

Assessing the Social Relations of Newborn Hearing Screening Technology

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Abstract

Following the implementation of newborn hearing screening internationally, screening to detect hearing loss in newborns has been introduced in some Australian hospitals over the past decade. Introduction of newborn screening has been premised on the understanding that the earliest detection of permanent childhood hearing loss, followed by quality early intervention, enhances a child's capacity to achieve his/her best possible communication and learning outcomes. Newborn screening introduces a compressed time period between birth, screening and diagnosis, yet no Australian research has thus far examined the implications of newborn screening and diagnosis from the perspective of the parents of diagnosed children. International research suggests potential negative effects of newborn screening and early knowledge of diagnosis on parent-child bonding, parents' confidence with their parenting skills, and family mental health and well-being. In this paper, we utilise a sociologically informed health technology assessment framework to reflect on research prospects that arise from considering parents' experiences of screening in order to facilitate a more family-centred, holistic policy and service delivery.

Keywords: Family, Deafness, Health Technology Assessment, Health Sociology

For new parents, the discovery that their child is hearing impaired is a challenging experience. With medical technological innovations now allowing the detection of hearing loss in newborns, it is gradually becoming accepted that early detection and intervention enhances a child's capacity to achieve communication and learning outcomes commensurate with his/her nonverbal cognitive abilities (Kumar et al. 2008). In particular, research by Yoshinaga-Itano and colleagues has argued that infants whose hearing loss was identified before the age of six months have stronger expressive language and comprehension abilities than those whose hearing loss was identified after six months of age (Yoshinaga-Itano et al. 1998; Yoshinaga-Itano and

Apuzzo 1998; Yoshinaga-Itano 2003). This research has been widely used to legitimate and support the earliest possible identification of hearing loss through implementation of newborn hearing tests. Indeed it has assumed the status of medical orthodoxy.

In response, newborn hearing screening programs are being established across both the developed and developing world (Young and Tattersall 2007). These programs involve three phases: screening, diagnosis, and transition to early intervention. In Australia, newborn hearing screening programs are currently being trialled or established in all states and territories except Tasmania (VIHSP¹ 2008). Indeed something of a technological imperative appears to be at work. Australia's Federal government recently announced an intention to press all states and territories to implement screening universally by 1st January 2011 (Clayfield 2009). Prior to the introduction of newborn screening in Australia, the average age of detection of permanent hearing loss was 18 months of age in New South Wales, and 7-9 months of age in Victoria. The modified Ewing Distraction Test, a hearing test done for infants in Victoria by Maternal and Child Health nurses, was discontinued in July 2005 (VIHSP 2008).

The timing, scope and type of newborn hearing screening technology currently being introduced varies across Australia's states and territories. Queensland and New South Wales provide universal screening, whilst Victoria and Western Australia each currently screen about 60% of newborns (Victorian Infant Hearing Screening Program 2009). The screening tool currently used in most Australian states, including Victoria, New South Wales, and Queensland, is Automated Auditory Brainstem Evoked Response, or AABR (Personal communication, Zeffie Poulakis, Director, VIHSP March 23 2009). The AABR involves sound being presented through an ear-plug or

headphone, and measurement of the baby's electro-physiological response to this sound via scalp electrodes. AABR screening is painless and is done while the baby is asleep or in a quiet state. Following screening, a number of babies are referred to diagnostic audiology for further testing and diagnosis (VIHSP 2008).

Each state health department is currently collecting and reporting quantitative data, including number of infants screened, number of referrals to diagnosis, and number of false positive results. Permanent bilateral moderate to profound hearing loss (defined as hearing threshold level of 56 db or greater across the range of speech frequencies) is detected in approximately 60 newborns each year in each of Australia's large states such as New South Wales and Victoria (Victorian Infant Hearing Screening Program 2008).

However, most effort so far has gone into the use of the actual AABR technology itself with particular emphasis given to screening protocols, for example screening instruments, various audiological tests and health workforce issues. Australian health policy makers and professionals currently lack information on the broader process of family experiences of newborn hearing screening in order to facilitate a more holistic, family-centred approach that addresses social and emotional needs as well as the audiological implications of hearing loss. As newborn hearing screening systems are established internationally, it is being recognised that the educational and social development of children identified with a hearing loss is crucially shaped by parents' reactions, acceptance and advocacy for their child (DesGeorges 2003).

In this paper we explore what is known from the Australian and international literature of parents' experiences of newborn hearing screening with a view to identifying what benefits might arise out of understanding the social and family dimensions of these processes. We employ a sociologically informed health

technology assessment framework (Willis 1997). Such an approach considers a technology not only as the object itself in the form of a machine such as AABR, but also the social relations that are embodied in such a technological innovation. So use of a technology for detecting newborn hearing loss should be seen not as an event but as a social process involving also the pathway to the test (information about screening given to pregnant women, for example) and the aftermath such as the consequences of diagnosis. To do this involves considering the social perspectives of the four groups of stakeholders; patients and their families, professionals, industry and the state. (see McKinlay 1977) . This framework comprises part of a broader theoretical tradition recognising that technology is never neutral or value-free. We consider not only how technology affects and shapes society but also how technology embodies the social and cultural context in which it is produced (MacKenzie and Wajcman 1999; Weiss and Thier 1988).

Parent experiences of newborn hearing screening

In his seminal article on the sociology of medical technology assessment, John MacKinlay (1981) traces the “career” of a medical technology “from promising reports to standard procedure”. With AABR accepted as the standard procedure for detecting newborn hearing loss, it brings with it a change in the social relations between stakeholders, that is patients/families, professionals and the state. Prior to the introduction of newborn hearing screening, diagnostic assessments often occurred when the baby was at least several months old, and were frequently an end result of parental concerns arising from observation of their child’s development. Diagnosis represented a validation of parental suspicion of hearing loss. The introduction of newborn hearing screening, however, introduces the technology much earlier and

brings with it a shift from parent-driven to system-driven identification; from a context where parents act on their suspicions to one where parents are instead acted on by the public health system. So rather than the detection of hearing deficiency being delivered mainly as a confirmation, now the diagnosis may be audiologist-driven, and given to parents who neither like the message nor asked for it to be delivered (Luterman and Kurtzer-White 1999).

To date, very little research in Australia has examined the experiences of newborn hearing screening programs from the perspective of parents and families. A study in Victoria based on open-ended written questionnaires indicated that parents need greater support and counselling during the (sometimes lengthy) testing period and at time of diagnosis. The study found that health professionals need more training in communicating abnormal test results to parents and in identifying and dealing empathically with likely parent reactions such as shock and denial (Russ et al., 2004). Other Australian and international research (VIHSP 2009; Fox and Minchom 2008) has offered only superficial analyses, using questionnaires to measure the level of parent satisfaction with the initial screening procedure; significantly, these studies have not inquired about parents' experiences of the diagnostic process or transition to early intervention.

Early indications of the impact of the introduction of newborn hearing screening suggest that the social relations of this technology are complex and need to be further studied. Since Australia's introduction of newborn hearing screening, Deaf Children Australia (a non-profit provider of information and support to families of children with a hearing loss) has anecdotally received reports from parents suggesting great variation in the relevance and scope of information received at the point of diagnosis. While a number of parents have reported positive experiences, some reported an

absence of clear, unbiased information or guidance from health professionals. Indeed, a number of parents described ongoing and unresolved grief, and some felt “dumped” by the system. Others were concerned that the domination of the medical model of deafness had impacted on their early interactions with their child. A number of parents reported a need to hear more than the professional voice, particularly the opportunity to inform themselves through learning about other parents’ experiences and choices. Other parents have described a high level of anxiety that had impeded their capacity to seek further information or support (Personal communication, Gene Reardon, Deaf Children Australia, March 3, 2009).

Moreover, some international research has highlighted potential negative impacts of newborn hearing screening and very early knowledge of diagnosis on parent-child bonding and attachment, parents’ confidence with their parenting skills, and family mental health and wellbeing. For example, quantitative research in Britain (Crockett et al., 2006) found that levels of maternal anxiety increase with the number of hearing tests required of newborns to confirm diagnosis. American quantitative research (Vohr et al. 2008) has also indicated increased stress on mothers of infants whose screening results and subsequent diagnostic findings indicated hearing loss. And qualitative British research, based on in-depth interviews with 45 parents/caregivers, found that early diagnostic knowledge of hearing loss can lead to distress when early knowledge-inducing timetables of expectations are not speedily met, and in a small number of cases can interfere with the normal processes of bonding (Young and Tattersall 2007; Young et al. 2004). Another qualitative study from the same data set found that communication style and manner of professionals is the most important issue shaping parent experiences, with ‘good’ professional communication involving clear, jargon-free explanations that use examples in context, sensitivity toward

parents' emotional needs, involvement of parents in testing procedures, and honesty and openness (Tattersall and Young 2006).

So what this research on the implications of the introduction of newborn hearing screening appears to indicate is that the social processes surrounding this technological innovation are in danger of becoming more professionally centred and less family centred. In order for newborn hearing screening programs to be more family-centred, it seems that parents should play a greater role in service provision, by, for example, serving on state-wide advisory councils, assisting in the development of educational materials, and supporting other families during the early identification process. The process by which deafness in newborns is diagnosed and then incorporated into the lived experience of that child appears to mean, as Des Georges (2003) has argued, that screening programs should ideally be infused with knowledge from multiple sources – including families of other deaf and hard of hearing children, deaf and hard of hearing adults, educational institutions, and professionals with specific expertise in the field of deafness – recognising the numerous and complex decisions parents have to make about their child's services.

The importance to families of strong social networks with other parents of deaf children has also been demonstrated in other research (Luterman and Kurtzer-White 1999). Such families have been shown to experience less isolation and have more robust emotional bonds with their child, better acceptance of their child and improved responsiveness during interactions (Wood Jackson and Turnbull 2004). This is a noteworthy point; up until at least the past two decades in Australia, deaf children typically experienced significant communicative and social isolation from their families, peers, and educators, leading to poor self-esteem and inadequate

socialisation. Australian Sign Language was seldom or never used in the homes of deaf children (Slegers 2007).

Toward a family-centred perspective: future research

Consideration of the available literature makes clear the need for qualitative inquiry in Australia to better understand the experiences of parents and families of infants with a permanent hearing loss detected by screening. In relation to each phase of the screening program (screening, diagnosis, and transition to early intervention) we need to better understand parents' experiences of the social processes involved including: the content of information provided, the timing of information provision, who provides the information, as well as the context and setting in which the information is provided. This work would need to identify how these information processes shape parent-child bonding, attachment and other issues relating to the socialisation of the hearing impaired child. Such research would have significant health policy implications in relation to the information and services provided to parents of newborns.

A key objective of such research would be to develop a more family-centred discourse to balance the primarily medical-professional discourse that currently appears to exist. A family-centred discourse would be consistent with perspectives from health sociology that view illness such as deafness within the social and cultural context in which it occurs (Germov 2009). This approach would be informed by an analysis of the terms and labels used to discuss deafness and hearing loss by medical and educational professionals in contrast to those used by deaf people (Padden and Humphries, 1988; Slegers 2007).

An important parental subgroup to include in such a study would be sets of parents comprising at least one parent who is deaf. Evidence suggests that about five percent of deaf children are born to one or more parents who are also deaf (Mitchell and Karchmer 2004). A number of studies in Western societies have indicated that attitudes toward the arrival of a deaf child in the family unit are fundamentally different between those families where parents are themselves deaf and those where the parents have no hearing loss (Padden and Humphries 1988; Carty 1994; Slegers 2008). The reactions of parents without a hearing loss on discovering their child has a permanent hearing loss are typically characterised by shock and grief over what they perceive might have been. The child they have been joyfully expecting is found to be unlike themselves, and they try to find advice on what course of action to take (Emerton 1998; Spradley and Spradley 1985). In contrast, parents who are deaf themselves tend to respond much more ambivalently to the arrival of a deaf child; many such parents express feeling positive, even joyful, in the knowledge that they will be able to communicate easily with their child, who will share the same first language – Auslan or another sign language – and identity with them. Research suggests such children have tended to grow up with healthy self-esteem and socialisation, and positive feelings about their identity as “deaf people” who are members of a “deaf community” (Padden and Humphries 1988; Carty 1994; Slegers 2007; Slegers 2008).

Alys Young and colleagues in Britain conducted qualitative inquiry about parent experiences of newborn hearing screening (Young and Tattersall 2007; Tattersall and Young 2006; Young et al. 2004) although not cast in a technology assessment framework. Parents were invited to tell their own stories in their own words through semi-structured interviews on stages of the social process including: the experience of

the screening from first screening test, through referral and diagnostic assessment to confirmation; the experience of early intervention and professional support, and their advice to other parents and professionals engaged in the same process. The interviews also explored how these processes may have shaped parent-child bonding, attachment, parental confidence, and other issues relating to socialisation of the child. The qualitative research proposed in Australia should borrow from this methodology, and could additionally include follow up interviews to assess how parents' perceptions and feelings evolve over time. Interviews would be conducted in a range of metropolitan and regional centres, in states where screening is universal as well as states where only a proportion of the hospitals have introduced screening.

Conclusion

The case for audiological screening for early detection of newborn hearing impairment is a strong one that governments are moving to act upon. However the effectiveness of such technological intervention will be diminished unless the technology is seen in a broader process rather than narrower event terms. Qualitative research on the social relations of the technological intervention is crucial so that maximum effectiveness for the subsequent lived experience of the child can be achieved. For many, this will involve consideration of the various technological aids and choices from cochlear implants to signing. Attending to such social relations involves consideration of how a more parent centred discourse can be balanced against the professional discourse in the interests of the child.

Notes:

- 1 Victorian Infant Hearing Screening Program

References

- Carty, B. (1994) 'The development of Deaf identity', pp. 40-44 in C. Erting, R. C. Johnson, D.L. Smith and B. Snider (eds.) *The Deaf Way: Perspectives from the International Conference on Deaf Culture*. Gallaudet University Press, Washington, DC.
- Clayfield, M. (2009) 'Rudd and Nelson share vision on hearing', *The Australian*, June 30, 2009.
- Crockett, R., Wright, A., Uus, K., Bamford, J. and Marteau, T. (2006) 'Maternal anxiety following newborn hearing screening: the moderating role of knowledge', *Journal of Medical Screening*, 13(1): 20-25.
- DesGeorges, J. (2003) 'Family perceptions of early hearing, detection and intervention systems: Listening to and learning from families', *Family Retardation and Developmental Disabilities Research Reviews* 9: 89-93.
- Emerton, R.G. (1998) 'Marginality, Biculturalism, and Social Identity of Deaf People', pp. 136-145 in I. Parasnis (ed.) *Cultural and Language Diversity and the Deaf Experience*. Cambridge University Press, Cambridge.
- Germov, J. (2009) 'Imagining health problems as social issues' in pp. 3-24 in Germov, J. (ed.) *Second Opinion: An Introduction to Health Sociology*. South Melbourne, Victoria: Oxford University Press.
- Kumar, S. et al. (2008) *A Systematic Review of the Literature on Early Intervention for Children with a Permanent Hearing Loss*, Technical report produced for Queensland Health, Brisbane, Australia.
- Luterman D. and Kurtzer-White, E. (1999) 'Identifying hearing loss: parents' needs', *American Journal of Audiology* 8(1): 13-18.
- McKinlay, J. (1977) 'The business of good doctoring or doctoring as good business; reflections on Freidson's view of the medical game', *International Journal of health Services* 7(3): 459-88.
- McKinlay, J. (1981) 'From promising report to standard procedure: seven stages in the career of a medical innovation', *Milbank Memorial Fund Quarterly* 59: 233-70.
- MacKenzie, D. and Wajcman, J. (1999) 'Introductory Essay: The Social Shaping of Technology', pp.2-27 in MacKenzie, D. and Wajcman, J. (eds.) *The Social Shaping of Technology*. Buckingham, [England]; Philadelphia, PA.: Open University Press.
- Mitchell, R. and Karchmer, M. (2004) 'Chasing the mythical ten percent: parental hearing status of deaf and hard of hearing students in the United States', *Sign Language Studies* 4(2): 138-162.
- Padden, C. and T. Humphries (1988) *Deaf in America: Voices from a Culture*, Cambridge, Massachusetts: Harvard University Press.
- Russ, S., Kuo, A., Poulakis, Z., Barker, M., Rickards, F., Saunders, K., Jarman, F., Wake, M., and Oberklaid, F. (2004) 'Qualitative analysis of parents' experience with early detection of hearing loss', *Archives of Disease in Childhood* 89(4): 353-358.
- Slegers, C. (2007) *Signing in: A socio-cultural study of deaf people in Melbourne*, unpublished PhD thesis, La Trobe University.
- Slegers, C. (2008) 'Family communication experiences of deaf Australians', *Proceedings of TASA 2008: the Annual Conference of The Australian Sociological Association 2008*. University of Melbourne, December 2-5, 2008.

- Spradley, T.S. and J. P. Spradley, (1985) *Deaf Like Me*. 2nd edition, Gallaudet University Press Washington, D.C.
- Tattersall, H. and Young, A. (2006) 'Deaf children identified through newborn hearing screening: parents' experiences of the diagnostic process', *Child: Care, Health and Development*. 32(1): 33-45.
- Victorian Infant Hearing Screening Program (2008) 'Victorian Infant Screening Program: General Information' URL (accessed 18 March 2009) http://www.rch.org.au/vihsp/info.cfm?doc_id=7684
- Victorian Infant Hearing Screening Program (2009) 'Victorian Infant Screening Program: VIHSP Parent Survey' URL (accessed 20 July 2009) http://www.rch.org.au/vihsp/news.cfm?doc_id=7686
- Victorian Infant Hearing Screening Program (2009) 'Victorian Infant Screening Program: News and Updates' URL (accessed 10 April 2009) http://www.rch.org.au/vihsp/news.cfm?doc_id=7686
- Vohr, B., Jodoin-Krauzyk, J., Tucker, B., Johnson, M., Topol, D., and Ahlgren, M. (2008) 'Results of newborn screening for hearing loss: Effects on the family in the first 2 years of life', *Archive of Pediatric Adolescent Medicine* 162(3): 205-211.
- Weiss, R. and Thier, S. (1988) 'HIV testing is the answer: what's the question', *New England Journal of Medicine* 319(15): 1010- 1012.
- Willis, E. (1997) 'The prostatic imperative and the social relations of medical technology', *International Journal of Technology Assessment in Health Care* 13(4): 602-612.
- Wood Jackson, C. and Turnbull, A. (2004) 'Impact of deafness on family life' *Topics in Early Childhood Special Education* 24(1):15-29.
- Yoshinaga-Itano C. and Apuzzo, M. (1998) 'Identification of hearing loss after age 18 months is not early enough', *American Annals of the Deaf* 143(5):380-387.
- Yoshinaga-Itano, C., Sedey, A., Coulter, D., and Mehl, A. (1998) 'Language of early- and later identified children with hearing loss', *Pediatrics* 102(5):1161- 1171.
- Yoshinaga-Itano, C. (2003) 'From screening to early identification and intervention: Discovering predictors to successful outcomes for children with significant hearing loss', *Journal of Deaf Studies and Deaf Education* 8(1):11-30.
- Young, A. and Tattersall, H. (2007) '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* 12(2): 209-220.
- Young, A., Tattersall, H., Uus, K., Bamford, J. and McCracken, W. (2004) 'To what extent do the characteristics of the object of the object of evaluation influence the choice of epistemological framework? – the case of universal newborn hearing screening', *Qualitative Health Research* 14(6): 866-874.