing and



## Any comments?

- Helpful to know what is available. You can't predict the help you will need
- Survey should be given with the aim of action being taken
- Fathers should be given the opportunity of being involved
- Interpreters are important
- Needs change; a survey could be useful at different times

## Summary (Part II)

- The Family Needs Survey was acceptable to parents
- 27/28 indicated they would find it helpful in identifying what they might need from a service
- All felt that sharing the information with professionals was acceptable to them

## A needs assessment tool e.g. Family Needs Survey

- Is a family-focused and practical approach which encourages partnership
- It creates expectation of action or response
- Gives families an opportunity to express their needs

*needs...goals....aspirations....hopes...dreams!*

Obtaining parents' views on services for children with permanent hearing impairment.

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## Overview of presentation

- Why we need parental views of services
- Different methods of obtaining views
- Some available survey instruments
- Advantages and disadvantages of approach
- How to decide appropriate method
- Recruiting parent participants
- Parents' views and service response
- Summary

## Why do we need parent views?

- Parents are experts about their child and life with a child who has a hearing impairment
- Parents know what they do and don't need
- To facilitate provision of accessible sensitive and responsive services
- Parents need a satisfactory experience of using health services. Dissatisfaction with elements of the services received can impact unfavourably on QoL (*Hind and Davis, 2000*)

## Why do we need parent views?

### Government policy

- Chapter 10 NHS Plan:  
User involvement (Parents are proxy users/ carers)
- Discussion Paper:  
Involving patients and public in health care  
Sept 2001
- Newborn Hearing Screening Programme:  
participating sites are to include parent participation in their Children's Hearing Services Working Groups

## Benefits to the NHS

- Restoration of public confidence
- Improved outcomes for patients
- More appropriate use of health services
- Potential for greater cost effectiveness
- Contribution to problem resolution
- Public sharing in responsibilities for health care

## How to get parent views?



## Different methods

- **Parent interview:**
  - Ad hoc during clinic appointment
  - Systematically selected
  - Structured Vs open-structured interview

schedule

- **Questionnaire survey:** Postal/Appointment
  - Forced-choice response, *or*
  - Open-ended response *combination*
- **Focus groups**
- **Voluntary parent groups**
- **Parent participant on Children's Hearing Services Working Group**
- **Suggestion book/box in clinic**
- **Patients' Forums** (Low incidence > no representation?)

## Parent interview at appt: Advantage

- Captive audience
- Potentially rich data (opportunity to explore comments)

## Parent interview at appt : Disadvantage

- Impact on clinic time allocation
- Restricted sample/restricted views
- Confidentiality and perceived possible impact on service for child may bias responses
- Parent may feel obliged to take part (could impact on subsequent clinic attendance)
- Interviewer may not have appropriate counselling skills

## Questionnaire survey: Advantage

- Potential to reach larger sample
- Does not intrude on appointment or impact on clinic
- Family friendly — does not 'compromise' the parent who does not want to participate
- Family friendly — less perceived threat to services if evidence of dissatisfaction provided (independent survey)
- Relatively rich data if open-ended response options

## Questionnaire survey: Disadvantage

- Questionnaire development requires appropriate expertise
- Poor response rate - bias?
- Reduced information if only forced-choice options
- Data entry and statistical analysis required (costly)

## Questionnaires available

- **Family Needs Survey** Bailey & Simeonsson (1988)
- Jane Dalzell's talk
- **IHR Outcomes Questionnaire** Hind & Davis (2000)
- Dynamic quantitative assessment of service satisfaction (re: support and information provided) supported by open comments
- Child Quality of Life
- Child behaviour index
- Quality of Family Life index
- Hearing aid/Cochlear implant usage
- **LEA Questionnaire for families** (DfES & RNID 2002)

# ADDRESSES

## Focus Groups: Advantage

- Potentially rich data
- Opportunity to explore issues
- No intrusion on appointment time
- Service users given an opportunity to learn of others' views

## Focus Groups: Disadvantage

- Restricted sample/restricted views
- Time consuming and potentially costly to set up

## Advantages and Disadvantages

### Voluntary parent groups: Advantage

- Usually varied experience of impact of hearing impairment
- Potentially rich data (opportunity to explore issues raised)
- No intrusion on clinic time

### Voluntary parent groups: Disadvantage

- May necessitate service personnel attending group meetings which would be time-consuming and may have an inappropriate impact on the dynamics of the meeting
- Risk of limitation of experience

## CHSWG's

### Parent Participant: Advantage

- Prospective and on-going parental advice
- No intrusion on appointment time etc.
- Inexpensive

### Parent Participant: Disadvantage

- Restricted sample
- Limited experience of children with PCHI e.g. Profound hearing impairment/multiple handicap  
*(May be countermanded if parent actively involved with other parents or if more than one parent participant appointed)*

## Which method to use?

Depends why parent view is required

- Audit of service satisfaction etc.
  - Questionnaire reaches wider sample
- In-depth exploration of dissatisfaction
  - Open-ended questionnaire survey
  - Parent interview (independent)
  - Focus Group (independent)
  - Parent participant (if truly representative)
- To help guide service provision generally
  - Parent participant in CHSWG
  - Focus Groups (held relatively regularly)
- Assessment of intervention (observing change)
- Review service produced information/To produce material

## Recruiting parents: Focus groups

- **Advertise**
  - Clinic waiting room
  - Local press
  - Voluntary sector publications/groups
- **Approach pre-selected parents direct** (known by you, or other professionals/Voluntary bodies)

- Parents known to have taken part in research
- Parents known to have views on service and capable of articulating them

*Simplest to commission experts to recruit and run Focus Groups*

## Recruiting parents: CHSWG's\*

*Information obtained from NDCS and telephone interview with 8 Audiology Depts*

### Known to Audiology

- Varying experience of deafness
- Interested in latest developments in audiology
- Interested in the service generally
- Interested in contacting other parents
- Has the time to be an effective member
- **Approaching local deaf children's societies/ Parent support groups etc.**
  - Active member of Local DCS/Support group
- **Advice from colleagues in other disciplines**
  - Known to Head of Sensory Services/Education

## Parents' reactions

- In 2 large surveys of services using the IHR questionnaire parents wrote and phoned in to say how much they had appreciated having the opportunity to express themselves
- Suggestions from the survey for service improvements included:
  - Identification as early as possible
  - Appropriate first hearing aids
  - Accurate accessible written and verbal information
  - Better co-ordinated services
  - More family friendly approach from professionals
  - Better responsiveness to concerns
  - A more holistic view of child and family AND extended family
  - Better support following diagnosis
  - Named dependable key worker who can be contacted as necessary

## Parent Views: Service Response

- Where possible, implement suggestions. Most are not unrealistic - often requiring only a more friendly, inclusive approach
- Personnel can change their behaviour (including ENT!)
- Be creative re: clinical processes etc.
- Ensure your inter-agency team/CHSWG is effective
- Ensure your inter-agency team/CHSWG is aware when any changes are being implemented
- Members of staff affected by change may require more support during the transition period; this may involve interagency support

## Summary

- Parent views on service need to be sought and acted upon (where possible)

- There are different methods for obtaining parent views
- The method/s used will depend to some extent on the reason the views are being sought
- The advantages and disadvantages of different methods need to be carefully assessed before decision-making
- Care should be given to the recruitment of parent participants to ensure appropriate representation across severity
- NDCS are currently exploring ways of recruiting parent participation and how to prepare recruited parents to present their and others' views as effectively as possible

## Conclusion

- If sufficient thought is given to the points mentioned, the process of information gathering should be satisfactory and rewarding for all involved
- Services will:
  - Be more family-friendly
  - Be potentially more cost effective
  - Be potentially more appropriately used
  - Provide a more satisfying environment for providers and users

Have you visited the NHSP website? [unhs.org.uk](http://unhs.org.uk)

*Public and Patient attitudes to the use of their health information*  
*Patient Electronic Record: Information and Consent (PERIC)*  
*Dr Rupert Suckling*  
*SCHARR University of Sheffield*

*Acknowledgements: Darren Shickle, Jane Carlisle, Peter Fryers, Susan Wallace, Anne Morgan, Michael Cork, Ian Bowns, Deryck Beyleveld, Andrew McDonagh, Chris McCabe.*

*Funded by the DoH and NHSE*

*18 month project (Started September 2000)*

## Why PERIC?

- Tensions between legal & policy requirement to protect health information and to use data to improve the quality of NHS services
- Expectation within Health Strategy that the public are supportive of the use of their personal data
- PERIC commissioned to assess acceptable boundaries on use of health information

## Legal and Policy background

- The Common Law
  - Source Informatics (1999)
  - Health Authority vs X (2001)
- The Data Protection Act 1998
- Human Rights Act 1998
- Health and Social Care Act 2001
- Europe
- Professional guidelines
  - Royal Colleges, MRC, GMC
- Committee Reports
  - The Caldicott Committee (1997)
  - House of Lords Select Committee on Science and Technology “Human Genetic

Databases: Challenges and Opportunities (2001)

- Public Inquiries
  - Bristol Royal Infirmary (2001)
  - Royal Liverpool Children's Hospital (2001)

## The PERIC Project

- Survey of general public
- Survey of patients and parents of paediatric patients
- Conjoint analysis
- Interviews with special groups (young people and their parents)
- Focus groups
- Randomised controlled trial

## Interviews with general public

- Market research (IPSOS Capibus Omnibus survey)
- Sample: Adults 15+ from Great Britain
- 3921 people interviewed over 2 weeks
- 200 vignettes
- 10 vignettes each
- Between 171 and 202 responses to each vignette
- **Person requesting information** (GP; hospital doctor; practice nurse; hospital nurse; GP receptionist; ward receptionist; manager; researcher; physiotherapist; social worker)
- **Use** (clinical care; clinical audit, financial audit, research, teaching, assess performance of doctors, public health surveillance)
- **Content** (current episode, all medical record, all medical history incl. sensitive info.)
- **Level of identification** (name & address; record number; anonymous)

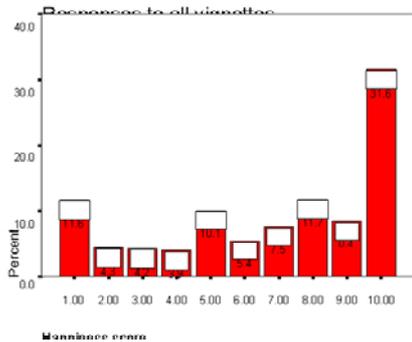
A doctor in the hospital would like access to your notes which contain information only about your current health problem as part of the health care that you are receiving. The information about you would contain your name and address.

# ADD9815

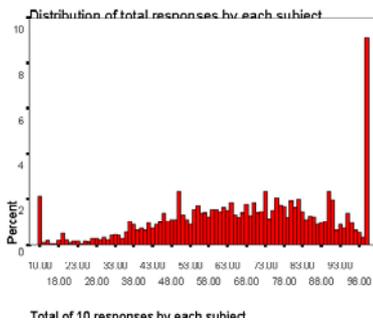
On a scale of 1 to 10 where 1 is very unhappy and 10 is very happy, how happy would you be for this person to use your medical information in this way?

## Main findings (1)

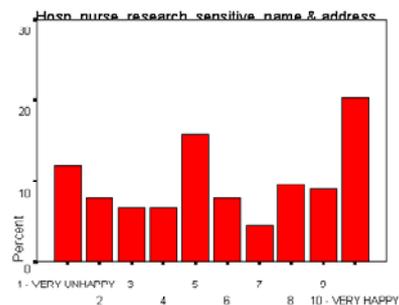
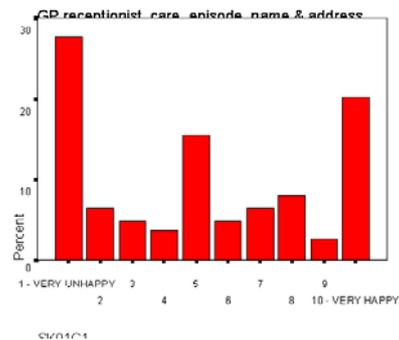
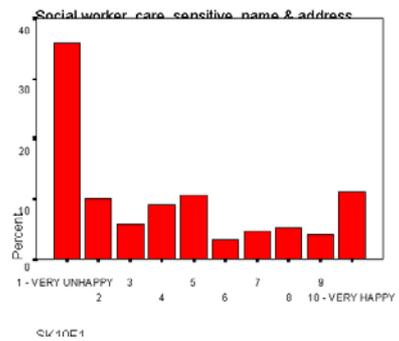
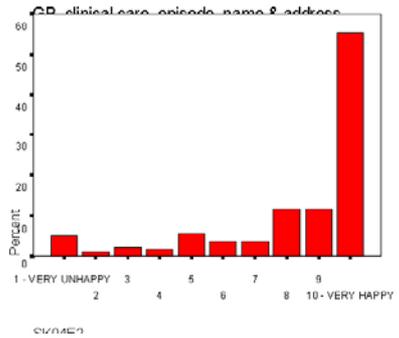
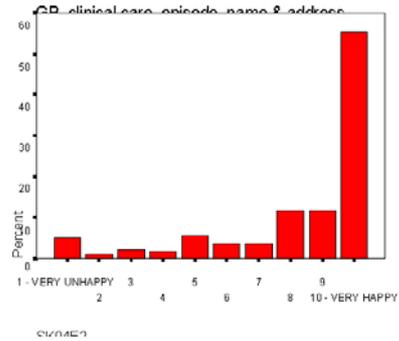
- Public are generally happy to provide access to their health information
- 31.6% of responses to vignettes where subjects said that they would be very happy to allow access (score of '10')
- 11.6% of responses to vignettes where subjects said that they would be very unhappy to allow access



- Almost a tenth (9.1%) of subjects said that they would be very happy to allow access within all of the vignettes that they were asked to assess
- In addition 2.1% of individuals said that they were very unhappy with all of the vignettes presented to them

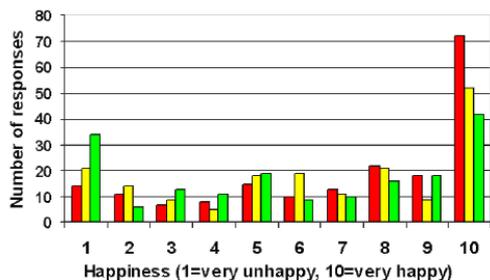


- Individuals from higher social groups, older people and males were more likely to be happy to give access to their health information
- The individual requesting information was the most important factor determining willingness to allow access to the health record
- Subjects were happier to release anonymised rather than personally identifiable data
- Content of the information to be released did not seem to be that important, even when the health record contained sensitive information
- With the exception of teaching students, the use of the information was not an important determinant of consent



Influence of mental illness and sexual problems

# AD9ENS



## Survivents

- 104 patients and 90 parents of paediatric patients in Sheffield
- Assessed 10 vignettes from the national sample
- Asked to rate happiness and whether they would give consent
- Asked to rank their knowledge of the NHS against an average patient

## Patients and parents of paediatric patients (2)

- Patients tended to be happier than parents of paediatric patients, who were happier than the general population
- Strong association between happiness and willingness to consent
- Patients who perceived themselves to be better informed tended to be happier and more willing to give consent

## Patients and parents of paediatric patients (3)

- Patients, especially with more knowledge of the NHS were more likely to allow access to their information than the general public
- Willing to provide consent
- Obligation to provide access?
- More exposure to form a judgement on the NHS approach to protecting health information?

## Attitudes of Young People to various uses of their health information

- Young people aged 14-17
- Paediatric dermatology, general surgery outpatients and general surgery paediatric wards
- Semi-structured interviews

## Characteristics of vignettes causing least concern

	% of 10's	Person	Purpose	Content	Identify
sk10hi	56.6	Hosp Doctor	Public Health	Past History	Anonymous
sk05f2	56.2	Hosp Doctor	Public Health	Episode	Anonymous
sk04e2	55.2	GP	Clinical Care	Episode	Name& Address
sk02a2	54.5	Hosp Doctor	Monitoring Doctors	Past History	Anonymous
sk02f2	54.5	Hosp Doctor	Research	Episode	Anonymous
sk05i2	54.2	GP	Clinical Care	Past History	Name& Address.
sk07e1	54.0	Hosp Doctor	Clinical audit	Episode	Anonymous
sk04h2	52.7	Hosp Doctor	Monitoring Doctors	Episode	Anonymous
sk09h1	50.0	Hosp Doctor	Research	Past History	Anonymous
sk06d2	49.7	GP	Clinical Care	Sensitive	Name& Address
sk01e2	49.2	Hosp Doctor	Research	Sensitive	Anonymous
sk02a1	49.2	Hosp Doctor	Clinical Audit	Past History	Anonymous
sk01a1	48.9	Hosp Doctor	Clinical Care	Episode	Name& Address
sk05i1	48.9	Hosp Doctor	Clinical audit	Episode	Record Number
sk10a2	48.0	Hosp Doctor	Clinical audit	Past History	Record Number
sk09j1	47.9	Practice nurse	Clinical audit	Past History	Anonymous
sk03d2	47.4	Hosp Doctor	Public Health	Episode	Record Number
sk04e1	47.0	Hosp Doctor	Financial Audit	Episode	Record Number
sk09h2	45.5	Hosp Doctor	Public Health	Past History	Record Number
sk05a2	44.8	Hosp Doctor	Monitoring Doctors	Episode	Record Number

- 11 young women and 9 young men

## Young people (2)

- Issues associated with consent
- Age of responsibility for giving consent
- Awareness of the medical record
- Disclosure to parents
- Views of parents

## Focus Groups - Implied Consent

- 13 men and 22 women, across the age range, variety of occupations
- 5 focus groups across North Trent
- Is consent unnecessary?
- Does obtaining consent distress the patient?
- Is obtaining consent unreasonable or would it be too expensive?

## Focus Groups (2)

- Medical intervention
- Health information
- Prescribing
- Passing information to other health professionals
- Disease surveillance
- Cancer registries

## Policy implications

- People may be unhappy about releasing data but still give consent and vice versa
- Just because people are very happy, it doesn't mean that they don't want to be asked to give consent
- Distinction between consent and informed consent
- Need to remember the rights of minority

## Register for hearing impairment

- Likely to be well received, provided of benefit to the person on the register/or in the public the interest.
- Concern likely to focus on who has access to the data rather than what it would be used for, but that this would be important.
- Ideally explicit informed consent.

## Characteristics of vignettes causing most concern

	% of 1's	Person	Purpose	Content	Identify
sk05f1	37.6	GP receipt.	Clinical Care	Sensitive	Name& Address
sk10f1	36.0	Soc. Worker	Clinical Care	Sensitive	Name& Address
sk02e1	31.7	Researcher	Financial Audit	Sensitive	Name& Address
sk01f2	29.3	Soc. Worker	Clinical Care	Past History	Name& Address
sk03b1	29.1	GP receipt.	Clinical Care	Past History	Name& Address
sk06i2	27.9	Ward Receipt.	Clinical Care	Past History	Name& Address
sk01c1	27.7	GP receipt.	Clinical Care	Episode	Name& Address
sk08g2	27.3	Ward Receipt.	Clinical Care	Sensitive	Name& Address
sk02c2	27.3	Soc. Worker	Clinical Care	Episode	Name& Address
sk08i1	27.1	Researcher	Public Health	Past History	Name& Address
sk10j2	26.7	Hosp Nurse	Teaching students	Sensitive	Name& Address
sk05b2	25.1	NHS manager	Clinical Audit	Sensitive	Name& Address
sk01g2	24.6	Researcher	Public Health	Sensitive	Name& Address
sk02f1	24.6	Hosp Nurse	Teaching students	Past History	Name& Address
sk06h2	23.9	Researcher	Financial Audit	Episode	Name& Address
sk04c1	23.8	NHS manager	Public Health	Sensitive	Name& Address
sk03c2	23.2	Researcher	Clinical audit	Sensitive	Name& Address
sk03h2	22.6	Hosp Doctor	Teaching students	Past History	Name& Address
sk04d1	22.1	GP receipt.	Clinical Care	Past History	Record Number
sk01i2	22.0	Hosp Nurse	Teaching students	Episode	Name& Address

### *Influencing Services: A Parent's Perspective* *Andy Ford*

#### Introduction

- NDCS Quality Standards in Paediatric Audiology
- Recommendations on family friendly services
- Audiology Working Groups developing into Children's Hearing Services Working Groups (CHEARS)

#### A Changing Service

- UNHS
- Digital aids
- Modernising Hearing Aid Services
- Closer links between the services
- Recognition of the need for more parental involvement

#### Surveys & Questionnaires

- Traditional approach
- Difficult to avoid bias
- Limited response and limited information
- Doesn't truly involve parents – non-participative

#### Children's Hearing Services (CHEARS) Groups

- Based on the Quality Standards recommendations
- Questions to be asked:
  - Representation
  - Constitution
  - Task Teams
  - Task Topics
  - The Chair

#### What Makes CHEARS Groups Effective?

- Take learning from established groups – speeds start up:
  - Membership
  - Reporting lines
  - Number of parents
  - Constitution/the rules
  - When and where to meet
  - How to keep things moving
- Shared professional/parent chair
- Limit main group size flexed by task groups
- Focus on only 3/4 improvement areas

- Single group reporting line (each area can report to their own line accordingly)
- Active senior management involvement

#### What Do Parents Want From Hearing Services?

- Early diagnosis
- Immediate and coordinated support
- Access to clear information
- Recognition of the importance of parents in all aspects of the process
- Continued involvement in child's development

#### What Are The Problems for Parents with CHEARS Groups?

- Getting parents to volunteer
- Parents won't necessarily have the right skills
- Parents feel daunted
- Certain professionals try to rule
- Finding times to meet that suit professionals and parents
- Childcare

#### What Will Make the Difference

- NDCS training events
- Parental involvement becoming the norm
- Parents mentoring other parents
- Finding tasks to which parents feel they can add value
- Demonstrating resultant improvement

#### The Challenges Ahead

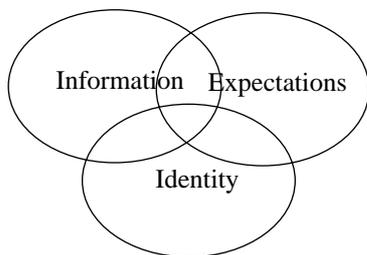
- New situation for parents
- Challenge for staff and their management
- Commitment needs to be kept up
- Tasks undertaken need to be completed and improvements made
- Senior management visibility and recognition

#### In Summary

- An opportunity to include parents and gain their buy-in and support
- A challenge for staff and management
- The work of CHEARS groups must be reflected in change and improvement
- Otherwise parents will not feel their voices are heard and the initiative will be lost

**Factors affecting communication choices in the first year of life**  
**Assessing and understanding an on-going experience**  
**Dr Alys Young (University of Salford)**

*Dynamics of Choice*



**Information**

- Information is a vital commodity for parents
- But there are still key problems in its provision to and use by parents.

**Information Dimensions:**

- Reliability
- Empowerment

**Reliability...**

- Partial, unbalance, biased information
- Parents' later discovery of alternatives/experiences of professional reluctance to tell
- Consequences: dependency
- Consequences: sadness, anger, guilt
- Consequences: professional rejection

**Empowerment**

- Giving parents the tools and structures to be evaluators of information
- Empowering parents to be active requesters and users of information
- Redressing professional/parent power imbalances

**Empowerment...** [from Chandra et al 1998]

*"Practitioners felt that parents needed to be more assertive in their dealings with professionals if they wished to obtain the information they wanted..."*

*"Many parents felt that even when given an opportunity to ask for information they did not always know what to ask. This made parents reliant on professionals for all relevant information and supported the belief that 'professionals know what we want'."*

**Parent/professional checklist (information)**

- Am I providing fair and good enough information?
- *Am I being told everything and do I understand?*
- Is the information I am giving reliable and verifiable?
- *How can I check out what I'm being told?*
- Am I enabling parents to use information for themselves?
- *Am I being helped to make my own decisions?*

**Expectations:**

- Deafness is an experience outside parents' "sphere of relevance"

- Communication choice is linked to the development of meanings of deafness for families
- Social assumptions about deafness strongly linked to communication methodologies

**Expectation dimensions:**

- Expectations of "the deaf experience"
- Expectations of "my child"
- Expectations of the chosen "method"
- Expectations of self as parent

**Parent/Professional Checklist (Expectations)**

- Am I expanding and challenging parents' assumptions about the deaf experience?
- *What are my assumptions about the deaf experience and am I right?*
- Do I know what I expect of these parents and is it realistic for them?
- *What are my expectations of my self and my deaf child?*

**Identity:**

- Parents and families existed before the birth of the deaf child
- Their pre-existing identity and characteristics will influence choice of communication approach

**Identity dimensions:**

- Values and priorities (personal, familial, social, cultural)
- Individual and family 'styles', resources and capacities for change
- But nature of influence may be unexpected
- Transformed family identities?

**Identity influences....**

*"What [the teacher of the deaf] had just demonstrated was simply not our way of doing things... The [ideas] that most appeal to us are those which have as their basis a firm respect for the rights of children as originators and decision makers in their own learning... It fits in with us as people, with our way of thinking"* [Fletcher 1987]

*"The most important thing ... is that [families] try anything to communicate and don't listen to professionals. Do what you think is best for you. Because you and your child won't suffer as much if you can communicate."* [a parent from Beazley and Moore, 1995]

**Parent/Professional Checklist (Identity)**

- Am I engaging with the values, priorities and style of these parents?
- *Do the choices I have made fit with my way of doing things?*

# ADDREMS

- Am I recognising and responding to challenges parents face to their previous ways of doing things/previous ways of thinking?
  - Am I being helped to face difficult challenges to how I have thought about my deaf child and family?
- Conclusion:**
- In understanding factors affecting the choice of communication method, it's vital to focus on the dynamics of choice for parents/families
  - Dimensions of Information, Expectation and Identity all interact with each other in highly complex ways individual to each family
  - Professionals' relationships with parents will strongly influence all aspects of that interaction
  - Assessing choice as an on-going process by parents and professionals is vital to a successful outcome for families.

*Investigation of Hearing loss - informed choice by parents*  
*Dr Breege Mac Ardle*  
*Nuffield Hearing and Speech Centre*  
*RTNE*

## **Aims of presentation**

- Look at Quality Standards
- Review the national BAAP/BACDA protocol for medical investigation
- How to make the protocol Family Friendly
- Way forward

## **Aetiological Investigations**

Primum non nocere

## **Family Friendly Services**

- meeting the needs of the family is more important than adhering to targets and standards (Baguely, Davis, Bamford, 2000) Quality Standards in the Early Years NDCS 2002

## **Aetiological Investigations**

- Families must be offered the opportunity for their deaf child to have aetiological investigations.
- These investigations must be carried out in accordance with local protocols based on nationally agreed standards.
- They should be offered counselling to understand these investigations and the implications.  
*Quality Standards in the Early Years NDCS 2002*
- Parents should be made aware that it is not always possible to obtain a conclusive result from investigations.

- **Some families may decline the offer of these investigations and their wishes should be respected**

*Quality Standards in the Early Years NDCS 2002*

- Parents must be given written copies of all results and reports.

*Quality Standards in the Early Years NDCS 2002*

## **BAAP/BACDA Working Group**

Dr. D Bamiou, Dr. S Fonseca, Dr. M Bitner-Glindzicz, Dr. B Mac Ardle, Dr. K Rajput

## **Aim of guidelines**

To propose a rational approach to investigation of deafness which is :

- evidence based
- includes the least invasive tests
- easily available investigation(s)
- considers costs

## **Subjects**

- All children with bilateral sensorineural hearing loss and thresholds over 70 dB HL in the better hearing ear averaged across 500, 1000, 2000 and 4000 Hz

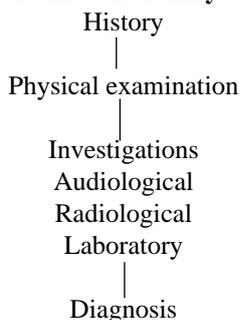
## **Grades Of Evidence**

Grade A - Requires at least one randomised controlled trial (RCT)

Grade B - Well co-ordinated clinical trials but no RCT's on the topic

Grade C - Requires evidence from expert committee report or opinions and/or clinical experience of respected authorities. Absence of directly applicable good quality studies

## Assessment of deaf child and family



## Which investigations? (1)

### Level 1

- Paediatric history , developmental milestones, risk factors for deafness,
  - Family History of deafness
  - Clinical Examination & photography
  - Family audiograms (1st degree relatives)
  - ECG for prolonged QT interval
  - Urine for microscopic haematuria
  - Referral to Ophthalmologist - v acuity, dilated funduscopy - delayed motor milestones - ?ERG
  - Connexin 26 mutation testing
  - MRI of internal auditory meati or CT of petrous temporal bone
  - Level 1 - to be performed on all children with *confirmed* bilateral severe to profound sensorineural hearing loss \*
- \* parental acceptance/local availability of tests /child's ability to cooperate

Level 2 - for **consideration** in all cases

### Level 2

Where clinically indicated :

- Serology : to exclude congenital infection, in maternal stored serum
- Haematology and biochemistry, metabolic screening (blood and urine), microscopic haematuria
- Thyroid tests
- Chromosomal Studies
- Immunology tests
- Renal ultrasound (pits, sinuses, clefts or Mondini cochlea)

### Consider in all cases:

- Referral to a Clinical Geneticist esp. if family history of consanguinity
- Vestibular investigations

## How to make protocol Family Friendly

Timing of investigation is important:

- Accurate diagnosis of deafness
- Family's needs and acceptance of deafness

## How to make protocol Family Friendly - information sharing

- Several sessions - timescale will vary

Information :

- Verbal
- Written - in progress
- Websites

### Parents should know :

- 1) Why it is important to investigate deafness
- 2) The causes of the deafness and their frequency
- 3) The type of tests - invasive versus non invasive and yield from tests
- 4) To give a more accurate prediction of risks of having another child with deafness
- 5) Not always possible to find a conclusive diagnosis
- 6) Investigation is an ongoing process

### Causation of deafness

- Genetic basis 50%
- Non genetic 25%
- Syndromal (200) 25%

### Which tests?

- Audiograms
- Blood tests / Gene testing
- Eye assessment
- Imaging
- Vestibular assessment
- Urinalysis
- ECG

### Genetic cause

- Audiograms on family members
- Eye examination
- Vestibular testing
- Gene testing
- MRI/CT scanning
- Blood tests

### Syndromal deafness

- Audiograms on family members
- Family history
- Gene testing
- Blood tests
- MRI/CT Imaging
- Eye assessment
- Vestibular assessment

### Non genetic deafness

- Audiograms on family members
- Family history
- Gene testing
- Blood tests
- MRI/CT Imaging
- Eye assessment

### Yield from investigations - imaging

Scans abnormal in 25 - 37% of cases

- Large vestibular aqueduct commonest abnormality - leads to counselling and possible investigation for Pendred's Syndrome

# ADD9EMS

- Implant candidates
- Severe anomalies associated with meningitis risk

## Gene testing

- Connexin 26 commonest cause of severe /profound deafness - ?30%- 50%
- 35 Del G - sequence the entire gene

## Eye assessment

- High incidence of eye abnormality 30 - 50%
- NDCS guidelines - Autumn 2002

## Aims of presentation

- Look at Quality Standards
- Review the national BAAP/BACDA protocol for medical investigation
- How to make the protocol Family Friendly
- Way forward

## Gaps in our knowledge

- Best way of presenting information to parents
- True diagnostic yield from our protocol
- Timing of investigations
- ? Repeat investigations

## Way forward

- Produce materials for families and pilot them
- Review of Guidelines in September 2002
- National Audit of the guidelines
- When should some of the tests be repeated ?
- ? Unilateral and mild to moderate losses

## Acknowledgements

- Parents
- BACDA/BAAP Working Group
- Mrs. Roberta Harte - (Family Services Co-ordinator Nuffield RNTNE)
- Colleagues at RNTNE

*Mainstream or Special School?*  
*Elizabeth Andrews*  
*Head of Education Policy, RNID*

## Summary

- The general and policy context regulating educational placement
- Information about the range of expertise available within the special school sector for deaf children
- Identification of key issues
- 5 reasons to place a child in a school for the deaf
- An update on current developments

## GENERAL CONTEXT OF CHANGE



## A dynamic context

- NHSP
- Development/modernisation of audiology services for very children
- Modernising Hearing Aid Services (MHAS)
- Access to digital hearing aids on the NHS
- Access to earlier cochlear implantation
- ... bringing new opportunities for deaf children and their families

## POLICY CONTEXT AND STATUS QUO

## A strong presumption in favour of inclusion

### Fundamental principles:

- a child with special educational needs should have their needs met
- the special educational needs of children will normally be met in mainstream schools or settings.

SEN Code of Practice (2001)



## Current placement of deaf pupils

At a time when an estimated 30-40%+ of deaf pupils have an additional disability or learning difficulty, over 75% (average hearing loss greater than 40dB) are placed in mainstream schools.

BATOD Survey 1998

## Deaf children in a generic context

- The revised SEN Code of Practice and SEN and Disability Act (SENDA) together support a stronger right for children to be educated in a mainstream school
- Parents of deaf children sometimes express a strong preference in favour of a special school placement.  
*... in step or out of step?*

## The SEN Action Programme

*'For some children, a mainstream placement may not be right, or not right just yet. We therefore confirm that specialist provision- often, but not always, in special schools- will continue to play a vital role.'*

*'There are many excellent special schools which provide good teaching and support and which are valued by parents and pupils. There will be a continuing role for specialist provision, including special schools. Special schools need to be confident, outward-looking centres of excellence. We want to build on their strengths, and ensure that they are an integral part of an inclusive education system for children in their area, and perhaps beyond.'*

Meeting Special Educational Needs: a programme of action DfEE (1998)

## SENDA (2001)

Section 1 of the Special Educational Needs and Disability Act (SENDA) says:

- *If no statement is maintained under Section 324 for the child, he must be educated in a mainstream school.*
- *If a statement is maintained under section 324 for the child, he must be educated in a mainstream school unless is incompatible with-*
  - a) **the wishes of his parent** or
  - b) the provision of efficient education for other children

## SEN Code of Practice (2001)

The code says:

*'Where an LEA proposes to issue a statement or amend part 4 of an existing statement, they must name the maintained school- mainstream or special-that is preferred by the parents, providing that:*

- *The school is suitable for the child's age, ability and aptitude and the special educational needs set out in part 2 of the statement*
- *The child's attendance is not incompatible with the efficient education of other children in the school and*
- *The placement is an efficient use of the LEAs resources.'*

## Where does this leave families?

This is good news and bad news for families who want a placement in a special school.

## The resource

- 28 schools for the deaf across England
- 120+ LEA advisory/support services for deaf children
- 350+ mainstream schools with a resource base for deaf pupils

An important element in the national and regional continuum of educational provision to support a diverse, low incidence SEN population

## A diverse resource

- Large and small
- Primary, secondary and FE phases
- Range of communication approaches
- Range of expertise
- Maintained, non-maintained, independent status

- Residential, day and 52 week provision

## Who needs this resource?

- Children with multiple/profound disabilities or learning difficulties
- Children who are failing in mainstream school
- Children who need a residential placement away from home
- Children who need smaller class sizes

## Key issues

- Parental/family choice
- Meeting the needs of the child and maintaining a range of educational provision to achieve this
- Funding arrangements

## Why place children in special schools?

### 5 good reasons

- **Access to concentrated/particular expertise**  
*e.g. MHGS, RSD Margate*
- **Access to a signing community**  
*e.g. Longwill School, Elmfield School*
- **Smaller classes and acoustically treated classrooms**  
*e.g. Ovingdean Hall School, St. John's BS*
- **Slower pace**  
*... and therefore better access to the curriculum*
- **Finding a peer group**  
*Deaf identity issues and more*

## Response from special schools

- Down-sizing and relocation to mainstream school sites
- Extending 'outreach' work
- Defining expertise and making it more widely available
- Supporting families through statementing and SEN Tribunal processes

## Ministerial working party DfES

- Remit is to look at the future and role of special schools and funding arrangements to support placement in special schools
- Met for the first time May 2002
- 6 month period of operation
- Ministerial Seminar December 2002 (?)

## *A Community Model for Screening Hearing in the First Month of Life: The Decision Process, Implementation and Early Results*

*C. Bunting, Associate Specialist (Paediatric Audiology), Team Leader Shropshire NHSP*

### **Abstract**

The decision to implement a community based universal newborn hearing screen in an English shire county was reached after consideration of local birthing and population data together with factors affecting the local performance of other screens. In this programme only babies in the Neonatal Unit are screened in hospital. Well babies are screened at home by their allocated Health Visitor using automated TEOAE equipment, as part of the primary visit protocol. Clinical assessment of risk for the development of later hearing impairment is also undertaken and determines follow up arrangements. Those who are referred from this stage of the screen receive AABR at home, performed by the local screen co-ordinator. Elements of planning, training, implementation and quality management are described. Early results for the first four months are: coverage of 98.7% and referral for AABR from the HV screen of 4.5%. The percentage of babies referred for threshold ABR from the well baby screen was 0.45%, and 4.8% from the NNU population, giving an overall rate of 0.7% for the screen as a whole. Two cases of monaural hearing impairment have been detected and two case of moderate bilateral impairment (one sensori-neural and the other probably of mixed type). The conclusion is that this model is a viable alternative to one based on maternity unit screening of well babies. It provides an alternative model for those planning local programmes and may be the preferred option if local conditions are similar to those described in this article.

### **General background**

The use of equipment that detects oto-acoustic emissions (OAE) or auditory brainstem responses (ABR) is well documented for screening populations of babies for significant congenital hearing impairment (Watkin 1996a & b) (Watkin 1999a) (Vohr 1998).

The limitations of a first stage OAE test have been calculated (Lutman 1997). The merits of each technique have been evaluated and compared (Norton 2000).

The combination of the two measures, transient evoked oto-acoustic emissions (TEOAE) and automated ABR (AABR) was thoroughly tested in the randomised control trial which has become known as the 'Wessex Project' (Kennedy et al 1998 & 1999). The study demonstrated that, if used sequentially, the two techniques produce a screening method of high specificity and sensitivity when applied to whole populations.

The higher incidence of permanent childhood hearing impairment (PCHI) in the graduates from Neonatal Units (NNU) has been demonstrated by several authors (Sanders 1985), (Davis 1992). The identification of auditory neuropathy in this group (Psarommatis 1997), (Deltre 1997), (Rhee 1999) means that sole reliance on detection of oto-acoustic emissions is clinically unsound and AABR is therefore the screening technique of choice for this subpopulation.

The development of machines which score against a predetermined template and produce an 'achieved' or 'not achieved' result, against preset parameters, has enabled these techniques to be applied by people who are not fully trained audiologists. In Holland nurses have been used to test in the community using AABR (Oudesluys-Murphy 1997). The Rhode Island study used some trained volunteers (Vohr 1998). In the UK Health visitors undertook this task in a pilot study (Owen 2001).

A comprehensive review of congenital hearing impairment detection in the UK was published in 1997 (Davis 1997). In 1999 The Paediatric Subcommittee of the National Screening Committee recommended a universal newborn hearing screen for England. The proposal for well babies, based on the stage 4 evidence from the Wessex project, was for a two technique screen (TEOAE followed by AABR on referrals from the OAE stage). An obligatory AABR stage for NICU babies was also proposed. One of the committee's concerns was the issue of parental anxiety, potentially generated by the screen, and the effect this might have on the parent / child interaction within the first week of life. Emphasis was therefore placed on full involvement of the parents and the supply of accessible, parent information and support at each stage of the process.

The factors involved in a screening programme as opposed to screening tests have been reviewed by Davis (2001).

### **Local background**

One of the prime factors of any screen is coverage, which must be a minimum of 95%. A corollary of this for a universal screen, which is equitable, is that it must be offered to 100% of the defined population. The working party in Shropshire felt this target would provide a stiff challenge for local implementation.

The elements in our assessment for our local provision were:

#### **(a) Coverage achieved for existing screens**

Audit of our local paediatric screening programmes yielded coverage statistics shown in Table 1.

**Table 1. Performance of other paediatric screening programmes**

	Sample	n	Coverage
PKU / TSH screen taken to baby	dob 30/5/99 – 31/8/99	1308	99.5%
6wk Development Exam as OP	1998 births	4947	95.4%
HVDT as OP Targeted Newborn HearingScreen	1998 births less TNS	4587	95.8%
(mostly as outpatient)	1995 – 2001	1444	86.6%

**(b) Assessment of additional service provision needed to achieve HVDT coverage**

Audit of the 1997 data for the HVDT revealed that to achieve 4983 attendances 7186 appointments were required. This equates to an extra 44% service provision to compensate for non-attendance.

**(c) Birth distribution and Population distribution**

Data from the child health computer on births and from the local authorities on population distribution revealed a marked mismatch between place of birth and area of residence (Table 2).

**Table 2. Births and population distribution.**

	Births	Population
District A	78%	23%
District B	9%	34%
District C	1%	12%
District D	3%	21%
District E	2%	10%
Move in at birth	5%	
Born at home	2%	

**(d) Early discharge pattern**

The local figures for early discharge after delivery of 3% after 6 hours and 39% within 48 hours are further compounded by the local practice of moving babies and mothers from the consultant unit to their local midwifery unit on the second day after delivery before final discharge.

The figures reflect the demographics of the county. 22% of births do not take place in the consultant obstetric unit but in small midwifery units, at home, or in out of county hospitals. Almost half of the babies born in the consultant unit are residents of a new town some 15 miles distant which is now the largest urban centre in the 'county'. A hospital based service could therefore, at best, yield 78% coverage as an inpatient service. It was considered that a local outpatient service to cater for the 'mop up' would need to be provided in at least 6 centres to enable reasonable access to services. No data were available on the feasibility of undertaking both OAE and AABR (where indicated) in a single outpatient visit.

A delay in identifying local funding, before national plans were revealed, provided the multi-agency working party an opportunity to consider the factors outlined above from a wider perspective. All programmes in the United States are

hospital based but this is probably a reflection of the health care systems in place there. In the UK there is established provision of services by primary health care professionals throughout the pre-school period and into the state school system. Birth is not the only opportunity to deliver public health services to all children.

**The pros and cons**

**(a) Against a hospital based programme**

It was apparent that a screen based on the main maternity hospital would produce a significant number of children requiring outpatient screening. From the outset a significant number of babies would require a different service to those screened in hospital. From an administrative viewpoint the plan was complex. Clinic space, appointing and staffing at a minimum of six sites were points considered. It was felt that it inherently contained inequalities of service provision dependent on place of birth. It was considered that the non-attendance (DNA) factor could result in difficulties achieving the 95% coverage target within the specified time-scale.

**(b) For a Community based programme**

The Wessex Project showed that one of the variables affecting specificity of the OAE stage in 'well babies' is the age at time of test with the number of false positives diminishing up to 48 hours. The statutory visit of the Health Visitor around the 10<sup>th</sup> to 14<sup>th</sup> day after birth was considered to be a suitable time to test. A feasibility pilot (Owen) had shown that the OAE screen can be performed satisfactorily by Health Visitors (HV) trained for the task. It was considered that this measure would eliminate the DNA factor thereby maximising the coverage. It was felt that the service would produce minimal disruption for the parents and baby and had the potential to be 'family friendly' in that the screen would be undertaken at home. It was also felt that stress resulting from the delivery and adjustment to the new arrival to have stabilised. The screener would be a named person with whom the family would have continuing contact on developmental issues until school age. The administration of the screen would be simple with few outpatient appointments or clinics to be arranged. Data could be recorded along with other child development records on a newly commissioned module of the Child Health Computer system.

**The decision and implementation flow**

Based on the considerations above a business plan for a community based screen for well babies was submitted as a bid for the first wave pilot.

Confirmation of our selection, together with 3 other areas planning a HV service, was received in December 2000. The business plan and local services received approval following a site visit in June 2001. A full time Local Co-ordinator (job share) with a background in audiology was appointed in October 2001. A 0.5 whole time equivalent administrative clerk was appointed to child health.

Training began in October 2001. The health visitors were divided into 3 cohorts. Each received a day of theoretical instruction in groups of 30 – 50 and a day of clinical and

# AOD9EHS

practical training in groups of 4-8 in local maternity units. Each cohort was completed within a month before the next received their 'theory' day. The programme was completed in January 2002. In total 120 Health visitors were trained. On completion of training each HV had access to an EchoCheck machine with LED numeric display. 56 machines were distributed on a ratio of one per HV base.

We aimed for a full service to all babies born on or after 1/02/02. Leaflet, consent form and labelled pre-carbonated 3 part result record sheet are sent out to the HV by the clerk who prepares the primary visit documentation. The record sheet is designed to fit in the Personal Child Health Record (PCHR).

Clear responses are required from each ear. 'Risk' factors, which may indicate the development of later impairment, are noted and determine the follow up schedule (Fortnum 2001). If clear responses are not obtained from each ear the HV arranges to undertake a retest. One copy of the result is returned to child health, one retained by the parent and one by the Health visitor. If no response is obtained from either ear and there are risk factors present (eg Family History of SNHL) the baby is referred for AABR from the first test.

If clear responses have not been obtained from each ear by the second test the baby is referred for AABR. Within a few weeks it became apparent that non-attendance for outpatient AABR was causing difficulties. A trial of home delivery of the AABR stage by the local co-ordinator was piloted

and rapidly proved to be effective. Babies tend to be more settled, partly because of less clothing and parents are more relaxed. This practice is now our standard protocol and is working well. The whole of the screen is now delivered as a domiciliary service.

## Results summary.

Although we did not aim to deliver a universal screen until 01/02/02 the results for the screen on babies born in January 2002 are included in the following figures as coverage for that month was 96.5%. The data are for babies born 01/01/02 to 30/04/02. Coverage, referral for AABR and referral for threshold ABR figures are shown in Tables 3 to 5. Yield of cases is shown in Table 6.

## Quality Issues

With any screening programme quality monitoring at local provision level is an issue (Watkin 1999b). With 120 health visitors undertaking the first stage of the screening test a simple method for monitoring individual performance is a requisite. This has been addressed by audit of the number of tests completed at first attempt. The number of OAE tests yielding 'Clear Responses' from both ears at first test on babies born between 01/01/02 and 30/04/02 is 1186 out of 1333 tests (89%). A further 6.5% have passed at retest. The individual score achieved by each health visitor has been audited on 2 dates, one in March another in May. Each Health Visitor has had feed back of her score. Seven screeners with

**Table 3. Coverage**

Births	Resident but opted for service elsewhere	HV tests	NNU tests	Screen out of county	Direct to ABR no screen	Total HV tested Screen + direct	Coverage 1434/1453
1456	3	1333	83	12	6	1434	98.7%

- Notes: 1. Parents of 2 babies have declined the screen (March)  
 2. Babies not screened Jan = 14; Feb = 1; Mar = 2; Apr = 2  
 3. Direct to ABR includes Cleft Palate and absent Ext. Auditory Meatus

**Table 4. Referrals for AABR from HV screen.**

One ear	Both ears	Total	No. Screened	Percentage
39	21	60	1333	4.5%

Note: Monthly average referral for AABR 15 (range 9 – 16)

**Table 5. Referrals for AC click threshold ABR**

From HV screen	From NNU screen	Total from screen	Others referred on clinical grounds
6 / 1333 (0.45%)	4 / 83 (4.8%)	10 / 1416 (0.7%)	6

**Table 6. Cases of hearing impairment identified**

	Type of Loss	AC ABR threshold	Risk factor identified
Case 1	Monaural SNHL	R 20 L 95	No
Case 2	Monaural SNHL	R 95 L 15	No
Case 3	Bilateral? mixed loss	R 40 L 45	NNU
Case 3	Moderate SNHL	R 70 L 65	No

scores below 70% who had not significantly improved their score between first and second audit are receiving further on site support from the local co-ordinator.

## Discussion

A service attempting to deliver universally at one point must have an effective service for those who miss at that point. Because of our reservations about the number of potential misses we have successfully spread this risk by diversifying the whole service geographically.

There are several advantages:

There is no time pressure in the first few days to deliver the service. This may have benefits for both parents and service providers. There is no specific need for action by parents as they do not need to arrange their lives to be anywhere other than home.

The service is delivered as part of the routine health care provided within the English health care system. The only additional staffing required is a local co-ordinator and half time clerical support.

The record of the screen is managed by the same system (Child Health System) dealing with other public health issues (eg PKU / TSH, immunisation and routine surveillance).

The number requiring AABR is easily manageable by the local Co-ordinator as home visits. No clinic appointments and clinic scheduling is required, other than for the small percentage requiring 'diagnostic' follow up.

There are some comparative disadvantages:

Because of the equipment requirement the capital outlay is high. The unit cost is an important part of the national evaluation. All elements of staff, time, equipment, travel, training, clinic costs and parent costs are being taken into account in the health economics domain of the national evaluation.

Training is a major commitment. It was the major component of the Team Leader and local co-ordinators' workload over a period of three months.

A screening programme for the neonatal unit must be in place independent of the well baby component of the screen. In our area this had been operated by the nursing staff of the neonatal unit for a year prior to the roll out to universal coverage. This has continued. We have not yet achieved additional OAE testing of all NNU babies as required by the national protocol, although this is undertaken on all who do not produce AABR responses, so that auditory neuropathy can be identified.

Data can be slow reaching the child health department. Our experience to date is that coverage statistics for a particular month are not complete until at least a month later. Reminders to HV's where a result has not been recorded by

the age of 30 days is needed to ensure against lost records, babies who have moved, and those residents who have opted for care from another PCT.

Machine derived data are held on a large number of machines and are accessible only by download of each machine. This has been addressed by the attendance of the local co-ordinator at the regular health visitor monthly meetings. On these occasions there is opportunity for two way feedback on screen issues. Health visitors arrange for their equipment to be brought to these meetings for download to a laptop.

## Conclusion

The well baby element of a universal newborn hearing screen can be effectively delivered as a community service.

It provides an alternative model for those planning local programmes and may be the preferred option under similar conditions to those described in this article.

The report of the national evaluation study is keenly awaited. Comparative data between screen models on issues such as parental acceptance / anxiety, coverage, referral rates and health economics are urgently required to assist decisions on the roll out of the national programme.

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## *Re-audit of the processes of referral and audiological outcomes of children who had proven bacterial meningitis / septicaemia in the North West*

*Dr. Gillian Painter NWRACAG Chair*

The North West Regional Audiology Clinical Audit Group (NWRACAG) has been meeting for twelve years and has a membership of more than 25. The group meets every two months and has done a number of regional audits. In 1995 it was decided to audit the process of referral to audiology following bacterial meningitis / septicaemia for children under the age of 16 years and the responsiveness of audiology departments to these referrals.

The generally quoted incidence of hearing loss following meningitis / septicaemia is 10% but different studies give a range from 3% to 30%<sup>1-5</sup>. It has long been recognised that children should be referred for audiological assessment following this illness because of the possibility of hearing loss<sup>6,7</sup>. In one study where paediatricians had been questioned about their practice of referral following meningitis, 89% said that they do routinely make this referral<sup>6</sup>.

It is essential that a hearing loss is diagnosed early so that amplification and rehabilitation can be commenced and where cochlear implantation is being considered there is always the possibility of ossification of the cochlea which may prevent insertion of the electrodes<sup>8</sup>.

### **Reason for the re-audit**

During 1995/96 an audit undertaken by the NWRACAG showed that only 75% of children who had had bacterial meningitis or septicaemia were referred for formal audiological assessment within 2 weeks of discharge, and only 55% were offered an appointment by the audiology department within 4 weeks of receiving the referral. Additionally only 35% were seen in the audiology clinic within 6 weeks of discharge.

Following the audit, numerous presentations were made in the North West by members of the group informing Consultant Paediatricians, Junior Staff and other interested professionals of the findings.

One of the recommendations of the original audit was to re-audit in order to determine if there had been an improvement to the service offered to these children.

A number of flaws were identified in the original audit and it was necessary to account for these in the new protocol.

- There must be clear guidelines for inclusion in the audit
- There must be clear referral guidelines especially with regard to tertiary children's hospitals
- All children in the North West must be included to allow determination of referral rate as well as speediness of response
- There must be clearer guidelines on the outcome of the appointment

### **Standards**

The referral and assessment of children were audited against the following standards:

- 1 100% are referred for audiological assessment on or before discharge from hospital
- 2 100% are offered an appointment by the audiology department within 4 weeks of discharge
- 3 100% have their assessment completed within 6 weeks of discharge

These standards are slightly different from those used in the first audit but were changed after discussion within the group and with local paediatricians. They are however more stringent than those used previously.

### **Method**

**Period of re-audit** The re-audit was undertaken between 1 June 1999 and 31 May 2000.

### **Criteria for inclusion**

All children under 16 years of age with a clinical diagnosis or laboratory confirmed bacterial meningitis/septicaemia living in the North West region were included in the audit. If the diagnosis of meningitis made on admission was revised by the time they were discharged, these children were not included.

### **Referral procedure to audiology**

Prior to the start of the audit, each audiological clinician had discussed audiology referral following meningitis/septicaemia with their local paediatricians to ensure that this was included in each hospital's meningitis protocol and that the referral should be made on or before discharge from hospital.

All referrals were made on a locally agreed referral form. This was either on the form designed for this audit or a local high risk referral form. The lead audiological clinician requested ongoing notification of children with bacterial meningitis/septicaemia from their local Consultant in Communicable Disease Control (CCDC). This was an attempt to ensure that no child was missed.

### **Administration procedure within audiology**

All audiology departments were asked to give priority to children referred following bacterial meningitis and/or septicaemia.

The time period from discharge from hospital to offering an appointment was measured in whole weeks. The lead audiological clinician was responsible for promptly forwarding out of district referrals to the appropriate audiology departments.

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## Clinical procedure within audiology

The aim was to offer an appointment within 4 weeks of discharge and to complete audiological assessment within 6 weeks of discharge.

The results of the assessment were recorded as follows:

- Normally hearing
- Sensorineural loss - hearing levels raised and tympanometry not consistent with conductive loss
- Conductive loss - hearing levels raised and tympanometry consistent with pure conductive loss
- Mixed loss - pure tone audiometry suggests sensorineural and conductive components to the loss
- Unspecified - raised levels but not clear if pure conductive or sensorineural element present

## Evaluation

390 forms were submitted from 20 districts. (See Table 1)

**Table 1**

Name of Trust/HA	Number of cases
South West Cheshire	24
Burnley	24
Blackburn	15
Manchester	29
Crewe (South Cheshire)	23
RLC (Liverpool)	40
Oldham	23
Wigan	28
Macclesfield (South Cheshire)	15
North Sefton	7
Wirral	34
Trafford	14
Bolton	24
Stockport	18
Tameside	21
Bury	20
West Lancs	1
Blackpool	2
Preston	1
Warrington	27
Total number for cases	390

## Standard 1. 100% referred for audiological assessment on or before discharge from hospital

Number reaching standard	298	76%	75%
Reasons for not reaching standard:			
· Service delay	84	22%	22%
· Child and family reasons	3	1%	
· No reason given	5	1%	

## Standard 2. 100% offered appointment for audiology within 4 weeks of discharge

Number reaching standard	256	66%	55%
Reasons for not reaching standard:			
· Service delay	119	31%	29%
· Child and family reasons	11	3%	
· No reason given	1		

## Standard 3. 100% completed their assessment within 6 weeks of discharge

Number reaching standard	219	56%	35%
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Reasons for not reaching standard:

· Service delay	102	26%
· Child and family reasons	64	16%
· No reason given	4	1%

## Audiological outcomes

Normally hearing	308	78%	76%
Sensorineural hearing loss	7	2%	3%
Conductive hearing loss	29	7%	21%
Mixed hearing loss	3	1%	
Unspecified	3	1%	
DNA	39	10%	12%
Not entered	1		

*\*percentages in italics are the figures obtained in the original audit*

## Sensorineural hearing losses identified

Unilateral loss	2
Mild bilateral loss	1
Mild high frequency loss	1
U shaped moderate loss	1
No further information	2

## Fitted with hearing aids

One child with a mild bilateral sensorineural loss was fitted with hearing aids

## Route of referral

Paediatrician before discharge	284	73%
CCDC	60	15%
Paediatrician at OPD	16	4%
HV	16	4%
CPCCH	4	
School nurse	2	
Already under review by audiology	2	
GP	1	
Parent	1	
Another audiology dept	1	
Not entered	3	

## Organisms causing infection

<i>Meningitis</i>	
Clinical diagnosis only	76
Laboratory confirmed	87
N. meningitidis	43
N. meningitidis B	14
N. meningitidis C	11
Streptococcus pneumoniae	7
E.coli	4
H.Influenzae	4
Streptococcus	1
Streptococcus Gp B	1
Pasteurella multocida	1
Not entered	1

<i>Septicaemia</i>	
Clinical diagnosis only	85
Laboratory confirmed	98
N. meningitidis	45
N. meningitidis B	28
N. meningitidis C	18
E.coli	2
Staphylococcus	2
Streptococcus Gp B	2
Staphylococcus aureus	1

<i>Meningitis and septicaemia</i>	
Clinical diagnosis only	20
Laboratory confirmed	23
N. meningitidis	11
N. meningitidis B	4
N. meningitidis C	4
E.coli	1
Streptococcus pneumoniae	3

The number of children referred by the date of discharge had remained much the same although direct comparison with the previous audit is not possible as the standard was changed slightly. 76% referred by discharge in this re-audit is compared with 75% referred within two weeks of the date of discharge in the previous audit. This was still well short of the 100% standard and the result was disappointing given the prominence that meningitis had received nationally during the year of the audit.

73% of children were referred directly from hospital on or by discharge. Other referrals were mainly from the CCDC.

The audit showed that there had been some improvement in the responsiveness of audiology services to referrals following bacterial meningitis/septicaemia (66% compared to 55% in previous audit). However, these figures are not directly comparable as in the original audit the period for offering an appointment commenced from the date of receiving the referral rather than the date of discharge. Taking the date of discharge was felt to be a more appropriate timescale, bearing in mind the importance of diagnosing hearing losses which may require urgent cochlear implantation.

The audiological assessment being completed within 6 weeks had also improved from 35% to 56% but was still far from the standard agreed.

The number of children included in the re-audit was significantly greater than in the previous audit (390 compared to 146) possibly due to there being more Trusts/HAs participating in the audit but also due to a greater awareness of the need for audiological referral as a result of the previous study.

There was one case of sensorineural hearing loss requiring hearing aids. All the sensorineural hearing losses identified were unilateral, mild or U-shaped moderate. It was possible that some of these were present prior to the illness.

The standards set all relate to the date of discharge from hospital. This meant that if the first standard was not met then it was difficult for the others to be reached. However there were still an unacceptable number of delays due to service delay.

## Recommendations

Audiological clinicians should present these audit results to their local paediatricians and discuss with them how the referral to audiology can be improved. Faxing the referral may save a few days delay. In districts where there is a lower referral rate from paediatricians or delays in the system it might be possible to undertake an audit of these cases to see whether there are any common features which could be addressed.

Audiology services should look at ways in which they can ensure that appointments are made within 4 weeks of the child's discharge. Keeping a slot free every week, particularly during the winter months, for the rapid assessment of these children was one suggestion. With the introduction of universal neonatal screening it may be possible for the screeners to undertake preliminary screening before the child leaves hospital. This might emphasise to parents the importance of audiological assessment following meningitis.

Some districts had surprisingly few cases of meningitis/septicaemia referred to them and it is suggested that in these areas an ascertainment study should be undertaken to see whether this was the true number of cases or whether there were others that were never referred.

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## Targetted New Born Hearing Screening Programme in Bolton 1994-99. Varghese C.M, Walmsley V, McKend K, Crichton A, Gray S

### Abstract.

An "at risk" neonatal hearing screening programme has been in place in Bolton since January 1994. For all babies born in the Royal Bolton Hospital, an "at risk" questionnaire is applied by the paediatricians. The health visitors in the community apply the "at risk" questionnaire especially for those babies born outside the district. All babies with one or more risk factors are referred for the screening. Transient Evoked Otoacoustic Emission (TEOAE) is used as the first line of screening followed by Auditory Brainstem Response (ABR) for those who fail TEOAE. A total of 2011 babies were referred in the six year period- 8.4 % of the total birth. 68 % were referred from the hospital and the rest from the community. Average waiting time was 20 days. 33% of babies were tested at home and 58 % were tested in clinics and very few were tested in the hospital. The non- attendance rate was 7%. 12% of those referred failed the screen. 16 were found to have bilateral hearing loss of 50dB or more. The overall risk factors for those referred are :- perinatal factors 40 %, family history -34 %, congenital anomalies of head and neck 4 %, chromosomal anomalies 1 %. 8% were seen because of parental and professional concern.

### Introduction

On an average one baby in a thousand births is born congenitally hearing impaired with moderate or worse degree of hearing loss in the better ear ( Fortnum et al 1997). Significant hearing loss interferes with development of phonological and speech perception abilities. The value of early diagnosis is widely accepted in terms of speech and language development, social and emotional development and educational attainment (Markides 1986,Ramkalavan et al 1992, Robinshaw HM 1995, Powers 1996, Yoshinaga-Itano et al 1998). The National Deaf Children's Society recommends that 80% of such cases should be diagnosed within the first 12 months of age and 40% should be diagnosed in the first six months (NDCS 1994). An audit has shown that in Bolton over a 20 year period from 1974 to 1993 the average age of diagnosis of congenital non -progressive deafness of 50 dB HL or worse in the better ear was 33 months (Range 8-78 months) with no cases has being diagnosed before 6 months of age , only 10 % cases were diagnosed before 12 months and 14 % diagnosed only after five years of age (Varghese CM 1997). Therefore an "at risk" neonatal hearing screening programme was introduced for babies born since January 1994, with the aim of reducing the average age diagnosis of sensorineural hearing loss and thus begin habilitation early. Approximately 1-3 % of at risk babies will have significant hearing loss (NIH Consensus Statement 1993) and 50% of all congenitally deaf children have "at risk" factors. We use an "at risk" questionnaire modified from the

At Risk Registry of the Joint Committee on Infant Hearing (American Academy of Pediatrics, Position Statement 1982). Chromosomal disorders were added as risk factors and in the case of family history second degree relatives with permanent hearing loss were included with the aim of improving the pick up rate of the programme. Hearing screening is offered if there is parental or professional concern. Copies of the "at-risk" questionnaire are made available in the maternity wards and with the health visitors in the community. The hospital paediatricians apply this questionnaire to all babies born in Bolton hospital and back up is provided by the health visitors particularly in the case of Bolton babies born outside the district or by home confinement.

### Aim of the study

To audit the "at risk" neonatal hearing screening programme for the cohort babies born in the six year period 1994-99 and to evaluate the referral characteristics, waiting time, place of testing , "at risk" profile and results of the screen and the diagnostic evaluation.

### Methods.

Babies with one or more "at risk" factors are referred to the children's hearing assessment centre. On receipt of the referral the details are entered into a register and a trained member of the staff proceeds with the screening process. In earlier years the audiology health visitor or a senior audiologist (MTO) would carry out the screening test. Now there is trained a health care worker who performs the bulk of the work. Until June 1995 ABR was the first line of screening. An appointment is sent to attend the clinic and if parents so request the test is done at home. For ABR screening a Medelec screener was used initially. Subsequently the equipment used was either Nicolet or Sabre. The skin is prepared with Omniprep (skin preparing gel) and disposable electrodes are applied to the forehead and mastoid processes assuring an impedance below 5 ohms. Click with a repetition rate of 37.1 per second is delivered into the ear canal through an ear tip of appropriate size and responses are averaged and averaged responses are replicated. The test was carried out at a stimulus level of 60 dBnHL and 40dBnHL in both ears. All failures at 60dBnHL and bilateral failures at 40dBnHL are assessed by diagnostic ABR, tympanometry and appropriate behavioural tests. In June 1995 Transient Evoked Otoacoustic Emission (TEOAE) was introduced as the first line of screening using ILO88 in the Quickscreen default mode. Screening using Otoacoustic Emission is non-invasive and less time consuming (Kemp et al 1993). A baby passes the test if a reproducibility of 50% or above in the 1600 Hz bandwidth and 70 % or above in the 2400, 3200 and 4000 Hz bandwidths. Test validity was monitored by stimulus stability

level, stimulus peak level, stimulus spectrum, noise level in the ear and number of low noise samples (Vohr et al 1993). Those who failed TEOAE bilaterally were screened again by ABR and those who failed ABR screening were assessed by diagnostic ABR without further delay. Recently ABR screen as well as OAE screen has been used for babies with history of perinatal risk factors. Unilateral TEOAE failures and bilateral partial passes were retested with TEOAE before ABR. All results were printed out and rechecked and all the relevant details were entered into a database. A data base using Microsoft access is in use and this has proved to be inexpensive, simple and very practicable.

## Results

Total birth during the period study	23830.
(Including all live births in Royal Bolton hospital and Bolton babies born outside the district).	
Total referred for hearing screening	2011
8.4 % of all babies were identified to have at risk factors and were referred for the screen.	
Male	1125 (56%)
Male:female ratio is	1.26
Ethnic minority	376 (18%)
Bolton residents	1840 (91%)
Adjacent districts	171 (9%)

## Source of referral.

Hospital source	1381 (68%)
Community source	630 (32%)

Health visitors have referred (Community source) "at risk" babies born outside the hospital and provided a back up to the hospital referral system.

## Waiting time

Average waiting time was 20 days.  
91% waited less than 30 days

Waiting time is inevitable for a community based programme. Some babies had to wait because of extreme prematurity and acute illness but in most cases long waiting time was due to service delay. The waiting time has fallen since TEOAE was introduced.

## Place of testing

The service is extended to the home of the baby if the parents wish. 33% of the initial screen was carried out at home during this period. The home based screening has been increasingly replaced by clinic based appointments now

## Method of testing

The hearing screening programme was commenced in January 1994 using ABR, testing babies at a stimulus level of 60 dBnHL and 40 dBnHL using a Medelec Screener. In June 1995 a change over was made to Transient Evoked Otoacoustic Emission. Those who fail TEOAE will have ABR screening test. The policy is to test both ears resulting in the early detection of unilateral sensorineural hearing loss which can have significant negative effect on the development of speech, cognition and social skills (White KR et al 1993). Both ABR screen and TEOAE are used for babies with multiple perinatal risk factors.

## Results of the screen

Average non-attendance rate was 7%.  
Average failure rate was 12% of those referred.  
Bilateral hearing loss above 50 dB selected for hearing aids = 16  
Unilateral hearing loss =24

## Causes of bilateral hearing loss

All the 16 cases were investigated for aetiology of hearing loss using a standard protocol.  
The causes of hearing loss were identified as follows.

Nonsyndromal genetic-7(consanguinity-3)
Perinatal problems-3
Waardenburg syndrome – 1
Cytomegalo virus infection-1
Charge association-1
Downs syndrome-1
Auditory neuropathy-1

## Degree of bilateral hearing loss

Profound-6 (37.5%)
Severe-4 (25%)
Moderate-6 (37.5%)

## Risk factors for the overall group

Perinatal factors	40%
Family history	34%
Congenital anomalies of head and neck	4%
Chromosomal anomalies	1%
Parental/Professional Concern	8.5%

## Discussion

There are 107 providers of neonatal screening or neonatal audiological assessment in UK carried out in 80 districts (A Davis et al 1997). This is an example of such a service based in the community. The percentage of all babies born in Bolton in 1994-99 having at risk factors for hearing loss is 8.4% assuming that 100% at risk babies have been identified. Health Visitors in the community play a very useful role in identifying at risk babies. A substantial proportion of the babies were tested at home. Failure to attend is fairly low and this is due to the readiness of the staff to extend the service to the homes of the babies. Transient Evoked Otoacoustic Emission is used as the first line of screening and a health care assistant carries out most of the tests. ABR/AABR is being used now for babies with NICU history.

One in 125 babies referred for screening had significant bilateral sensorineural hearing loss and if unilateral sensorineural hearing loss is included this figure is one in 50. A large proportion of those who underwent diagnostic audiological assessment were found have normal hearing and most of them are from the group who failed ABR screening at 40 dBnHL but passed at 60 dB.

Babies with NICU history should have AABR and TEOAE to identify cases of auditory neuropathy. There are two babies in this cohort who had normal neonatal OAE and

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later developed hearing loss and both had family history of permanent hearing loss. It is important to follow up not only NICU babies but also babies with family history.

Targeted neonatal screening programme with a good coverage can meet the NDCS target of diagnosing 40% of the cases in the first six months and it is the way forward where universal neonatal screening programme is not feasible.

If neonatal hearing screening is confined to special care baby units, then only 40% of the "at risk" group would be covered in the cohort. Family history, consanguinity and parental or professional concern are significant proportion of the total referred for screening.

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