

Family and parenting implications of newborn screening Gene Reardon and Sharon Ewing


Abstract

For over a decade, Yoshinaga-Itano and colleagues (1998, 2003) have argued that infants whose hearing loss was identified before the age of six months have stronger expressive language and comprehension than those who were diagnosed after 18 months of age. This research has been widely used to support the earliest possible identification of hearing loss through implementation of newborn screening tests. In response, programs of newborn hearing screening are being implemented across both the developed and developing world. However, there has been no comprehensive social research in Australia exploring the family impacts of newborn hearing screening from the perspective of parents as consumers. Research suggests that families with strong social networks with other parents of deaf children 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).

Introduction: Context for discussion paper

In this discussion paper we recognise the importance of newborn hearing screening in terms of its potential positive impact on life long options for children who are born deaf. We suggest that to adequately support families, and to secure optimal outcomes for children, we need to create a robust information and support system for families from the time of diagnosis.

Context: Australia

 Deaf Children Australia

Newborn Hearing Screening

- Currently 83% of newborns are screened for hearing loss
- Infrastructure work is nearly completed
- Observable and reported large variations in parental responses
- Time for a family centred response

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Australia is in the process of introducing universal newborn hearing screening programs, and nationwide we are currently screening 83% of our newborn population.¹ Health policy makers have given special attention to screening protocols, for example screening instruments, audiology testing methodologies and health workforce issues. This has all been essential foundation work for the introduction of newborn hearing screening programs in Australia.

¹ Professor Greg Leigh, Chair, Renwick Centre/Conjoint Professor of Education, University of Newcastle, Royal Institute Deaf Blind Children Australia 2009

However, qualitative evidence would suggest that policy makers also need to be informed of families' experience of newborn hearing screening in order to help provide a holistic, family-centred approach. That is an approach that addresses the social, emotional, and developmental needs of the child in the family as well as addressing the audiological implications of hearing loss.

Since the introduction of newborn hearing screening programs, Deaf Children Australia has received anecdotal evidence from parents about their experiences. Stories from parents demonstrate large variations in the quality of information received at the point of diagnosis and the quality of support services offered post diagnosis.

In Australia the challenge is to ensure that during and post screening, parents are not left without support. To “screen and leave” has potential to harm the family wellbeing and therefore the future potential and wellbeing of the deaf child.

We believe that understanding the views of parents and families, and learning from people who have “lived the life of deafness”, is critical to designing a good family support system. In developing a responsive service system we also believe there are benefits to be gained from understanding childhood deafness from a “family systems” perspective.

Aims of Discussion Paper

This paper aims to examine the range of family support services that have the potential to best position the child and family to enjoy a good quality of life. We will do this through an exploration of information we have from Australian families about their needs, and also through a review recent literature that examines childhood deafness from a family systems perspective.

Discussion Overview



During the next 25 minutes we will :

- Explore: qualitative information from families
- Discuss family systems perspectives as a framework for understanding the support services required
- Suggest implications for improving the service response to families, to secure long term wellbeing of the developing child and the family.

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We adopt a family systems perspective, because we recognise that the birth of a child into the family has an impact on the whole family and the family's community. There are usually diverse emotions, physical, intellectual and spiritual challenges; there are new survival and communications skills to be learnt, the whole family system changes. For example changes in interaction patterns, in resources requirements, in the development of the parenting approach, and in the orientation to support the child. These changes happen in the nuclear family, the extended family, and the community of friends and neighbours into which the child is born.

This morning we have the opportunity to examine the challenges to the family system, when a baby is born with deafness. In particular we will examine what families tell us about their experiences, we will also explore the relationship between these reported experiences and indicators of the quality of family life. Following our exploration of this material we will suggest program ideas to improve the type of support offered within the service system. By improving the support offered within the newborn hearing screening service system, we hope to improve lifelong wellbeing opportunities for deaf children, and for their families.

The Australian Scene

But first let us begin by looking at qualitative information from Australian families about their experience of learning about their baby's deafness. We ask the questions: how do families describe their situation? What do they tell us about their family needs for information and support? What does this mean as we attempt to develop service systems in response to newborn hearing screening in Australia? What could it mean for the lifelong wellbeing of the developing child and their family's wellbeing?

Australia: Newborn hearing screening



- How do families describe their situation?
- What do families tell us about their support needs?
- What does this mean for the developing service system?
- What are the implications for the lifelong wellbeing of the child and the family?

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How do families describe their situation? Let's review parental reactions to news that their infant is deaf.

Mother; "We didn't know what was ahead of us, it seemed huge and we would need to climb this mountain together and face all of the stumbling blocks and enjoy all of the vistas it would throw in our way. I believed that we could embrace it together and to me there was no going back. I wanted to cherish every moment of our time together. I thought we would find out about the Deaf Community, their language, and their culture; totally uncharted waters for us" ²

² O'Brien D The Cochlear Implant, *Parents tell their story* 2002, published by Full Moon Press pg 33

Parents at Diagnosis

- Mother; “We didn’t know what was ahead of us, it seemed huge and we would need to climb this mountain together and face all of the stumbling blocks and enjoy all of the vistas it would throw in our way. I believed that we could embrace it together and to me there was no going back. I wanted to cherish every moment of our time together. I thought we would find out about the Deaf Community , their language , and their culture; totally uncharted waters for us”

(O'Brien; The Cochlear Implant 2002)

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One father, who heard the words “your son is deaf”, four weeks after their son was born, said “That was the frightening thing at the start. We had never really experienced it. Of course we had heard of it, but we hadn’t any experience of deafness before. You think you are bullet proof until it happens, but you are not and that is what took us back at the start.”³

Parents at Diagnosis

Four weeks after their son was born their lives changed. The parents heard the words “your son is deaf”.

The dad, says “That was the frightening thing at the start. We had never really experienced it. Of course we had heard of it, but we hadn’t any experience of deafness before. You think you are bullet proof until it happens, but you are not and that is what took us back at the start.”

(O'Brien; The Cochlear Implant 2002)

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The language of these parents is compelling. It suggests evidence of the degree to which family adjustment is required at the point of diagnosis. The words reflect dramatic new directions, for example “there was no going back”; “totally uncharted waters”; “we hadn’t any experience of deafness before”. There is also evidence of the emotional implications, for example the phrases, “we didn’t know what was ahead of us”. “That was the frightening

³ O’Brien D *Ibid* p78

thing". As we go through our presentation this morning we will observe the language of parents , and at the point of diagnosis it is common to find words that relate to shock , , devastation, fear, uncertainty , numbness, overwhelming, sadness, a sense of challenge, motivation and urgency. What we learn from this is the significant range of emotions that families may experience

Given that it is widely reported that parental anxiety and distress can impact on parent – infant bonding, a key question we have is, how can we alleviate this anxiety through our systemic approach to newborn hearing screening? How can we give deaf children the best start?

In 2005 Deaf Children Australia decided to explore these emerging stories, and we developed a survey that questioned the attitudes and opinions of parents in relation to the quality of **information** received at the time of diagnosis. The survey also asked about the **support** received both at diagnosis and during the 6 months following a diagnosis of deafness. Importantly, the survey also asked parents for **their views** on elements that they would like to see included in the **systemic design of newborn hearing** screening programs.

Surveyed families were asked to complete 28 questions, which were divided into 4 sections.

Part A: asked for background information on the family/baby.

Part B: explored the parent's experience of support and information received at diagnosis.

Part C: examined the parent's views on the type and usefulness of the support received.

Part D: explored parent ideas on ways to improve the system.

The results of this survey enable us to discuss in more detail the experience of parents at diagnosis and beyond diagnosis. We must remember that in 2005 there was mixed implementation of newborn hearing screening practices across Australia. Some States performing screening for at risk infants only, others on the way to implementing universal screening and at least one State and one Territory not committed.

Deaf Children Australia 2005 Survey



- Mixed implementation of screening programs
- 45 parents/ 52 babies participated
- Survey in 4 parts:
 - Part A: background
 - Part B: diagnosis process and information
 - Part C: Support Received
 - Part D: Looking to the future
- 8 Families through NHS
- Observed that 4 years on similar stories continue

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Forty - five parents participated in the survey, representing 52 babies or children. The age of diagnosis of the babies surveyed was from birth to 3 ½ years with an average age of diagnosis of 17.8 months.

The survey demonstrated that while a number of parents reported positive experiences, some reported an absence of any clear, unbiased information or guidance from professionals. Indeed, some parents reported ongoing and unresolved grief as part of their experience. Some felt “dumped” by the system, while others were concerned that the domination of the medical model of deafness had impacted on their early interactions with their child.

For the purpose of the presentation today we have re-examined the forty five survey returns, and extracted information from those files that identified that the parent had been through the newborn hearing screening system. There were eight families identified using this criteria.

Most parents reported to Deaf Children Australia a need to have more information than the professional voice. Audiological information was seen as very important, however in addition they would have liked the opportunity to inform themselves through learning about other parents’ experiences, and also through meeting with adult people who had successfully lived a life of deafness. Some parents also reported a high level of anxiety that impeded their capacity to seek information or support.

This is how parents describe their reaction to diagnosis:

Parents describe their first reaction

- P1: Deep shock immobilised with fear for days
- P2: After everything we had been through it was the straw that broke the camels back.
- P3: Shock and sadness
- P4: Being Deaf myself I was okay about it but I knew we would face many challenges
- P5: Shock horror fear sadness & devastation.
- P6: Even though I knew hearing loss was possible I was still saddened and disappointed
- P7: No reaction since we have got many deaf relatives
- P8: Overwhelmed

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The following slide tells us what parents said about the relevance of information provided at diagnosis:

What did parents tell us about their need for support

Information:

- 50% said the information provided at diagnosis was not relevant
- 25% reported it was somewhat relevant
- 12.5% reported it as all relevant

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Parents answered a question about whether anything was said to them during newborn hearing screening diagnosis that was unhelpful. Fifty percent reported a yes answer to this question.

Support needs contd


Was anything said that was unhelpful?

- Yes : " at newborn hearing screening staff attitudes about methods
- Yes: " You've just been told your child's not normal its OK to be sad"
- Yes: " Not to worry too much as deaf people today are not like deaf people of the past"
- Yes..." I was given no support, I was given The Choices booklet and told to go home and read it"

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Parents were asked what they would have liked within a month of diagnosis

Parents report on what they would have liked.



What support would you have liked within a month of diagnosis?


- 100% reported they would like a parent mentor
- 87.5% reported they would have liked a parent support group
- 62.5% reported they would have benefitted from meeting adult Deaf or hard of hearing people

In addition 50% reported family and friends were their greatest supports

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Parents were asked about other support needs, and this is what they reported:

Other comments on support needs




In addition to the perceived positive benefits of meeting adult Deaf people and other parents, the parents reported that:

They would have liked more information about early intervention, communication approaches, and audiology. There were also comments about the need for quality and unbiased information, and that they would have liked someone to guide them through this.

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Parents were asked to consider the first month after diagnosis and responded to the question “if you were able to design a new support system for parents what would you recommend?”, They answered as follows:

Parent System Design Ideas



Consider the first month after diagnosis if you were able to design a new support system for parents what would you recommend?

- P1 Telephone counselling and home visitation by an experienced parent, a resource booklet. Need reassurance that deaf and hard of hearing children can grow up to be happy and successful adults
- P2 Connecting new parents with parents of older deaf kids, who can empathise with what they (the new Parents) are going through.
- P3 Contact with deaf people to see that my son could live a normal happy life Contact with parents of hearing children- especially hearing parents
- P4 An advisor to give out information on different options and guidance. An advocate who has experience themselves and does not provide biased options. Funding for child care and a communication aid ongoing

Parent System Design Ideas (cont'd)



Consider the first month after diagnosis if you were able to design a new support system for parents what would you recommend?

- P5 Contact with early intervention professionals and Deaf adults living normal lives.
- P6 Definitely contact with other parents who have been down the same road already- maybe with a similar loss: the need for early intervention without any bias.
- P7 Would love to have a parent support group when my kids were born. There wasn't a parent support group at that time.
- P8: New parents with old parents -discuss how to deal with deaf child and other issues. Contacts with other parents are more important so they can share the grief and understanding on what we need for our deaf children. E.g. Coffee once or twice a week to support each other. Parent mentor.

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Table1 summarises the parent responses to selected questions.

TABLE 1					
Deaf Children Australia: Parent Responses to survey questions on newborn hearing screening experiences 2005					
What was your first reaction?	How relevant was the information?	What information was most helpful?	What additional information do you believe would have assisted you?	Who did you receive support from at the time of diagnosis?	Who did you receive support from in the first two weeks?
Deep shock immobilised with fear for days	Not relevant at all	A friend told me about a little deaf boy she knew at school who was doing quite well speaking etc	Talking to other parents and seeing their children	No one: I was given the choices booklet and go home to read it	Friends
After everything we had been through it was the straw that broke the camels back.	All I know is that we were distraught and the situation was not handled with any sensitivity what so ever	There was no information	No answer	No answer	Friends
Shock and sadness	All Relevant	Information about further testing by AHS	No answer	Family	Family
Being Deaf myself I was okay about it but I knew we would face many challenges	Somewhat Relevant:	The choices booklet	No answer	Geneticist; audiologist	No one
Shock horror fear	" no information was received"	" I received no information"	Early intervention options	No one except family members rated high , the level of support from the audiologist was rated low	No one except family members rated high , the level of support from the audiologist was rated low
Sadness & devastation. Even though I knew hearing loss was possible I was still saddened and disappointed	Somewhat relevant	The need to establish contact with AHS at that stage I thought early intervention was probably an option that I wouldn't need.	At the initial consultation I had to cope with the complete shock that my child had a hearing loss as well as the information given to me. Needless to say only half of what I was told was able to be digested. One reference point at that stage would have been sufficient.	Family and friends & shortly after diagnosis the Early intervention professionals	Family, audiologist, early intervention professionals, maternal health nurse.
No reaction since we have got many deaf relieves	Not answered	To be given the names of the early intervention services	More information on early intervention and communication modes.	Early intervention service provider	My husband and his family
Overwhelmed	Not relevant	"that you are not alone"	Someone to talk to about choice of service that was non-biased.	Friends and family	Child Health Worker

Consider the first month after diagnosis if you were able to design a new support system for parents what would you recommend?	Who would you want to deliver the information?	What information do you think is relevant at diagnosis?	What information do you think can wait until later?(for example 6 months)	If there was a parent to parent support network offered would you access it?	Would you be interested to train as apparent mentor?
Telephone counselling and home visitation by an experienced parent, a resource booklet. Need reassurance that deaf and hard of hearing children can grow up to be happy and successful adults	Audiologist and social worker	1. what its like to grow up deaf / hard of hearing 2. Information about early intervention, 3.support and counselling services,	Communication approaches	Yes	Yes
Connecting new parents with parents of older deaf kids, who can empathise with what they (the new Parents) are going through.	I think it is important that medical staff & students who are doing the testing are trained in how to deliver bad news (i.e. the news that your child is deaf) in a sensitive and empathic way. Maybe it could be done in a meeting with other health professionals, But a casual "oh by the way your child's deaf" was not empathic....	Support counselling services early intervention professionals	No answer	yes	No answer
Contact with deaf people to see that my son could live a normal happy life Contact with parents of hearing children- especially hearing parents	Audiologist	Audiology centres, Early intervention services, support and counselling services, what its like to grow up deaf, communication approaches	Genetic counselling, respite care	Yes	yes
An advisor to give out information on different options and guidance An advocate who ahs experience themselves and does not provide biased options. Funding for child care and a communication aid ongoing.	Audiologist and social worker	Early intervention services, support and counselling services, communication approaches	Cochlear implants, genetic counselling, respite care.	Yes	yes
Contact with	Not answered	Support and	Cochlear	yes	yes


early intervention professionals and Deaf adults living normal lives		counselling services/ Early intervention /Education centres	implants, hearing aids, genetic counselling, respite care, what its like to grow up deaf		
Definitely contact with other parents who have been down the same road already-maybe with a similar loss: the need for early intervention without any bias.	Good question in my case I had no previous or further contact with the audiologists giving me the diagnosis so in retrospect it was fairly clinical. Whilst it needed to be someone with knowledge about the loss it would be beneficial to follow though with that person for a period of time.	Audiology services and support and counselling services. At the actual time of diagnosis any more would go in one ear and out the other!	Genetic counselling	Yes	yes
Would love to have a parent support group when my kids were born. There wasn't apparent support group at that time. New parents with old parents -discuss how to deal with deaf child and other issues. Contacts with other parents are more important so they can share the grief and understanding on what we need for our deaf children. Eg Coffee once or twice a week to support each other.	I would like to self diagnose.	Early intervention/ Support and counselling information	Genetic counselling respite care	Yes	yes
Parent mentor	Doctor, audiologist	Audiology, early intervention, support &counselling services ,communication approaches hearing aids, what its like to grow up deaf or hard of hearing	Genetic Counselling Cochlear implants	yes	yes

To summarise the key findings from the tables above, we note:

1. It is clear that a range of emotions emerge at the point of diagnosis, many relate to fear, sadness and not knowing what the future holds.
2. 12.5% found the information at diagnosis completely relevant. 50% said the information was not relevant.
3. Parents reported they thought it would have been useful to have information about other parents, to have someone to talk to about choices, or information about early intervention, support and communication options. Most thought that information on respite or genetic counselling could wait until post 6 months.
4. 50% reported that family and friends were their greatest support at diagnosis.
5. If given the chance to develop the service system, 87.5% recommended opportunities contact & support from other parents to be available within one month of diagnosis.
6. 62.5% said they would like to have the opportunity to meet a Deaf or Hard of Hearing adult.
7. 100% said they would like a parent mentor, and
8. 100% said they also be willing to be trained as a mentor.

We observed in these parents a majority expression/view to: build in better quality information systems, more highly trained professionals in the art of communication, create opportunities for parent to parent contact and support; and a desire to meet with adult deaf role models.

These ideas are summarised below.

Summary of Views 

The strong themes from this group of parents appear to be:

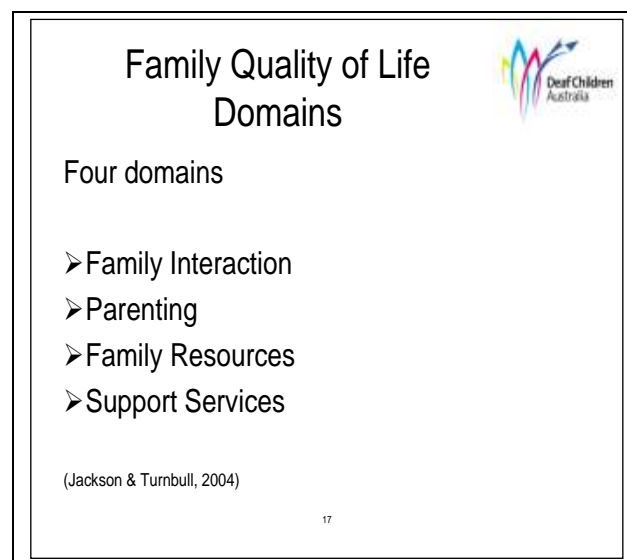
- That there is room for improvement in the content and delivery of information
- To provide opportunities for parent to parent support
- To have the opportunity for parent mentoring
- To provide opportunities to meet adult Deaf people

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Family Systems Perspective

In advancing our system design in Australia, it is essential to consider research into how the family responds to deafness. We have started to look at this through the qualitative survey results presented thus far, we would now like to turn our attention to the understanding of these issues through the exploration of a family systems perspective on deafness.

A comprehensive review of the literature by Jackson and Turnbull in 2004 described the potential impact of deafness across four areas, or domains, of family life. The four domains are family interactions, family resources, parenting and support services.



It is the interaction of these domains that influences the overall **quality of life for families**, a concept which attempts to describe the extent to which family member's needs are met, the extent to which they enjoy their time together as a family and the extent to which they can do things that are important to them.

After examining some key messages from family experiences and reviewing the literature regarding the four domains of family quality of life used by Turnbull and Jackson, we will discuss the implications for improving and enhancing family supports and services as part of a *family systems* approach to newborn hearing screening.

We have already summarised some Australian family experiences from the Deaf Children Australia survey of 2005. We will also be drawing from the "Face to Face" report, a


consultation by Helen Spork conducted in 2006 on behalf of the Queensland Health, Healthy Hearing Program. In developing the *Face to Face* report, a total of 19 parents of deaf and hard of hearing children from varied backgrounds and various ages ranging from 1-21 years old, were involved in focus group consultations and semi-structured personal interviews. Issues, patterns and themes were identified using qualitative thematic analysis.

We wish to acknowledge here that the majority of parents who participated in the Face to Face report did not experience Qld Health's newborn hearing screening program as it currently exists. Positive service and organisational changes informed by the Face to Face report, have occurred since 2006. Queensland Health continues to refine and progress service delivery in close consultation with families and key stakeholders. It appears that good progress is being made in Queensland, and other States are also developing initiatives. However there remains little consistency across Australia in the level and type of support offered to families post screening, and so there remains considerable room for improvement.

So let's look at the domains of family life and consider how they can inform us of the type of supports needed to ensure the life long wellbeing for deaf children.

1) Family Interaction

The domain of "family interaction" encompasses such aspects as the family's ability to solve problems together, to communicate openly, enjoy time together and have good relationships with extended family members (Jackson and Turnbull 2004). For the purposes of this presentation, we will explore family problem solving and decision making.

 Deaf Children Australia

Domain 1: Family Interaction

This domain includes:

- The family's ability to solve problems together
- To communicate openly
- To enjoy time together, and
- To have good relationships with family and friends.


(Jackson & Turnbull 2004)

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Family problem solving/decision making:

Calderon and Greenberg (1999) reported that families of children who are deaf experience increased stress associated with making difficult decisions and choices. The implementation of Newborn Hearing Screening now means that parents are confronted with the challenge of making decisions about communication methods, the use of sensory devices, medical procedures, health and early intervention providers, location and type of services, much earlier than in the past, and often with limited information about the expected outcomes for their infant. Gene has previously discussed parental reactions and this demonstrated that many parents are making these decisions during a period in which they are required to make significant emotional adjustment to their child's diagnosis.

Research indicates that families may experience increased conflict during decision making due to different views, priorities and preferences with the resulting stress affecting family interactions (Freeman, Dieterich and Rak, 2002; Jackson, Traub and Turnbull, 2008). For some parents, their common concern brings them closer together, whilst for others, the stress and conflict causes the relationship to deteriorate (Kayshap, 1986).



Problem solving

Family problem solving may be impacted by the new unanticipated challenges that are placed on the family. This can result in:

- **Increased stress**
- **Increased conflict or tension**
- **Variable impact on the marital relationship**

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The literature also indicates that many families of deaf children feel that they did not have sufficient resources to make decisions (Eleweke & Rodda, 2000; Prendergast, Lartz and Fiedler, 2002), and that their stress and uncertainty in decision making may be amplified by the controversies surrounding methods of communication and education (Calderon, Bargones

& Sidman 1998). This is supported by the findings of surveys and consultations with Australian families.


The Face to Face consultation indicated that parents consider a very broad range of factors when making decisions about intervention centres and communication options. Furthermore the process of having to make choices is indeed often stressful and complicated by inadequate information. A general finding was that parents found their experiences of accessing and receiving information “problematic and exhausting”. The report indicated that “information needs of families are very individual” and that “specific information may be needed but is not easily accessed, can be misleading, too late in coming or fragmented between systems.” (Face to Face Report 2006 pg15)

Yoshinaga-Itano, 2009, reported that having immediate contact with a professional who is knowledgeable about

- hearing loss,
- screening,
- identification and amplification,
- intervention choices and
- outcomes data,
- grief counselling, and
- trained in parent-child interaction,

assists parents with the resolution of grief an important task for successful adjustment of both family and child.

Improving the system: problem solving



Yoshinaga – Itano 2009 reported that immediate and easy contact with a professional who is knowledgeable about:

- Hearing loss
- Screening
- Identification and amplification
- Intervention choices,
- Outcomes data,
- Counselling, and trained in parent – child interaction

****Yoshinaga-Itano 2009 Queensland workshop *Beyond Newborn Hearing Screening*

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Parents in the Face to Face consultation also indicated a great desire to have the option of access to a support professional from the time of diagnosis, for

- Emotional support and counselling
- Timely and sensitive provision of information, advice, referrals and networking
- Assistance with planning, phone calls, research and information and
- Accompanying them to interviews and visits to intervention centres

(Face to Face report, 2006, pg14)

Whilst parents were open to receiving information in different forms – such as in written or audio visual formats, their preferred way of receiving and processing information was through TALKING to PEOPLE. They wanted professionals to talk through all information “objectively, plainly and openly, with a commitment to a through presentation of all perspectives and options” (Face to Face, 2006, p 16).

From this we can conclude that a following diagnosis of hearing loss many families face a stressful period that requires problem solving and decision making, which can impact negatively on their marital relationship. During this period, there is a significant need to have a knowledgeable professional to support the family as well as talk through the vast amount of information that they need to understand in order to make decisions.

2) Parenting

Another area of family life that research indicates is challenged is how to effectively parent the deaf child. This domain of parenting, as defined by Park et al 2003, describes the activities which adult family members engage in to help children grow and develop in multiple areas of life. This domain involves aspects such as knowing how children learn best, having time to meet the needs of all family members, and having information needed to make decisions (Jackson and Turnbull 2004)

Domain 2: Parenting

This domain involves aspects such as:

- The Parent understanding how children learn best,
- Parents having time to meet the needs of all family members, and
- Parents having information needed to make decisions

(Jackson & Turnbull 2004)..

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All new parents rely on role models of parenting they have seen within their own circle of family and friends. If those models do not represent parenting a deaf child, and in almost all instances they do not, parents may have no knowledge base from which to proceed.

Bodner - Johnson 2001 commented that “being a mother or father of a deaf child means assuming a new role and a new set of responsibilities, a role they had not anticipated and for which they probably have had little preparation”.


As a result of this, parents often experience uncertainty about their parenting skills and competence (Freeman, Deiterich and Rak 2002).

Research indicates that parents can gain a much better understanding of their situation through connecting with other parents of deaf children, (e.g. Nunes, Pretzlik & Ilicak, 2005; Turnbull et al, 2008) as well as deaf adults (e.g. Hintemair, 2000; Watkins, Pitman and

Walden, 1998), and that such interaction provides them with role models as they discover their lives as parents and families with a deaf child.

Research by Hintemair (2000) investigating the stress experiences of 317 parents with hearing impaired children, indicates that the positive impacts of parents having social contact with other parents included reduced feelings of isolation, greater acceptance of their child, and improved responsiveness in parent-child interactions. The parent-child relationship of parents who had frequent contact with other parents was described as warm, accepting and trusting.

Improving the system: enriched parenting ..(1)

Deaf Children Australia

Hintemair reported positive impacts of parents having social contact with other parents, including


- reduced feelings of isolation,
- greater acceptance of their child, and
- improved responsiveness in parent-child interactions.

The parent-child relationship of parents who had frequent contact with other parents was described as warm, accepting and trusting.

(Hintemair 2000)

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In addition to finding positive impacts of parent to parent contact, Hintemair's research found that parents who had contact with Deaf adults reported less depression, reduced isolation, increased acceptance of and improved interactional responsiveness to their child. The study found that parents who had many contacts with deaf or hearing impaired adults demonstrated a strong sense of competence in regard to their child's upbringing.



Improving the System: enriched parenting...(2)

In addition to finding positive impacts of parent to parent contact, Hintemair's research found that parents who had contact with deaf adults reported


- less depression,
- reduced isolation,
- increased acceptance of and improved interactional responsiveness to their child.

The study found that parents who had many contacts with deaf or hearing impaired adults demonstrated a strong sense of competence in regard to their child's upbringing (Hintemair 2000)

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Hintemair concluded that social support should be regarded as a cornerstone of psychosocial intervention.

This is supported by the Face to Face findings, which indicated that parents want and need ongoing sensitive support from the time of diagnosis, not only from case-support professionals, but from other "like" parents, including parents who are deaf. (Face to Face Report 2006, pg 55-57). Parents identified that they would like access to trained mentor/support parents in an official support role, as well as via other networks such as parent support groups. Parents also saw benefits in having the opportunity to talk to members of the Deaf community.



Summary : Parenting

Research would suggest that

- Parent to parent mentoring programs, and
- Opportunities to meet Deaf or Hard of hearing adults

Should form an important part of the services response, if we are to promote child and family wellbeing


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From this we can see that parenting confidence improves with access to role models. We can conclude that parents benefit from having support from "like" parents, including those who have specifically trained to be parent mentors, and that contact with deaf and hard of hearing

adults can be both beneficial and desired. We propose that a family systems approach to newborn hearing screening could embrace these aspects in order to improve outcomes for families and children.

3) Family Resources Requirements

The family quality of life domain of family resources includes indicators such as the family's access to information, social networks, and access to healthcare. (Jackson and Turnbull 2004) For the purposes of this discussion we will focus on the family's social networks.

 Deaf Children Australia

Domain 3: Family Resources

This domain includes indicators such as the family's

- access to information,
- social networks, and
- access to healthcare.

For the purposes of this discussion we will focus on the family's social networks.

(Jackson and Turnbull 2004)

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The degree to which family members feel supported by others may vary post newborn screening. Various studies have shown that families with deaf children often feel isolated because of stigmatization, social exclusion, and by rejection from family and friends (Gregory Bishop and Sheldon, 1995, Seligman and Darling 1997, Morton 2000). Social supports that were strong before the diagnosis may prove to be fragile afterwards. Even close friends and relatives may withdraw because they feel at a loss as to what to say or do. Extended family members have less access to informed professionals and services than the parents, (Luterman, 1987; Nybo, Scherman and Freeman 1998) and may therefore not be in a position to know how to be supportive and/or interact with the child. Worsening the situation is the need for medical and audiology appointments, therapy and other deafness related “issues” as this reduces the amount of time and energy available to devote to maintaining

relationships with friends and extended family. Gregory, et al 1995, found that one third of surveyed parents reported negative changes in their relationships with others when their child was diagnosed with deafness.

Yet social support is an important factor in family adjustment and coping, and this in turn affects the child's outcomes. Calderon & Greenberg, 1999 found that mothers who reported satisfaction with their social support were more likely to be better adjusted, regardless of the degree of life stress or severity of the child's hearing loss.

Parents who participated in the Face to Face consultation reported varying levels of understanding and acceptance from family, friends and the community, and that they experienced stigmatisation by society. (Face to face Report 2006 pg 92-93)

**Improving the System:
Family Resources**



The Face To Face consultation indicates that parents do indeed see value in forming connections and relations partially for reasons of social inclusion and social experiences.

The report reveals that parents have been attempting to link and network together with varied success.

- Given these findings it appears that our service response should promote and support access to parent networks.

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Parents also reported that they did indeed see value in forming connections and relations partially for reasons of social inclusion and social experiences. The report revealed that parents had been attempting to link and network together with varied degrees of success. (Face to Face Report, 2006, pg 59)


Given these findings it appears that a holistic service response to a diagnosis of deafness through newborn hearing screening should promote and support access to parent networks.

4) The support needs for the child

This domain includes such aspects as

- Access to service providers with expertise in deafness
- Availability of needed services to make progress
- Support for the child to make friends and be included in the community (Jackson and Turnbull 2004).

Domain 4: Support



This domain includes such aspects as

- Access to service providers with expertise in deafness
- Availability of needed services to make progress
- Support for the child to make friends and be included in the community.

(Jackson & Turnbull 2004)

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We will focus on the aspect of access to services:

Access to services


Research indicates that families can have difficulty finding services providers who specialise in working with children who have a hearing loss (Arehart & Yoshinaga-Itano, 1999). Families may also be frustrated by systemic barriers, such as insufficient staffing resources, inexperienced clinicians, service providers with limited signing ability, high rates of turnover, and problems with program delivery (Freeman et al 2002).

The Face to Face report, 2006, pg 43-53, supported these research findings, indicating that parents encountered difficulties such as:

- Time delay between the hearing loss being identified and receiving support and information
- Problems accessing services (eg test procedures) if living in regional areas
- Barriers to learning sign language

- Large variations in satisfaction levels with schooling options available and educational services received
- Difficulties accessing childcare that would meet the needs of deaf children.

**Improving the system:
greater support**



The implications of this for newborn hearing screening programs are that parents not only require access to professionals who have expertise in deafness but who can also assist in advocating to reduce systemic barriers or otherwise assist them in harnessing all available resources.

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The implications of this for newborn hearing screening programs are that parents not only require access to professionals who have expertise in deafness but who can also assist in advocating to reduce systemic barriers or otherwise assist them in harnessing all available resources.

In Conclusion

By considering the reported experiences and needs of families and the evidence presented in the literature, we can begin to formulate a family systems approach to Newborn Hearing Screening.


The family systems perspective challenges us to support not only the child, but the whole family. In doing so we are addressing the social and emotional wellbeing of the family, with the aim of improving long term outcomes for the child.

From the research and the consultations documented in this paper there emerge some key areas that families identify as being highly desirable. These have the potential to improve family quality of life and include:

- quality and adequacy of information at the time of diagnosis

- information is delivered by a knowledgeable and sensitive professional
- access to social support through parent groups and opportunities to meet Deaf and Hard of Hearing adults.
- opportunities for learning and support through parent to parent mentoring

Moving Forward
Consistency of Policy and Practice



To embrace family and child wellbeing the newborn hearing screening system needs to

- ensure the quality and adequacy of information at the time of diagnosis
- ensure information delivery by a trained professional who is knowledgeable and sensitive to the parents emotional well being
- enable the parent to access social support through access for example to parent support groups and opportunities to meet with adult Deaf or Hard of Hearing people.
- enable opportunities for learning, and support through parent to parent mentoring programs.

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We have noted that a number of States have commenced work on some of the ideas documented above. For example, to mention just two States: the Queensland Government has introduced a quality information package for families and has established a team of professional case support workers to provide information and support for families from the point of their child's diagnosis through to school entry. The Victorian Government has commenced the first newborn hearing screening parent to parent mentoring program, which is co-ordinated by Deaf Children Australia.

There is, however, more work to be done in order to embrace a family systems approach, and to strategically incorporate the ideas from this paper within the newborn hearing screening system in Australia.

Deaf Children Australia plans to review family outcomes through a proposed joint study with La Trobe University and this research will allow us to explore some of these themes further. It

remains for all services to continue to evaluate and research the outcomes for families and to explore the best ways of providing family -oriented support following diagnosis.

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