Institution: The University of Manchester

Unit of Assessment: 3

Title of case study:
From hearing screening to early intervention for deaf children and their families. (*ICS-04)*

1. Summary of the impact

Around 800 children are born each year in England with congenital permanent bilateral hearing loss and significant consequences for language development and social-emotional wellbeing. A 15-year programme of inter-disciplinary research made the case for the implementation of universal newborn hearing screening in England; now the NHS standard of care. Our subsequent studies developed a model of professional practice adopted internationally. Our tools to evaluate service quality have been adapted for use in the US, Canada and Australia. We have trained over 500 professionals in 6 countries.

2. Underpinning research

See section 3 for references [1-6]; see section 5 for corroborating sources (S1-S10); UoM researchers are given in bold. In REF3a and REF5 this case study is referred to as ICS-04.

The overarching aim of our research programme was, and continues to be, to analyse the impact of routine early identification of deafness (in the first few weeks of life) on families and services.

The research on which this case study is based began in 1997. The key staff involved at the University of Manchester (UoM) are drawn from the disciplines of audiology, social work, deaf education, epidemiology and psychology.

Key research staff:

- **John Bamford** (Professor of Audiology, 1995-2008; retired)
- **Adrian Davis** (Professor, 2003-2009)
- **Alys Young** (Senior Lecturer, 2001-2005; Professor, 2005 to present)
- **Kai Uus** (Research Fellow, 2001-2004; Lecturer, 2004 to present)
- **Wendy McCracken** (Senior Lecturer,1995 -2012; Professor, 2012 to present)
- **Gwen Carr** (Senior Lecturer, 2003-2009)
- **Helen Tattersall** (Research Assistant, 2002-2006)
- **Ros Hunt** (Research Associate, 2007-2011; Lecturer, 2011-2012)
- **Maria Gascon-Ramos** (Research Associate, 2006-2009)

The key steps were:

1. We were co-applicants leading an HTA review in 1997 which demonstrated sufficient evidence to justify a pilot implementation within the NHS of universal newborn hearing screening in England [1].
2. We led the national evaluation of the implementation of universal newborn hearing screening in England, funded by DH, from 2002-2004, which was a multi-centre, mixed methods study. Covering 4 domains (maternal anxiety; cost-effectiveness; parents' evaluation of hearing screener and diagnostic practice; impact on audiological, educational and social care services), the results demonstrated that: (i) adequate specificity, coverage and yield could be achieved, justifying progression to a national roll out of universal newborn hearing screening beyond the pilot sites; (ii) cost effectiveness was acceptable; (iii) National Screening Committee concerns about undue maternal anxiety resulting from universal screen were not justified; (iv) the impact on parents of early identification and early service engagement created new challenges in psychosocial adjustment, which we defined [2, 3].
3. Through a subsequent grant from the National Deaf Children's Society and the Department for Education and Skills (2004-2006) we developed, by means of systematic review of literature, an underpinning theoretical model driving a new approach to service provision for

families with deaf children (informed choice) which was published as guidance by DfES/DH and adopted internationally [4].

4. We extended our work to incorporate a pan-disability perspective, leading the national evaluation of the DfES/DH Early Support programme for families with deaf and disabled children throughout England (2004-2006) [5].
5. In a prospective study of the child and family development of early identified deaf infants (2005-2008), we developed a standard instrument for analysing the quality of multi-professional early intervention with deaf children and their families from the perspective of parents. Its reliability and validity were proven and it is now used widely in research and professional practice [6].

3. References to the research

1. **Davis A, Bamford J,** Wilson I, Ramkalawan T, Forshaw M, Wright S. A critical review of the role of neonatal hearing screening in the detection of congenital hearing impairment. *Health Technology Assessment*, 1997, 1, 1-176. http://www.hta.ac.uk/fullmono/mon110.pdf

2. **Uus K, Bamford J.** Effectiveness of population-based newborn hearing screening in England: Ages of interventions for identified babies and profile of cases*. Pediatrics*, 2006, 117, e887-893. http://www.ncbi.nlm.nih.gov/pubmed/16651292. DOI:10.1542/peds.2005-1064

3. **Young A.M**, **Tattersall HJ**. Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development. *Journal of Deaf Studies and Deaf Education*, 2007, 12, 209-220. http://www.ncbi.nlm.nih.gov/pubmed/17277310 DOI: 10.1093/deafed/enl033

4. **Young, A.M., Carr, G., Hunt, R., McCracken, W**., Skipp, A., **Tattersall, H**. (2006). Informed choice and deaf children – underpinning concepts and enduring concerns. *Journal of Deaf Studies and Deaf Education,* 2006*,* 11: 322-336. DOI: 10.1093/deafed/enj041

5. **Young, A.M**., Temple, B., **Davies, L.,** Parkinson, G., Bolton, J. Disabled children (0 to 3 years) and integrated services – the impact of Early Support. *Health and Social Care in the Community*, 2008, 16 (3), 222 - 233. DOI: 10.1111/j.1365-2524.2008.00765.x

6. **Young, A.M**., **Gascon-Ramos, M., Campbell, M. Bamford, J**. The Design and Validation of a Parent-Report Questionnaire for Assessing the Characteristics and Quality of Early Intervention Over Time. *The Journal of Deaf Studies and Deaf Education*, 2009, 14 (4), 422-435. DOI: 10.1093/deafed/enp016

4. Details of the impact

See section 5 for numbered corroborating sources (S1-S9).

The national implementation of universal newborn hearing screening was completed in 2006 and to date over 5 million babies have been screened and over 9,500 identified with permanent bilateral hearing loss (S1). The impact of our research work, which coincided with the initial implementation of universal newborn hearing screening, has continued well into the current assessment period (2008-2013). Both the follow-on research we have completed and the international recognition of our original studies have formed the basis of national hearing screening and early intervention developments around the world.

Our original research pinpointed the potential challenges that the post-screening agencies, most importantly Paediatric Audiology Services, faced when dealing with the assessment and management of very young infants and providing appropriate support to their families [2]. It has influenced developments in paediatric audiology following early identification of deafness both in the UK and internationally (S2). The empirical studies of how families conceptualised the impact of early identification and its influence on their expectations of services and their children's development were the first such studies of their kind and have had a strong influence on how universal newborn hearing screening has been implemented in several countries. Our studies have contributed to and been cited in international consensus statements including *Best Practices in Family Centred Early Intervention for Children who are Deaf and Hard of Hearing: An International Consensus Statement* (2013) (S3) and *Guidelines for Identification and Management of Infants and Children with Auditory Neuropathy Spectrum Disorder* (2008) (S4) where our unique contribution is noted: "*Your discussion of challenges to both parents and professionals in the identification of a potentially transient finding is particularly important and continues to be a vital consideration in discussions of the evaluation of management of ANSD*" (S4).

Our research on the model of informed choice in multi-professional service resulted in two guidance documents published by the Department of Health, on informed choice practice for professionals and parents (S5). The work has formed the basis of how British Columbia, Canada, has developed its approach to early intervention services for families with deaf children: "*Your research articles and training on the topic of "Informed Choice" have had significant impact on services for families with Deaf babies in British Columbia...This included: Provincial standards for verbal and written information provided to families after identification of hearing loss, ensuring families had access to full and unbiased information. Provincial training of all service providers on the topic of Informed Choice. A Program Evaluation Family experience survey, which included questions to capture the parent experience of services through the lens of informed choice*" (S6).

The research work on informed choice resulted in an international training programme led by **Young** and **Carr**, who have trained over 500 early intervention professionals working with early identified deaf children, in British Columbia (2008) [150 professionals], South Africa (2009) [90 professionals], in Norway (2011) [120 professionals], Quebec (2013) [100 professionals], Victoria and New South Wales, Australia (2013) [80 professionals]. The *International Consensus on Family Centred Early Intervention* (2013) draws extensively on our research (S3): *"Dr. Young's work on the theoretical model of informed choice forms the foundation of the third core principle in this document. The third principle provides guidelines for working with families to support informed choice and decision making. Dr. Young's research factors prominently into the concepts presented in this landmark document"* (S7). Our work also forms a key component of the international *Global Coalition of Parents of Children who are Deaf and Hard of Hearing* statement (2010), which supports the work of various parent-driven organisations internationally; *"Informed choice, as outlined in the guidance documents, is a key component of the protocols and practices we wish to be implemented across the world to improve outcomes for deaf children and their families"* (S8).

The development of the standard instrument for assessing the quality of multi-professional services for families with deaf children (the MVOS) has been made freely available for translation and adaptation through a University of Manchester web link since 2010 (S9). To date 48 people/organisations have registered their use of it across 6 countries. The version for Queensland Australia (MVOS Qld) is now used as a standard element of assessment protocol with all families of early identified Deaf children in that region (S10).

5.Sources to corroborate the impact

S1.http://hearing.screening.nhs.uk/5million

S2.American Academy of Audiology profile of John Bamford outlining the influence of his contribution to hearing screening research and practice.
http://www.audiology.org/about/information/honors/Pages/Bamford_John.aspx

S3.Available at: http://jdsde.oxfordjournals.org/content/18/4/429.full.pdf+html

S4.Available at: http://www.childrenscolorado.org/conditions/speech/danielscenter/ANSD-Guidelines.aspx
A corroborating statement from Professor, Department of Hearing and Speech Sciences, Vanderbilt University, USA, on the impact of the international guidelines on ANSD and the contribution of the work at the University of Manchester.

S5.DfES/DH. *Informed Choice, families and deaf children: professional handbook*. 2006
Archived at: http://dera.ioe.ac.uk/id/eprint/1929
DfES/DH. *Helping you choose: making informed choices for you and your child*. 2006
Archived at
http://media.education.gov.uk/assets/files/pdf/h/helping%20you%20choose%20-%20making%20informed%20choices%20for%20you%20and%20your%20child.pdf

S6.A letter from the director of the British Columbia Early Hearing programme on the influence of the theoretical work on informed choice in shaping the province wide screening programme and the contribution to training of the related documents published by the Department of Health and written by the research team.

S7.A corroborating statement from Director, Center for Childhood Deafness, Boystown Hospital, Nebraska, USA, on the influence of the research work on family adjustment to newborn hearing screening and informed choice on international practice in family centred early intervention with deaf children and their families.

S8.Position statement available at:
https://sites.google.com/site/gpodhh/Home/position_statement
A letter from the CEO of Aussie Deaf Kids, a parent driven organisation for deaf children and their families which is an affiliated member of the Global Coalition of Parents of Children who are Deaf and Hard of Hearing (a service user organisation) demonstrating the use of the research work in supporting families and services post early identification and its impact on families.

S9.https://apps.mhs.manchester.ac.uk/surveys/TakeSurvey.aspx?SurveyID=922Lno2

S10.A letter from Research and Service Development Co-ordinator, Hearing Impaired Children's Therapies Inc., Queensland Australia on their adaptation and use of the MVOS.