

Education and Lifelong Learning Committee

Presentation from RNID Cymru - February 2004

Background

In Wales one or two babies in every thousand (around 40 in total) are born each year with a level of deafness significant enough in one or both ears to affect their understanding and development of spoken language. Early diagnosis offers the best possible chance to develop language and communication skills at the same rate as hearing children.

If a deaf child is undiagnosed, there is likely to be an effect slowing their social and educational development that is likely to go on to affect many areas of their progress.

Newborn Hearing Screening uses two quick and simple tests, both painless for the baby, to see if there is a need for further investigation.

1 Early education intervention is important for young deaf children

1.1 Deafness in young children interrupts the developmental process for acquiring language normally observed in hearing infants. Where deafness is significant and permanent, the consequences of early failure to develop communication, language and speech affect cognitive development, social development and later educational progress including literacy.

1.2 Earlier identification of deafness and effective family-friendly intervention support offer the best chance of preventing the language and communication deficit deaf children develop in comparison to hearing children and will dramatically improve the chances of successful inclusion of deaf children into mainstream schools and society. To capitalise on the potential advantages Newborn Hearing Screening offers, early intervention services must be developed within a single, co-ordinated delivery strategy.

1.3 Evidence from the USA, where the development of deaf children identified and receiving early intervention/support services before 6 months of age has been tracked longitudinally against the development of children identified later appears to be extremely positive and has attracted world-wide attention (Yoshinaga-Itano, 1998; 2000).

1.4 Early intervention/support services are provided to early identified deaf children and their families:

to enable deaf children to enter the Foundation Stage with age-appropriate language, communication and

speech, to maximise their attainment in the early years, and provide a basis for ongoing support

to empower families to take positive action on behalf of their child by ensuring that they understand the effects of deafness and have access to unbiased, accurate and up to date information

to provide practical advice and support to families through the very early stages of

language, communication and speech development, and wider social development

to establish effective use and maintenance of hearing aids, personal FM systems and/or cochlear implants in the home

to establish sign communication in the home, where families elect to use sign combined with spoken language or British Sign Language

to help service users make contact with other families with deaf children

to begin development of a positive deaf identity

2 Partnership with parents

2.1 Families must be at the heart of any decision making process about their child and need accurate, accessible, up to date information to support their understanding of how to respond positively to deafness in their child and to decide what to do. Information is at the heart of service provision, whether deafness is the main factor impacting on a child's development or one of a number of factors that will have an effect.

2.2 The very young age of the children involved, means that the general

principles of working in partnership with parents set out in the SEN Code of Practice (2001) have particular relevance. Sections 2:6 and 2:7 of the Code are particularly relevant:

Positive attitudes to parents, user-friendly information and procedures and awareness of

support needs are important. There should be no presumption about what parents can or

cannot do to support their children's learning. Stereotypic views of parents are unhelpful

and should be challenged. All staff should bear in mind the pressures a parent may be

under because of the child's needs.

To make communications effective, professionals should:

acknowledge and draw on parental knowledge and expertise in relation to their child

focus on the children's strengths as well as areas of additional need

recognise the personal and emotional investment of parents and be aware of their feelings

ensure that parents understand procedures, are aware of how to access support in

preparing their contributions, and are given documents to be discussed well before meetings

respect the validity of different perspectives and seek constructive ways of reconciling different viewpoints

respect the differing needs parents themselves may have, such as disability, or communication and linguistic barriers

3 Effective service delivery

3.1 The experience of implementing Newborn Hearing Screening in other countries suggests the following are essential to harness the potential benefit of early identification of deafness:

clear systems for multi - agency service delivery to ensure continuity of support for families through the initial/follow up screens, confirmation of deafness and early intervention and support

clear definition of where responsibility for the provision and funding of early intervention services lies

clear quality assurance systems to evaluate the effectiveness of the early intervention services provided

3.2 Effective multi-agency working in this field requires:

mutual respect between the agencies and professional groups involved

clear role definition, particularly where roles and responsibilities in relation to a common client change over time

a clear management structure with well-defined decision making and referral procedures

transparent, practical communication mechanisms to facilitate the sharing and exchange of information

between agencies

regular scheduled meetings where participating agencies or team members, parents and voluntary organisations, can meet to discuss issues of common concern, alongside the on-going and frequent networking and informal contact

4 Professional Development

4.1 Working with the families of very young deaf children will clearly bring new challenges for all the professionals involved and requires a flexible attitude on service delivery options to be maintained as Newborn Hearing Screening is implemented.

4.2 By merit of their MQ(HI) training and experience, teachers of the deaf have particularly relevant knowledge, understanding and skill to contribute. It is for this reason that they are often identified as key worker, even in the case of very small babies. Families are looking for very specific information, knowledge and guidance to complement the information and equipment they receive from paediatric audiology services. Families may, however, wish to exercise choice where more than one potential key worker is available.

4.3 The numbers of teachers of the deaf trained and available in Wales must be properly assessed and planned for. RNID Cymru estimates early intervention will require the services of an additional 4 or 5 teachers in Wales. The predicted retirement profile of Wales' current complement of shows that up to 25% of current teachers of the deaf will retire in the next five to ten years. Clearly action has to be taken to train new teachers.

5 Evaluating the effectiveness of services for children:

5.1 The key measure of effective service provision in the first three years of life is the

proportion of deaf who move through Foundation Stage with age-appropriate language, communication and speech. Age appropriate language and communication is needed if the achievements of deaf children are to fall within the expected range for Communication, Language and Literacy and other Stepping Stones.

Evaluating the effectiveness of services for families

5.2 The very young age of the children involved means that key elements of intervention and support for the child are mediated through the child's family. Families have important information to contribute on the effectiveness of the services provided. A simple questionnaire is one way of measuring how families rate the services provided to them. It provides a fairly straightforward means of asking families for their views, but it clearly should be supplemented by other steps such as regular discussions and structured interviews.

6 Performance indicators for service delivery

6.1 LEAs should look for evidence of the following:

general development against developmental norms for hearing children in the first year of life

the child's developing ability to attend to/respond to sound and voice using hearing aids and/or cochlear implant

the child's developing ability to attend to/contribute to conversational interaction

the child's developing understanding and emerging use of spoken language

the child's understanding and emerging use of British Sign Language or sign

communication to support spoken language, where a sign bilingual or total

communication approach is being used in the home

6.2 As part of the work being carried forward under the DfES-sponsored Early Support Pilot Programme (ESPP), a multi-agency service audit tool is being produced. This will serve as a framework against which services can plan for service development and track progress. It will have regard to the principles set out above and will also aim to be accessible to parents.

For more information on the Early Support Pilot Programme visit www.espp.org.uk or contact john2.ford@rnid.org.uk

The Major source of information for this paper is Developing Early Intervention/Support Services for Deaf Children and their Families (May 2003, Department for Education and Skills) available at: <http://www.espp.org.uk/pilot/guidance/2/DevelopingEarly.pdf>

Appendix I References

Developing Early Intervention/Support Services for Deaf Children and their Families (May 2003)
Department for Education and Skills

Bamford J

Infrastructure Supporting Infant Hearing Programmes

Presentation to the International Conference on Newborn Hearing Screening Diagnosis and Intervention

Milan (October 2000)

Bamford J, Battersby C, Beresford D, Davis A, Gregory S, Hind S, Moore L, Owen V, Reeve K
Assessing Service Quality in Paediatric Audiology and Early Deaf Education
British Journal of Audiology, Vol. 35, December 2001
Paediatric Audiology Service Index (PASI) Deaf Early Education Services Index (DEESI)

Chamba R Ahmad W Jones L
Improving Services for Asian Deaf Children
The Policy Press (1998)

Davis A et al
A Critical Review of the Role of Neonatal Hearing Screening in the Detection of Congenital Hearing
Impairment
Health Technology Assessment (1997)

DfES
SEN Code of Practice (2001)

Evans R & Robinshaw H
Service Provision for Preschool Deaf Children
Report to the Nuffield Foundation (1999)

Luterman D
The Young Deaf Child
York Press (1999)

National Deaf Children's Society
Quality Standards in the Early Years: guidelines on working with deaf children under two years old and
their families (2002)

Powers S et al
A Review of Good Practice in Deaf Education
RNID (1999)

RNID/NDCS joint initiative on training issues for professionals working with
deaf children under five and their families
Statement of Competencies Required by Professionals Working with Deaf Children 0-2 and their
Families (2000)

Tait M
Video Analysis: Monitoring Progress in Young Cochlear Implant Users

Nottingham Paediatric Cochlear Implant Programme

Turner S & Lynas W

Teachers' Perspectives on Support for Under-fives in Families of Ethnic Origin
Deafness & Education International Vol 2 No 3 (2000)

Yoshinaga-Itano C et al

Language of Early and Later Identified Children with Hearing Loss
Pediatrics Vol 102 No 5 November 1998

Yoshinaga-Itano C

Successful Outcomes for Deaf and Hard-of-hearing Children
Seminars in Hearing Vol 21 No 4 (2000)