

**PARENT AND PROFESSIONAL PERSPECTIVES OF THE  
WESTERN AUSTRALIAN INFANT SCREENING FOR HEARING PROGRAM**

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**ABSTRACT**

This study was undertaken to evaluate the Western Australian Infant Screening for Hearing (WISH) Program from the perspectives of parents, newborn hearing screeners and Telethon Speech and Hearing (TSH) professionals who have been involved in the WISH Program. Three questionnaires were used to gather information from 16 participants which included five families, five screeners and six TSH professionals. Overall, results showed that families and staff involved in the WISH Program were satisfied with the hearing screening, audiological, early intervention and counselling services provided by the WISH Program and TSH. Recommendations were offered by participants to assist in improving services, as well as continuing the quality of services being offered. One of the major recommendations was to continue efforts to implement a state-wide newborn hearing screening program in Western Australia (WA), which includes continuation of the WISH Program for the private sector at no cost to parents. Other suggestions included consistent and clear information from screeners to parents; an enhanced database system and ongoing data entry; supply of feedback to screeners; and, promotion of the WISH Program through improved education to hospital professionals and parents.

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## **INTRODUCTION**

Hearing loss can have a significant impact a child's language and learning development (Yoshinaga-Itano, Sedey, Coulter & Mehl, 1998). Health and education

professionals support the early identification of hearing loss in children as a means of improving their communication and overall academic outcomes (Yoshinaga-Itano et al., 1998). Newborn hearing screening can benefit children and their families with an earlier diagnosis of hearing loss (Davis, Bamford, Wilson, Ramkalawan, Forshaw & Wright, 1997). Without early diagnosis and management, severe delays in speech, language and cognitive development can occur (Erenberg, Lemons, Sia, Trunkel & Ziring, 1999).

Newborn hearing screening in itself does not improve a child's learning outcomes but enables the opportunity for early access to intervention. This in turn facilitates access and exposure to language and communication from an earlier age (Yoshinaga-Itano, 2004). If a child's hearing loss is identified early, there are no additional disabilities, and the child is provided with adequate intervention, he/she can develop age-appropriate language skills (Yoshinaga-Itano, 2004). The earlier the diagnosis of hearing loss, the sooner the opportunity for appropriate intervention. Detection of congenital hearing loss prior to 6 months of age has been demonstrated to significantly improve a child's language skills (Moeller, 1996; Yoshinaga-Itano et al., 1998). For most babies or children, the appropriate intervention begins with a hearing aid fitting (Yoshinaga-Itano, 2004). Many children diagnosed with hearing loss and fitted with hearing aids by the age of six months, have been found to develop age-appropriate speech and language skills (Robinshaw, 1995).

Where newborn hearing screening is implemented, such as in Colorado in the United States of America (USA), hearing aid fitting occurs, on average, at five weeks of age (Yoshinaga-Itano, 2004). In the United Kingdom (UK), babies diagnosed without newborn hearing screening received intervention at approximately 32 months (Davis et al., 1997). Due to the recent introduction of newborn hearing screening, babies in the UK are now being identified with hearing loss at a median age of 10 weeks (Bamford, Ankjell, Crockett, Marteau, McCracken, Parker, Tattersall, Taylor, Uus & Young, 2004). Even though newborn hearing screening is widely utilised throughout the USA, Canada, UK and many European countries, as yet it has not been consistently implemented throughout Australia (Wake, 2002). Universal newborn hearing screening has commenced or is being implemented by all states and territories in Australia, except Western Australia (WA) (McMahon, 2007). In other countries such as the UK, there is no longer a focus on justifying the need for newborn hearing screening, but rather, on quality improvement of these services (Young & Tattersall, 2005).

## **The Screening Pathway**

Screening can be defined as “the systematic application of a test or enquiry to identify individuals at sufficient risk of a specific disorder to benefit from further investigation or direct preventive action, among people who have not sought medical attention because of symptoms of that disorder” (Strong, Wald, Miller & Alwan, 2005, p. 12). As mentioned by Strong et al. (2005), the World Health Organisation (WHO) recommends that the components of an organised approach to screening include the following:

- Clear objectives of the program and its predicted health benefits
- Identification of the individuals who will benefit from the screening
- Measures to ensure high coverage and attendance
- Resources to record health information for evaluation and monitoring of the program appropriate facilities available for testing and interpreting results
- Organized quality control for the screening tests and their interpretation
- Adequate facilities for diagnosis and appropriate treatment
- A referral system for management of any abnormalities found and for provision of information on normal screening tests
- Maintenance of program data to evaluate and monitor the program regularly

The WHO principles have guided the development of significant population based screening programs in Australia and overseas, including the National Cervical Cancer Screening Program (Australian Health Ministers Advisory Committee Council Cervical Cancer Screening Evaluation Steering Committee, 1991). According to J. Straton, WA Department of Health (Personal communication, June 12, 2007) and based on WHO principles and guidelines, an effective statewide newborn hearing screening program will need to address all of the following key components known collectively as the 'screening pathway':

- Recruitment and newborn hearing screening
- Follow-up of abnormal screening results
- Diagnostic assessment
- Early intervention, management and counselling services
- Co-ordination, monitoring and evaluation of the program
- Public and professional education

## **Hearing Screening Methodology for Newborns**

The Joint Committee on Infant Hearing (JCIH, 2000), in their Principles and Guidelines for Hearing Detection and Intervention Programs, recommend the following newborn hearing screening technologies: Auditory Brainstem Responses (ABR); Otoacoustic

Emissions (OAE); or, a combination of ABR and OAE testing. The JCIH (2000) position statement also outlines the principles for effective Early Hearing Detection and Intervention, as well as how to implement and maintain successful programs including:

- Access for all babies to hearing screening within one month of birth
- Follow-up assessments for those babies who “refer” within three months of birth
- Intervention to commence, for children diagnosed with hearing loss, within six months of birth

## **Review of Current Programs Overseas and in Australia**

### ***The United Kingdom***

England, Wales, Northern Ireland and Scotland all offer universal newborn hearing screening. Since 2006, parents of every newborn in England have been offered the opportunity for hearing screening. Over 1,600 newborns are now screened in England every day as part of the Newborn Hearing Screening Program (NHSP) (NHS screening, 2006) and of the two million babies screened by NHSP, 3400 have been diagnosed with hearing loss (Brooks, 2007).

The need for effective communication during the screening process, including diagnosis, is acknowledged. NHSP has developed two leaflets which are provided to parents during the hearing screening process in England. A third is given to those parents whose children are referred for follow-up diagnostic testing. The leaflets aim to: “provide parents with the information that they will need to make informed choices about the screening and to provide clear and accessible information about each stage of the screening in order to minimize the anxiety felt by parents” (Newborn hearing screening”, 2007).

Three booklets are also provided to parents whose children are diagnosed with hearing loss which aim to “support the information given to parents by the audiologist at the time of the identification of deafness. This can be an extremely emotional time for parents and information can be difficult to take in and remember. The booklets can assist parents remember this information and make parents aware of some of the sources of support that are available to them” (Newborn hearing screening, 2007).

### ***The United States of America***

There are currently 37 states in the USA that have commenced legislation for hearing screening to be performed on all newborns in hospitals and birthing centres (Stevens-Wrightson, 2007). As part of the USA federal government's 'Healthy People 2010' the

aim is that access to hearing screening will be provided to 100% of all babies born 2010 (JCIH, 2000). The USA utilise guidelines from the JCIH position statement as goals in their state-sponsored newborn hearing screening programs (JCIH, 2000) and follow the “1-3-6” rule; screen by 1 month of age, assess by 3 months of age and intervene by 6 months of age (Minnesota newborn hearing screening program”, 2007).

### ***Australia***

With the exception of WA, all Australian states and territories either have established universal government funded programs or are in the process of implementing these programs (McMahon, 2007). In New South Wales, South Australia and the Australian Capital Territory there has been a full roll out of newborn hearing screening services. Of the population of babies born in each of these states or territory in 2006, greater than 95% were screened for hearing (McMahon, 2007).

Both the Northern Territory and Tasmania received state/territory–wide funding approval and/or program development for newborn hearing screening in 2006 (McMahon, 2007). The Victorian Government has committed to providing access to hearing screening for all newborns by the end of 2010 through the Victorian Infant Hearing Screening Program (VIHSP, 2007). Victoria screened 42,197 newborns between February 2005 and April 2007, and referred 397 infants for diagnostic assessment. Of these, 186 were diagnosed with a hearing loss (Panjari, 2007).

In 2006, the Queensland Government completed implementation of their newborn hearing screening service via a staged roll out across the state (Young, 2007). This service commenced in 2004 and the Healthy Hearing Program has now been implemented in 44 public hospitals and 17 private hospitals (Queensland Health, 2006). The two staged Automated Auditory Brainstem Responses (AABR) process captured 99% of all babies born in Queensland between September and December 2007 (Young, 2007).

### **Current hearing screening services in Western Australia**

In WA the population of babies screened for hearing in 2006 was 46% of all babies born in the state (McMahon, 2007). As at November 2007, the WA Government has not committed to state-wide newborn hearing screening (McMahon, 2007) and there are currently two programs operating:

### ***The WA Newborn Hearing Screening Program***

The WA Department of Health (DoH) provides newborn hearing screening in several metropolitan public hospitals including King Edward Memorial Hospital, Osborne Park, Joondalup, Kaleeya, Rockingham and Armadale/Kelmscott. There is no additional charge to parents for this service. This program currently screens children born in Perth public metropolitan hospitals only. It does not provide services to families in country areas or those choosing to use the private hospital system (N. Davies, Telethon Speech and Hearing, Personal communication, May 29, 2007).

Between February 2000 and 30 June 2001, 12708 babies were screened as part of a pilot program in Perth, WA, and of those screened nine were diagnosed with bilateral permanent hearing loss (Bailey, Bower, Krishnaswamy & Coates, 2002). The prevalence of congenital bilateral sensori-neural hearing loss was recorded by Bailey et al. (2002) as 0.7 per 1000. It is noted that this figure did not include babies diagnosed with unilateral or conductive hearing loss, nor is it a true representation of all WA births (Bailey, et al., 2002). Parents' acceptance of this program was reflected by only 0.4% refusing screening (Bailey, et al., 2002). Early hospital discharge was noted as the main reason for parents not having their babies screened for hearing (Bailey, et al., 2002).

### ***The WA Infant Screening for Hearing (WISH) Program***

In the absence of a universal newborn hearing screening service in WA, Telethon Speech and Hearing (TSH) have coordinated an additional screening service for WA children known as the Western Australian Infant Screening for Hearing (WISH) Program. The WISH services provide access to hearing screening for families outside of the WA metropolitan public hospital system. WISH provides screening services to seven private maternity hospitals in Perth and Bunbury. Given that these services are not funded through the public hospital system, families must pay a fee to cover the costs associated with the screen. The fee for the screen is currently \$65.00.

The WISH Program services a number of private hospitals including St John of God (SJoG) Subiaco, SJoG Murdoch, Joondalup Private, Mercy, Attadale, Glengarry and SJoG Bunbury. This program currently records an uptake of 60% of all babies born in these hospitals. It is considered that this figure could be significantly higher if there were some form of Medicare or health insurance rebate available to parents, or it was funded by the WA Government (N. Davies, TSH, Personal communication, May 29, 2007).



### **Prevalence of hearing loss through WISH**

The WISH Program screened 10,149 infants between February 2005 and April 2007. Of the infants screened, eight were diagnosed with bilateral sensori-neural hearing loss, four with unilateral sensori-neural hearing loss and two with conductive hearing loss. This data indicates that the prevalence of congenital bilateral and unilateral sensori-neural hearing loss diagnosed through WISH over this period was 1.18 per 1000 births (N. Davies, TSH, Personal communication, May 29, 2007). The prevalence rates may change as more data is accumulated and these data should not be regarded as definitive rates until 100,000 babies have been screened (P. Higginbotham, TSH, Personal communication, November 21, 2007).

### **WISH Program**

The WISH Program was established in February 2005 based on the JCIH Principles and Guidelines for Hearing Detection and Intervention Programs (2000). WISH adopted AABR technology using Algo 3i Newborn Hearing Screeners. These portable machines test the whole hearing pathway from the outer ear to the brainstem and can detect Auditory Neuropathy (damage to the auditory nerve). This is a non-invasive test that can be performed quickly and accurately while the baby is sleeping. It can be undertaken in hospital or in a community setting such as at TSH.

Parents generally receive a brochure about WISH services when they register with one of the participating hospitals (see Appendix A). A specially designated screener employed by WISH will visit the hospital on varying days to perform a hearing test on newborns over 34 weeks gestational age. The test can be performed on babies as early as six hours old. The AABR screen is generally conducted at the mother's bedside and the results are discussed immediately with the parents. The results from the screen are recorded in the "purple book" and the mother's patient notes. If mothers are discharged before the opportunity for screening, the WISH coordinator contacts the parents to arrange a hearing screen at TSH.

The hearing screen separates those babies with no hearing loss ("pass") from those who may have a hearing loss ("refer") and require further investigation. A "refer" may also be due to fluid or debris in the ear, or the baby was too unsettled to obtain a reliable result. In these circumstances the parents are advised that the test was inconclusive and they are required to attend a follow-up diagnostic assessment with an Audiologist at TSH or Princess Margaret Hospital for Children.

All parents are provided with a 'Newborn Hearing Screening Result' card after the hearing screen. The yellow “pass” result card (Appendix B) informs the parent on the hearing screening result and what the result indicates, the possible need for further testing, baby hearing milestones and TSH contact details. The green “refer” result card (Appendix C) informs the parent on the hearing screening result (left and right ear) and what the result indicates, why there is a need for further testing, how to arrange a follow-up diagnostic appointment and how to prepare the baby for the appointment, what the appointment will involve, what happens after the test and TSH contact details.

WISH newborn hearing screeners are currently employed with a variety of backgrounds and expertise (e.g. nursing, child care and teaching). According to N. Davies, TSH (Personal communication, 29<sup>th</sup> May, 2007) screeners receive initial on-the-job training to follow communication guidelines with parents which includes:

- Using consistent terminology and explanations to avoid confusing parents
- Reassuring parents that the test is non-invasive and won't harm the baby
- Being positive about the result and encouraging parents to attend any follow up appointments
- Advising parents that if they require additional information, they can talk with the screener or contact TSH
- If parents are distressed, arranging appointments for follow-up prior to discharge

TSH aims to arrange diagnostic follow-up appointments for babies within a week of discharge. Particular appointment times are currently set aside to enable this. The Early Intervention Coordinator is also made available at these times should a hearing loss be diagnosed. If this occurs, the Coordinator is introduced to the family, to provide them with support and to answer any further queries. It is at this time that the families are first informed of the available support services, including counselling. Weekly team meetings and regular professional development days are held for early intervention, audiological and counselling staff.

According to J. Klass, TSH (Personal communication, October 15, 2007) the WISH screeners are trained with an experienced screener for approximately three to four sessions or until they feel confident enough to screen on their own. They also have a session at TSH with an audiologist. Professional development meetings are held three to four times a year and are run by a TSH audiologist. Regular meetings are held between the screeners, the TSH CEO and business manager, an audiologist and the

WISH program coordinator. There are no meetings between hospitals and screeners. The Newborn Hearing Screener Coordinator liaises on a regular basis with the hospitals and hospital staff.

## **Evaluation of Newborn Hearing Screening Programs**

### ***The United Kingdom***

Bamford et al. (2004) evaluated the first phase of the implementation of the Newborn Hearing Screening Programme (NHSP) in England and highlighted the importance of:

- Effective communication between health professionals and parents in newborn hearing screening services
- Developing a partnership between parents and health professionals and of providing knowledge to parents across the screening pathway
- Ensuring the parents had good knowledge of why their baby was referred for further assessment to reduce anxiety
- Shortening the waiting time to no more than four weeks for follow-up audiological diagnostic assessment
- Checking the parents understand what the screen result implies rather than providing a reassuring message

According to Bamford et al. (2004) suggestions made by parents to improve the NHSP services in England included:

- Providing mothers with a follow-up appointment date and time before discharge
- Audiological services setting aside regular time slots for follow-up assessments so appointments are available
- Engaging parents in the testing procedures
- Providing good explanations at follow-up assessments using real life examples that are familiar to the parent
- Notifying parents of the duration of appointments in advance so they can arrive prepared

A further paper, based on the English evaluation, reaffirmed the excellent screening practice in the NHSP but highlighted the need for checking parental understanding of the screening process (Young & Tattersall, 2005). A couple in the study felt that because the screener failed to mention that their baby might not be passing the screen because it may have had a hearing loss, this prevented them from preparing for the diagnosis (Young & Tattersall, 2005). Other parents thought that by playing down the

possibility of hearing loss was the right thing to do because they would have become alarmed unnecessarily (Young & Tattersall, 2005). Although explanations by screeners were well-meaning, their comments were interpreted differently by different families. This raised the important question on how to best provide a screening service which caters for all considering “one message will never fit all” (Young & Tattersall, 2005, p. 140).

Parents found being given the statistics on how few babies were identified with hearing loss comforting and commented positively on screener's kindness, patience, and understanding (Young & Tattersall, 2005). Many parents stressed the value they placed on how “kind,” “patient,” “nice,” and “understanding” screeners were and how their confidence and reassurance were key to parents not being worried that their baby needed to be re-screened (Young & Tattersall, 2005, p. 138). Interestingly, the authors noted that it was “not just about what screeners say, but how they seem as people. The descriptions used were often about the screeners' personality and character, not just their professional communication” (Young & Tattersall, 2005, p.138). Parents also placed value on the screener's confidence and ability of handling a newborn baby (Young & Tattersall, 2005).

### ***Australia***

As a means of evaluating the Victorian Infant Hearing Screening Program (VIHSP), Russ, Kuo, Poulakis, Barker, Richards, Saunders, Jarman, Wake and Oberklaid (2004) carried out qualitative research using semi-structured questionnaires. Parents of 82 children, screened by the VIHSP and diagnosed with hearing loss, responded to a questionnaire which enabled them to recount their personal experiences. Russ et al. (2004) analysed the comments and found that:

- Support and counselling for families was needed at the time of diagnosis of hearing loss
- Long delays between the initial hearing screening and diagnosis of hearing loss created feelings of “helplessness” and “anxiety”
- Providers needed to check the parent had understood the information given
- Simple to understand language was required during diagnosis and supported with written information and references to other information sources (e.g. websites)
- The post diagnosis support for families appeared excellent
- Early intervention teams were seen to provide valuable support
- There were no negative comments about the overall screening process

- Specialised training in counseling is needed for audiologists and other staff who assist in the diagnosis of hearing loss
- Electronic case tracking is needed to avoid children being “lost in the system”

Researchers also recommended further evaluation of newborn hearing screening programs, and implementation, in order to adequately meet the needs of children with hearing loss and support their parents (Russ et al., 2004). To date, there has been no formal evaluation of the WISH Program or the services it provides.

### **AIM OF THE STUDY**

The aim of this study was to examine the WISH Program from the perspectives of parents, newborn hearing screeners and professionals from TSH, who have been involved in the WISH Program. The information gathered helped identify aspects of the WISH Program which the parents, screeners and professionals support, as well as recommendations to improve the services.

### **METHOD**

#### **Participants**

The participants in this study were five families, whose children were diagnosed with hearing loss through WISH, five WISH newborn hearing screeners and six TSH professionals who have been involved in the WISH Program. In total, there were 16 participants. An additional parent contacted the researcher by email wishing to contribute to the research. She subsequently telephoned the researcher to provide a detailed account on her family's experience of newborn screening.

#### **Materials**

A range of questions were developed for each of the three groups. Parent participants were asked questions related to newborn hearing testing services, further audiological testing services, early intervention and counselling services (Appendix D). Newborn hearing screeners were asked questions related to training, service provision and communicating/working with other professionals and organisations (Appendix E). TSH professionals were asked to provide feedback in relation to service provision, service enhancement and recommendations for improved services (Appendix F).

#### **Procedure**

A total of 31 potential participants were invited to participate in this research project because of their involvement in the WISH Program.

A senior staff member at TSH identified 14 families, from the WISH data base, who had their children screened by WISH, and were diagnosed with conductive or sensorineural hearing loss at TSH. Invitation packages were mailed by a TSH staff member to ensure the confidentiality. The packages included a cover letter from Telethon Speech and Hearing (Appendix G), a cover letter from the researcher (Appendix H); a plain language statement (Appendix I) and a specifically designed questionnaire for families (Appendix D).

There were nine newborn hearing screeners identified as potential participants due to their current employment with the WISH Program. They were mailed packages which included a cover letter from Telethon Speech and Hearing (Appendix J), a cover letter from the researcher (Appendix K); a plain language statement (Appendix I) and a specific questionnaire seeking their view as a screener (Appendix E).

Packages were also sent to eight professionals from Senior Management, Audiology, Early Intervention, Counselling and Data Entry at TSH. These members of staff were identified as potential participants due to their involvement in the WISH Program and the families whose children are identified with hearing loss through WISH. The packages included a cover letter from the researcher (Appendix L); a plain language statement (Appendix I) and a specific questionnaire seeking their views (Appendix F).

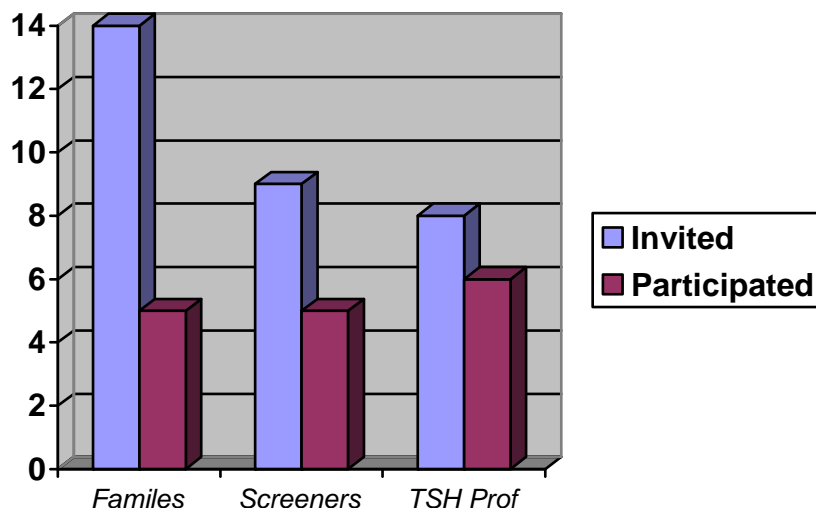
### **Ethical Approval**

Approval for the research project was obtained from the Ethics Committee at the University of Melbourne (Appendix M).

### **RESULTS**

A total of 31 questionnaires were distributed and 16 replies were received, giving an overall response rate of 51.6%. The participants included five out of 14 families, five out of nine screeners and six out of eight TSH professionals.

**Table 1            Response rate of families, screeners and TSH professionals**



## **Recruitment and Newborn Hearing Screening**

### ***Delivery of screening services***

Four of the five families indicated that they were happy with the screening services offered by WISH. The remaining family reported “Through no fault of the marvelous people providing the service there is no rebate from Medicare on the hearing test service”. The aspects of the WISH Program with which professionals expressed most satisfaction included the acceptance of the program by private hospitals, the provision of a regional service in Bunbury and the delivery of a high standard of services by screeners in the hospitals.

### ***Uptake of newborn hearing screening***

TSH professionals and screeners explained that the uptake of the WISH Program had improved significantly since it commenced. Although support and awareness of screening was improving, staff would like to see a higher participation rate in the program. The majority of participants from all categories considered that providing a free hearing screening service would encourage greater usage of WISH services. Respondents felt that cost was a major barrier to parents taking up the offer of a hearing screen. A TSH professional reiterated the need to continue lobbying for government funding for a statewide hearing screening service and for WISH to continue providing for the private sector but to make this at no cost to the parents.

Promotion of the service was also considered to have a major influence on its uptake. This applied to both families and health professionals alike. One family felt that the

WISH program and its services were not well promoted at the hospital. Screeners also reflected this with comments such as “If parents were informed about the statistics of hearing impairment in their ante-natal classes and the importance of early intervention then I think it would make a difference. It's hard to make an informed decision after a quick knock on the door by a screener”.

The screeners first meet families when they arrive at the hospital offering hearing screen services. By this stage the parents have had many interactions with other hospital staff and health professionals. Feedback from newborn hearing screeners indicated that they believed that professionals can strongly influence the parents' decision on whether or not to have their baby screened. As one screener commented “A handful of obstetricians and paediatricians do not support the program and therefore do not encourage their patients to have the screen done and some even advise against it”. Another screener communicated that families were choosing not to have their baby screened because a health professional had not suggested it.

### ***Parental bonding***

Babies are screened between one and seven days of age according to family and screener participants. Most families, of babies diagnosed with hearing loss, expressed that screening at this age had a positive effect on their relationship with their baby, noting that “I love him even more. I communicate/read to him more than I probably would have done with a normal hearing baby”. At the same time one parent reflected that screening affected their relationship with their baby initially due to the shock, but still felt it is necessary to diagnose hearing loss as early as possible.

Other parents felt that an undiagnosed hearing problem could have potentially affected their relationship with their baby. This was supported by a parent who voluntarily contacted the researcher to express her story of what can happen when newborn hearing screening is not accessible... “My child was not diagnosed until 18 months of age. It definitely impacted on my relationship with him. I stopped singing to him when he didn't respond. We had difficulties in communicating with each other. We have a relaxed enjoyable relationship now. At swimming and during bath time though, when he is without his equipment, I am reminded of the battles we had”.

### ***Screening environment***

The WISH Program screens within private maternity hospitals, therefore the majority of women have their own room. All screeners said they felt this was an appropriate and



adequate environment to screen newborns' hearing. Screeners supported the use of the mother's room because it was personalized and private, of adequate size and quiet. Two screeners mentioned that occasionally they are required to screen babies in the hospital lounge or spare room. This occurs if the patient is in a share room or it is an outpatient appointment. One screener felt this was not an appropriate place to screen babies hearing due to a lack of privacy.

### ***Family counselling***

Screeners considered newborn hearing screening to have a positive effect on parental bonding for parents whose babies received a “pass” result. Screeners reflected that parents expressed relief and joy when their baby passed the hearing screening test but experienced some anxiety when their baby needed to be referred for further assessment. To address this, screeners recommended providing counselling services to these parents at the hospital.

### ***Screener training***

All screeners received on the job training and four of the five screeners also received a one day training session with an audiologist. Information was collected from screeners on how their training could be improved. Two screeners and two professionals from TSH requested extra training for screeners on an on-going basis. Other suggestions included the provision of “a more concise job description, daily duties, running of machines, list of contacts”, “a collection of FAQs and answers” and “a list of procedures for each hospital (e.g. where to locate files, baby books etc)”.

### ***Screener communication***

All screeners responded with thorough explanations on how they communicate with parents when further audiological testing is required. Most screeners mentioned that they state common reasons why the baby has referred, provide appropriate handouts, reassure the parents and ask if they can arrange a follow-up appointment for them. Communication appeared to be consistent and all parents stated that they were happy with the screening service provided by WISH. However, one parent made the following comment about her experience “It picked up the hearing loss, but I felt I was given a false sense of hope. I was told it was probably nothing – just muck in the ear. So when I found out it was a hearing loss – it sounds crazy but I didn't expect it and was therefore devastated”.

### ***Screener employment conditions and support***

When asked for recommendations on how to improve the WISH services, three screeners raised concerns over employment conditions. One screener suggested that screeners be paid double time rate on public holidays so screeners are encouraged to screen on the unusual days rather than skipping those days and possibly missing patients. Another screener expressed feelings of guilt over claiming correct hours on their timesheet "I often get the feeling that I should reduce claims on my timesheet... I do extra stuff in own time etc and I feel that maybe other staff have the same 'guilt trip'". A further screener had concerns about the time required for them to contact the bank to verify payment banking details through Eftpos machines and suggested screeners had access to mobile phones in order to facilitate client payment for screening services.

Two screeners out of five felt they had adequate access to counselling support when needed. One used the hospital support system where they screened and the other contacted audiologists at TSH or other screeners. The remaining three screeners expressed the need for on-going support including guidance from more experienced staff members, regular team meetings and "debriefing sessions - how to talk with parents when the second screen is a refer".

A professional from TSH was concerned about screeners and their level of support as follows "As a team member I would also like to hear more from the screeners about their experience of the job – the sorts of things they come across in their role and how they deal with it. I would also like to be reassured they feel supported and confident in their role and are not pressured to spend less time with the families than optimal (e.g. for financial reasons)".

### ***Equipment***

Professionals considered that the provision of the Algo 3i Newborn Hearing Screeners in each hospital resulted in a significant improvement for the WISH service rather than having to share this equipment between hospitals. They also expressed their satisfaction with referral rates resulting from the use of AABR technology with the Algo 3i machines. One professional commented "From my point of view I am happy with the referral rates, we are not seeing many children that are referring on the screening that don't have some issue to resolve – we have seen a couple of little ones that have been treated for significant middle ear".

### ***Single AABR protocol***

Professionals indicated that the use of single AABR protocol been useful in reducing the time taken from detection to diagnosis. They feel that this has had a positive impact on parents' anxiety levels.

### **Follow-up of Abnormal Screening Results**

#### ***Managing clients through the screening pathway***

Most screeners indicated that they offered to arrange follow-up appointments for babies screened who have been identified for further diagnostic assessment.

According to families, the wait time for further audiological testing at TSH after initial screening with WISH was an average of 7.6 days. All parents indicated that they would have been very distressed had their appointment been delayed any longer. They used the terms “frustrated”, “stressed” and “anxious” to describe how they would have felt should this have occurred. TSH professionals also recognised the importance of minimum wait time, which they considered to be a significant quality of the WISH Program.

### **Diagnostic Assessment**

#### ***Delivery of audiological services***

All families stated they were happy with the TSH audiological staff describing them as “friendly”, “compassionate”, “helpful” and “understanding”.

#### ***Diagnostic ABR***

Professionals felt they had seen an improvement in staff skill in performing diagnostic ABR although they would like the time taken for these assessments reduced. They felt that this would be most likely to be further reduced through technological improvements. Families also found that the two hours taken to assess babies was too long and requested faster machines. A family recommended a breastfeeding pillow during this assessment period to help support the weight of the baby (see Appendix N).

### **Early Intervention, Management and Counselling Service**

#### ***Support for families***

TSH professionals expressed their satisfaction with the support services they provided to families during diagnosis. One professional explained “I am quite satisfied with the counselling service which is implemented while the families are in the sound booth during the actual diagnostic assessment (once hearing loss has been established). This means the parents can ask questions as the process is underway, they are under no pressure to talk, there can be long periods of silence but there is information

available regarding the baby's educational future on hand. Support is offered to the parents and they leave feeling more prepared for the path ahead". Families reported that the TSH staff and their services were supportive of their needs although one recommendation included a request for more privacy when being advised of results. Overall a typical comment from families regarding the support provided was "Very compassionate and understanding in a difficult situation".

All families who attend early intervention at TSH indicated that they were informed of their options. Their reasons for deciding to enroll at TSH included ready access to a range of expertise, caring staff, "atmosphere", "location" and "comfort level". Families also noted that TSH provided them with the opportunity to meet and talk with other parents who were sharing similar experiences.

Professionals felt that having a cohesive team of dedicated staff available for parents (e.g. Audiologists, Early Intervention Coordinator, Psychologist, Teachers of the Deaf, Speech Pathologists and Occupational Therapists) greatly enhanced support to families at this time. As one professional explained "... the family can hopefully have most questions that they pose answered by a specialist in the field and have most budding issues prevented or dealt with promptly to provide the child the best chance to reach their potential".

### ***Counselling Service***

TSH professionals strongly supported the provision of counselling services, noting parents' need for emotional support during time of diagnosis and the provision of a "range of coping strategies". Four out of five families who responded to the questionnaire indicated that they were aware of the counselling service and supported the need for it if required. One of these families used this service five months after diagnosis and reported that the service met their needs. Parents felt that some of their queries were already being addressed in fortnightly sessions provided by TSH, but additionally felt a "compulsory counselling appointment early on" could be beneficial.

### ***Management***

There was one recommendation by a TSH professional relating to management of services, which suggested having the TSH Audiology Department managed on a full time basis.

### **Co-ordination, Monitoring and Evaluation of the Program**

### ***Monitoring of Programs***

According to TSH professionals, the TSH early intervention and counselling service is continually monitored through self evaluation and family feedback forms to “ensure it is the most supportive but professional service that it could be. The team is constantly together discussing the intake, Individual Family Service Plans, playgroup and kindergarten learning areas, parent education and orientation/transition processes to tweak and improve it at any and every stage”.

### ***Data management***

Four of the six TSH professionals who responded raised concerns over the collection and recording of WISH data. Recommendations were made by these staff to improve the current system to enable improved tracking of data through an enhanced database system and the practice of ongoing data entry.

### ***Feedback to screeners***

Screeners were unanimous in their request to be provided with feedback relating to babies who they had referred on for further assessment. They felt this would help with their interaction with parents who often sought statistical information on detection rates of babies referred. One out of five screeners had received feedback and they commented “It is always great to receive feedback about children who have been diagnosed with a hearing loss and to hear how well they are doing and the difference it has made to their lives”. Professionals at TSH also expressed their viewpoint that screeners should be receiving on-going statistical feedback on babies they have assessed.

### **Public and Professional Education**

#### ***Public education***

Parents expressed that they would like to be better informed of the WISH services before meeting the screener and noted that there was a need for improved promotion of the service. A typical comment was “Didn't seem to be promoted very much at (our hospital) – was mentioned once at booking in visit, not on ward”. Screeners would also like to see parents receive more information on the WISH Program, and the benefits of early detection of hearing loss, before visiting them in their hospital rooms.

#### ***TSH professional and parent education***

Two TSH professionals noted that the running of the WISH Program has resulted in a greater number of families joining the TSH early intervention program with younger

babies. To accommodate this, a baby playgroup was set up with staff required to up skill in working with babies. TSH also recognised the need for, and provided for, parental support and education. "Since the WISH program began the parents have been enrolling earlier in their child's life and therefore have different needs to parents of older children. With this in mind the 'baby playgroup' now has an even more important focus on parent-parent support, and parent education." Another professional noted that additional funds would help improve services to families as it would allow for more professional development and training for staff. It would also allow for more staff to work on special projects, research and/or development.

## **DISCUSSION AND RECOMMENDATIONS**

The aim of this study was to examine the WISH Program from the perspectives of parents, newborn hearing screeners and professionals from TSH, who have been involved in the WISH Program; and to identify the aspects of the program which they support, as well as those that they feel require improvements. Findings of this research may be useful in optimizing the quality of service offered to families by the WISH Program.

At present, universal newborn hearing screening has commenced or is being implemented by all states and territories in Australia, except WA (McMahon, 2007). In the event that the Western Australian Government implements state-wide funding for newborn hearing screening, results from this research project may be useful.

### **Recruitment and Newborn Hearing Screening**

#### ***Continuation and expansion of service***

A major recommendation is to continue efforts for a state wide newborn screening program to be implemented in WA, with WISH to continue providing for the private sector at no cost to parents. According to the majority of families, screeners and professionals at TSH families would be more likely to have their babies screened for hearing if they were not charged for the service. The WISH Program currently records an uptake of 60% (N. Davies, TSH, Personal communication, May 29, 2007). This is significantly less than the figures recorded by the Bailey, et al. (2002) study which reported 99.6% parental acceptance during a pilot program in Perth, WA, which was free of charge to parents.

#### ***Satisfaction of service***

Most families and professionals indicated they were satisfied with WISH Program screening services. This reflects the findings of the English evaluation of NHSP which

also identified a high level of satisfaction in the screening practice (Young & Tattersall, 2005).

### ***Screening environment***

The screeners in this study all supported the use of the mother's room for screening because the majority of mothers had a room to themselves. However, in some private and most public hospitals, women are in a shared room which raises privacy issues. In these situations it would be advised to remove the parents and the baby to a room where they could experience the hearing screen in private. Bamford et al. (2004) found that parents in England wanted to be involved in the NHSP testing procedures. WISH screeners reported that by screening in the privacy of the mother's room the parents are able to watch, experience and assist in the screen. This finding suggests we should encourage screeners to continue parental involvement when conducting their screens.

### ***Family counselling***

Screeners felt parents expressed anxiety when their baby needed to be referred for further diagnostic assessment. Provision of adequate support and counselling for these parents, while still in hospital, needs to be addressed further.

### ***Screener communication***

As noted in the Bamford et al. (2004) study, checking the parents understanding of what the screen result implies, rather than simply providing a reassuring message is crucial. A parent commented that they received "false hope" from a screener when their baby had been referred and was later "devastated" when their child was diagnosed with hearing loss. By not advising parents that their baby may have been referred because it could have a hearing loss, prevents them from preparing for possible diagnosis but also avoids unnecessary alarm (Young & Tattersall, 2005). Comments from screeners are interpreted differently by different families. This highlights the importance of ensuring consistent terminology and explanations from screeners which, according to N. Davies, TSH, (Personal communication, 29<sup>th</sup> May, 2007) WISH newborn hearing screeners are trained to use.

### ***Screener employment conditions and support***

Attention is required in the area of WISH screener employment conditions. The screeners raised various concerns regarding wages and conditions and these need to be addressed to ensure staff satisfaction. This reinforces the recommendation for regular meetings with the Newborn Hearing Screening Coordinator and their screeners

to provide an opportunity to discuss these issues. Participation by the TSH CEO may be required to clarify the concerns raised (i.e. public holiday pay, claiming of hours, and provision of mobile phones).

The majority of screeners would like to have a form of support provided especially to debrief after they have referred parents for follow-up diagnostic testing. It appears from their comments that regular meetings with the Newborn Hearing Screening Coordinator and other screeners may assist in this process. The provision of a contact name and number for screeners would also be advised should they need further support.

Considering the importance parents place on a screener's personality and confidence (Young & Tattersall, 2005) a recommendation would be to ensure provision of day's professional training with a psychologist for all screeners. This session could address screeners' concerns on "how to talk with parents when the second screen is a refer".

### **Follow-up of Abnormal Screening Results**

#### ***Managing clients through the screening pathway***

If babies refer twice on the hearing test, most screeners explained that they asked parents if they could arrange a follow-up appointment for them. Provision of a follow-up appointment date and time before discharge, was seen by parents in England as a way of improving NHSP services (Bamford et al., 2004). It would therefore be recommended for screeners to continue with this procedure.

Parents and professionals stressed the need to have as short a wait time as possible between the referral and diagnostic assessment. This reflects the review of the VIHSP (2004) which identified that delays between initial hearing screening and diagnosis resulted in the parents having feelings of "helplessness" and "anxiety". The evaluation of the NHSP in England (2004) recommended providing a waiting time of no more than four weeks for follow-up. Families utilising the WISH Program and TSH audiological services identified an average wait time of one week and therefore had their needs met with regard to a short waiting period. Ensuring an adequate referral system for the management of abnormalities is a key component of the WHO organised approach to screening (Strong et al., 2005).

### **Early Intervention, Management and Counselling Service**

#### ***Support for families***

The evaluation of the Victorian and English infant hearing screening programs have



both stressed the importance of providing good parental support and communicating effectively with parents, particularly at the time of diagnosis of hearing loss ( Russ et al., 2004, Bamford et al., 2004). Participants utilising the WISH Program found the early intervention and counselling staff highly supportive. However it is noted that although several parents were aware of the availability of the counselling service, they did not utilize the service and suggested for a counselling session to be organised early in the diagnosis period. It is therefore recommended, that an appointment with a counsellor be offered at the time of diagnosis.

### **Co-ordination, Monitoring and Evaluation of the Program**

#### ***Data management***

A system to collect and record WISH data on an on-going basis is recommended. WHO recommends that the components of an organised approach to screening includes the maintenance of program data in order to regularly monitor and evaluate of a population screening program (Strong et al., 2005). Furthermore, the VIHSP evaluation suggested that electronic case tracking was required to avoid children becoming “lost in the system” (Russ et al., 2004).

#### ***Feedback to screeners***

Screeners requested that they be provided with feedback regarding the babies they refer for further audiological testing as they believe this would improve their understanding and satisfaction in the workplace.

### **Public and Professional Education**

Public and professional education is acknowledged by WHO as a key component of a screening program (J. Straton, WA Department of Health, Personal communication, June 12, 2007).

#### ***Screeners***

Screeners who received on the job training by an experienced screener as well as a one day training session with an audiologist appeared satisfied. Therefore, it would be recommended to continue this training with all new screeners. Professional development for WISH screeners is currently held three to four times a year (Personal communication, J. Klass, TSH, October 15, 2007), however, four participants in the study requested extra training for screeners on an on-going basis. It would therefore be advised to provide on-going professional development for screeners as well as creating a “screener file” containing the information they suggested (e.g. job description, daily

procedures, running of equipment, list of contacts, FAQs and answers for parents and sample dialogue of what screeners should say when further audiological testing is required).

### ***Health Professionals***

Improved education, for midwives, obstetricians, paediatricians and hospital staff, on the benefits of early detection of hearing loss, was suggested as a positive approach in gaining professional support of the WISH Program. By making hospital professionals and staff more aware of the benefits of early detection of hearing loss it is more likely that they will promote hearing screening to parents.

### ***Public***

Educating parents during ante-natal classes was also seen as a way of assisting parents to make an informed decision on having their child screened for hearing.

### ***TSH Professionals***

Given that the WISH Program has facilitated the diagnosis of hearing loss in children at an earlier age, TSH have subsequently provided professional development to ensure their staff are adequately skilled in working with babies.

It is recommended that public and professional education be an integral component of the WISH Program or any screening program that is developed within WA.

## **CONCLUSION**

Researchers have clearly demonstrated that identification of hearing loss in newborns enables timely access to early intervention and amplification, and subsequent improved outcomes in their speech and language (Davis et al., 1997, Yoshinaga-Itano et al., 1998, Yoshinaga-Itano, 2004). Universal newborn hearing screening services are well accepted overseas and are gradually being implemented throughout Australia. It is envisaged that information from this study may assist to improve the services offered by the WISH Program, as well as provide recommendations in the event that a state-wide newborn hearing screening program is implemented in Western Australia.

This study has shown that overall families and staff involved in the WISH Program were satisfied with the screening, audiological, early intervention and counselling services provided by the WISH Program and TSH. Recommendations have been made to improve services, as well as continuing the quality of services being offered.

The main recommendations resulting from this study included:

- Continuing efforts to implement a state-wide newborn hearing screening program in WA, with continuation of the WISH Program for the private sector at no cost to parents
- Investigating ways of providing support for parents in hospital when their babies are referred for further audiological assessment
- Ensuring screeners provide information to parents that is consistent and clearly states what the screen implies
- Arranging regular on-going meetings for WISH screeners to discuss employment conditions and as a means of guidance and support
- Supplying screeners with feedback regarding the babies they referred for further diagnostic assessment
- Creating a “screener file” containing relevant information such as a job description, daily procedures, running of equipment, a list of contacts, FAQs and answers for parents and a sample dialogue of what screeners should say when further audiological testing is required
- Offering to organise an appointment with a counsellor for all families at the time of diagnosis of hearing loss
- Maintaining a data system to monitor and evaluate the WISH screening service on a regular basis
- Promoting the WISH Program by providing improved education to midwives, obstetricians, paediatricians and hospital staff
- Informing parents of the WISH Program and the benefits of early detection of hearing loss during ante-natal classes
- Providing WISH screeners with regular on-going training

It is also recommended that the following services continue:

- Screening of babies hearing in the mother's room and involving the parents in the screening procedure
- Using single AABR protocol
- Training screeners on the job with an experienced screener as well as providing them with a one day training session with an audiologist
- Offering parents in hospital a follow-up appointment date and time before discharge
- Providing short waiting times between referral and diagnostic assessment

- Supporting families with a dedicated team of professionals and opportunities to meet and talk with other parents sharing similar experiences
- Monitoring and evaluating the audiology, early intervention and counselling services at TSH on an on-going basis to ensure the most supportive and professional service
- Providing TSH staff with on-going professional development to ensure their skills are continually updated

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