



**Queensland  
Government**



## ***FACE to FACE:***

***the experiences, decisions, issues, and  
needs of parents who have a child who is  
Deaf or has a hearing loss***

a report of consultation findings to inform the  
Healthy Hearing Program  
Queensland Health

**April 2006**

*“... it’s a team effort...it takes a bit of an army to  
carry my child. And we’re all batting for him,  
and heading for that same finishing line.”*

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### 1. THE CONTEXT OF THE CONSULTATION

This consultation has been conducted on behalf of the Healthy Hearing Program, Queensland Health. One component of the Healthy Hearing Program has been to make universal newborn hearing screening available to all babies born in Queensland. Newborn hearing screening aims to identify babies with a permanent hearing loss. Hearing screening occurs on the premise that early identification of permanent childhood hearing loss creates the opportunity for enhancing a child's development in a number of important domains (including social, educational, and vocational) through effective early intervention programs.

As well as the provision of newborn hearing screening, the Healthy Hearing Program aims to make the early days after identification of a permanent hearing loss as effective as possible in addressing the needs of children, parents and families. It is the intention of the Healthy Hearing Program to develop and enhance services to ensure the provision of:

- relevant and flexible support
- comprehensive and accessible information and resources
- accessible and coordinated services and programs.

The Healthy Hearing Program considered that a consultation with parents who have a child who is Deaf or has a permanent hearing loss was one important way to gather vital information which could guide and inform this endeavour.

### 2. THE AIMS OF THE CONSULTATION

The aims of this consultation were to explore parents':

- personal experiences of seeking and/or receiving **ASSESSMENT AND IDENTIFICATION OF DEAFNESS OR HEARING LOSS**;
- **DECISION MAKING** processes to address the communication needs of their child;
- **SERVICE AND SUPPORT** needs of their child, the family, and themselves;
- **INFORMATION AND RESOURCE** needs from the time of identification of Deafness or hearing loss;
- **DAILY LIFE AND PERSONAL RELATIONS** as they support and nurture their child.

The above aims form the structure for the findings of this consultation which are presented in Sections 7 to 11, of Part B of this document.

### 3. SERVICE AND ORGANISATIONAL PARTNERS TO THE CONSULTATION

The implementation of this parent consultation involved active co-operation and partnership between the Healthy Hearing Program and a range of services and organisations. The services and organisations which assisted this consultation project were:

- Catholic Education
- Deaf Children Australia
- Education Queensland
- Hear and Say Centre
- Queensland Deaf Society
- Royal Children's Hospital
- St Gabriel's Auditory Verbal Early Intervention Centre

### 4. CONSULTATION PROCEDURES

#### 4.1 Consultation techniques

- The investigation techniques used for this consultation were focus group and personal interview.
- The consultant acted as the facilitator / investigator for each of the focus groups and personal interviews.
- Interpreters were used, as appropriate and as requested, to enable the full involvement of all participants.
- The details and features of the investigation techniques, as implemented in the consultation, are summarised in Table 1 below:

Table 1: Summary of consultation techniques used

Consultation method	FOCUS GROUP	PERSONAL INTERVIEW
Degree of structure to the process of consultation	semi-structured	semi-structured
No. conducted	4	5
No. of participants (TOTAL = 19)	2 to 5 participants per group; total of 14 participants across the groups	1 participant per interview; total of 5 participants interviewed
Length of consultation	3 to 4 hours each	1 to 2 hours each
Consultation mode	face to face	phone

## 4.2 A profile of the parents who participated in the consultation

Within the practical boundaries of the project, there were strong efforts to capture as broad a spectrum of parents as possible. Table 2 below summarises the profile of the parents who participated in this consultation according to 10 variables. These variables were considered as important for bringing the relevant diversity to the consultation discussions. All participating parents had at least one child who is Deaf or has a permanent hearing loss.

It is acknowledged that the resulting profile of participants had a greater proportion of parents who have a child with a more severe hearing loss (HL), and that all participating parents were female (mothers).

**Table 2:** Profile of the parents who participated in the consultation

<b>Child's age</b>	birth -1yr ( <i>no</i> =1) 4yrs ( <i>no</i> =2) 8yrs ( <i>no</i> =1)	1yr ( <i>no</i> =1) 5yrs ( <i>no</i> =2) 11yrs ( <i>no</i> =1)	2yrs ( <i>no</i> =3) 6yrs ( <i>no</i> =3) 12yrs ( <i>no</i> =1)	3yrs ( <i>no</i> =2) 7yrs ( <i>no</i> =1) 21yrs ( <i>no</i> =1)
<b>Child's age at identification of Deafness or HL</b>	0-4wks ( <i>no</i> =4) 6mths-1yr ( <i>no</i> =1)	1-2mths ( <i>no</i> =2) 2yrs ( <i>no</i> =7)	3-6mths ( <i>no</i> =4) 3yrs ( <i>no</i> =1)	
<b>Parent hearing status</b>	hearing ( <i>no</i> =16) Deaf or hearing loss ( <i>no</i> =3)			
<b>Parent gender</b>	female / mother ( <i>no</i> =19) male / father ( <i>no</i> =0)			
<b>Type of HL of child</b>	sensori-neural ( <i>no</i> =19)			
<b>Degree of child's HL</b>	mild ( <i>no</i> =1) moderate-severe ( <i>no</i> =2)	mild-moderate ( <i>no</i> =2) severe-profound ( <i>no</i> =7)	mild-severe ( <i>no</i> =1) profound ( <i>no</i> =6)	
<b>Technical device/s used by the child</b>	hearing aid ( <i>no</i> =11) hearing aid + cochlear implant ( <i>no</i> =8)			
<b>Communication method used by the child</b>	Auditory-Verbal ( <i>no</i> =5) Oral / Total Communication ( <i>no</i> =6)		Sign ( <i>no</i> =4) Sign / Oral ( <i>no</i> =4)	
<b>Residential location of family</b>	Brisbane + Surrounding Areas ( <i>no</i> =15) Regional ( <i>no</i> =4)			
<b>Family structure</b>	Nuclear ( <i>no</i> =16) Single Parent ( <i>no</i> =3)			

## 4.3 The identification, selection and invitation of parents for the consultation

Potential parents to invite to this consultation were identified in cooperation with the service and organisational partners listed in Section 3. This process of identification involved a confidential and anonymous sharing of variables of parents of children who are listed on the data bases of these services and organisations. Consequently, a general parent profile for each service and organisation, and across the multiple variables described in Section 4.2 above, was generated.

The appropriate number of parents were selected from these general profiles, with attention to giving equitable representation of parents from each service and organisation (and the communication approach each represents), and to attempting the best possible spread of variables.

Those parents selected were approached informally (by phone or personal contact) by a professional from the associated service or organisation that the parent was familiar with. This informal approach was to gauge the interest or capacity of the parent to participate in the consultation, and to bring a personal “touch” to the consultation procedures in acknowledgement that some parents may be in stressful or vulnerable positions. Formal invitations (via post) were then extended to those parents who expressed interest during the informal approach.

#### **4.4 Informed consent and other ethical considerations**

The informed consent of parents to participate in the consultation was sought through an *Information Package* which was posted to parents along with their official invitation. This *Information Package* can be found in Appendix 1 of this report. The package includes such standard elements as a detailed description of the purpose of the consultation, what participation in the consultation would mean for the parent, the ethical procedures put in place which protect the privacy, safety, and rights of all participants, and a consent form.

#### **4.5 The question schedule for guiding the consultation discussions**

Refer to Appendix 2 of this report for the *Question Schedule* which was used to guide the discussions within the focus groups and personal interviews. This schedule was used in a semi-structured mode, and therefore formed a loose guide to discussions thus allowing for incidental ideas to be explored and for the discussions to flow naturally.

#### **4.6 Data management, analysis, and reporting**

All focus groups and personal interviews were audio-taped for maximal capture of data. The audio-tapes were fully transcribed. All names and identities of individual participants were removed from the transcribed data, and replaced with neutral anonymous phrases such as ‘my child’, ‘the teacher’ etc. All data and codes are stored securely to ensure protection of all participants. More specific details about data management and security are outlined in the *Information Package* which is found in Appendix 1 of this report.

Qualitative thematic analysis has been applied to the data in order to identify issues, patterns and themes.

Prior to the release of this report, all parents who participated were provided the opportunity to review a draft copy of the report and identify any of their own quotes, or components of their quotes, that they preferred were not included in the final report. These quotes have been excluded from the final report.

## 5. A SUMMARY OF CONSULTATION FINDINGS

The findings of this consultation are fully detailed in Part B of this report. These findings are presented under 5 main categories, which are:

- 5.1 Assessment and Identification
- 5.2 Decision Making
- 5.3 Services and Support
- 5.4 Information and Resources
- 5.5 Daily Life and Personal Relations.

Here, an overview or summary of these consultation findings are presented. For each category, a brief synopsis of its focus and the central findings are outlined. No specific illustrative data is presented in this summary.

### 5.1 *Assessment and Identification of Deafness or Hearing Loss*

This section of the consultation findings focuses on how parents experience the period of time in which they are seeking and / or receiving assessment and identification of their child's Deafness or hearing loss. Interactions and events which occur between parents, family members, various specialists, GPs, and services during this period are described. Parents' emotions, concerns, beliefs, questions, and issues which arise along the way are also detailed.

The general findings are:

- **The process of parents getting effective assessment and identification of Deafness or a hearing loss for their child can be a strenuous and confusing process for parents**
  - Parents can feel that getting a correct and final identification of Deafness or hearing loss for their child is a prolonged process of obstacles, unreliability, and inconsistency. Parents can feel stressed, angry, and frustrated by this
  - Parents can experience barriers in the process of referrals from one system to another, with feelings of anger and frustration resulting from this
  - Before hearing assessment is undertaken, parents can feel that their beliefs and intuitions about their child's hearing are disregarded by professionals
  - Parents can experience professionals' communication of their child's Deafness or hearing loss as insensitive and shocking
- **Parents can experience strong emotions upon being told that their child is Deaf or has a hearing loss**
  - Some parents experience feelings of emotional pain such as loss, fear, devastation, and numbness
  - When a child has serious and / or multiple medical problems at the same time they are identified as being Deaf or having a hearing loss, their parents' emotions about the Deafness or hearing loss may range from despair to relief
  - Parents can experience a sense of loss when they consider that their child may face limitations:
    - *in life options*
    - *in experiencing the "beautiful things" of the hearing world*
  - Parents may question whether they have contributed in some way to their child's Deafness or hearing loss
  - Parents' emotional responses to their child being Deaf or having a hearing loss may include gladness
  - For the parent, coming to terms with the necessary complex challenges ahead can be overwhelming

- **The family background or experience of the parent may influence how they feel about having a Deaf child or child with a hearing loss**

**Parents who have a family background or experience with Deafness, hearing loss, or disabilities, may have different responses to those who do not**

- The influence of personal belief systems held about Deafness and hearing loss (as a disability; as normal; as cultural)
  - Differing hearing status and background between parents and family members can result in unmet emotional needs, or conflicts in reactions and hopes
- **Mothers can feel that a delay in identification of their child as being Deaf or having a hearing loss can have a positive impact on their opportunity to bond with their child because of the period of “worry-free” time prior to concerns arising**

## **5.2 Decision Making**

This section of the consultation findings focuses on the decision making processes and experiences of parents as they select the communication options and early intervention centres / organisations for meeting the needs of their child and family. The factors that influence parents’ decision making, as well as the impacts and consequences of making particular choices, are explored.

The general findings are:

- **Parent choice of early intervention centre / communication development option is made around a range of factors**
- Competent professional standards and expertise are observed
- An open professional attitude about options and choices is found
- A friendly and helpful atmosphere is experienced at the centre, including a good rapport with and attention to the child
- A family member or partner expresses a preference
- The centre appears able / not able to provide the required approach or supports
- Dissatisfaction is experienced with a previous centre / option; the parent searches for something better
- The convenience of multiple services at one centre
- Observation of / information received from other parents and their children
- A convincing direction is gained from self-research or the opinion of a professional
- The child’s previous hearing background
- The child’s medical background
- The geographic accessibility, financial imperatives, and religious orientation of the centre
- Parent desire for the child to have speech as the fundamental mode of communication
- Avoiding negative responses from others
- Personal perspectives on the potentials of identifying predominantly with the Deaf or hearing community
  - *Creating opportunities for the future*
  - *Enhancing family relations / sharing the same culture*
  - *Access to a new culture*
  - *Enhancing social opportunities*
  - *Maintaining personal identity*
  - *Seeking physical comfort*

- **Parent choice of early intervention centre / communication development option can involve decisions to relocate place of residence for better / easier / wider access**
  - Emotionally, socially, professionally disruptive
  - Financially disadvantageous
  - Breaking family and parent ties
  - Life restricting
  - Issues of equity
- **Parents can see value in seeking multiple communication options / a combination of communication development options;**
  - Open access wanted to more than one centre / organisation at any time
  - Options are seen on a continuum, rather than as separate entities
- **Parents want to be able to change early intervention centre / communication development option within a supportive environment;**
  - Respect for parents as knowing what is best for their child
  - The intervention to fit the child rather than the child to fit the intervention
- **Parents who change early intervention centre / communication development option can experience unsupportive responses from others**
  - Pressure from professionals
  - Alienation from centres
  - Closed reactions from parents and communities
  - Requires individual resolve to follow your own choice
  - Creates 'the keeping of secrets'

### **5.3 Services and Support**

#### **Services**

This section of the consultation findings focuses on parents' views and issues concerning the provision of services which they use for meeting the needs of their child and family. Services which are addressed within the findings include child care, transport, education, information support, hearing assessment, and provision of hearing devices. Service access, availability, timing, approach, adequacy and standards are explored.

The general findings are:

- **Parents can experience an uncomfortable lapse of time between identification of their child being Deaf or having a hearing loss and receiving of service support and information**
  - Delayed attention to the needs of the child and family
  - Sense of no follow-through
  - Feeling lost and without direction
  - Experiencing emotional / mental anguish

- **Lack of appropriate child care can be a severe hindrance to families, and parents can feel this compromises their child's development**
  - No coordinated system of listed child care centres that can cater for Deaf children or children with a hearing loss;
    - lack of child care workers who are competent in using Signed English or Auslan;
    - time consuming and disillusioning for parents to search endlessly
  - Significant impacts on family finances as the child's mother chooses not to go to work in order to support their child;
    - or long distances are travelled each day;
    - especially significant for single mothers and mothers in regional areas
  - Lack of precise attention to the basic daily needs of the child within the child care centre context e.g. care of hearing aids and cochlear implants
  
- **There are large variations in parent satisfaction levels with the schooling options available and educational services received**
  - Parent concern that public state education / schooling is not accommodating the needs of their child
    - *Signing support*
    - *Social / behavioural support*
    - *Educational standards*
    - *Diversity in / access to education / communication options*
  - Classroom teachers require further specific training in order to accommodate the needs of a child who is Deaf or has a hearing loss;
    - parent vigilance and presence at the school is sometimes deemed / predicted to be necessary
  - Support and awareness-raising systems can be lacking in the school environment and community
  - Advisory visiting teachers are an invaluable support, and are needed as early as possible
  
- **Transport to education facilities can be a major concern for parents and is seen by some as a major equity issue**
  - Rights of the child to receive the most appropriate schooling
  - Concern about possible future cutbacks to taxis
  - Geographic boundaries which decide taxi access can be inflexible and limiting
  - Limited options in mainstream schooling can mean excessive time spent in driving children to school
  
- **Hearing parents who want their child and family to learn Signed English or Auslan can experience barriers to doing so**
  - Families and children need easy access to teachers / courses for learning Auslan or Signed English
  - Parents can experience stress when they can't keep up with their child's growing need to communicate
  - Difficulties accessing the current Signed English dictionary
  
- **Access to services can be problematic for families in regional areas**
  - Extended travelling
  - Unstable connection to professionals
  - Unavailability of some essential technical or medical testing procedures

- **Parents need professionals to work alongside them – cooperatively, inclusively, sensitively**
  - A team effort between all – parents, child, therapist, audiologist, AVT, school, social worker – with common goals
  - Understanding the WHOLE family – beyond the clinical
  - Understanding Deaf issues, culture and language
- **Mothers want to be mothers, with a balance between parenting and doing therapy / teaching in the home**
  - An over expectation from professionals that parents (mothers) will do therapy at home i.e. the therapy as a lifestyle
  - Over emphasis on therapy and teaching in the home can be impoverishing to the bonding and enjoyment between parent and child; the child can become “work” rather than “joy”
  - There can be child resistance to doing MORE therapy beyond the actual appointments – causing stress for the mother
  - Should be an emphasis on helping parents to be parents – to build loving relations
- **Issues around hearing aid supply and care can frustrate parents and increase concern for their child’s development**
  - Waiting times for replacements, repairs and parts can feel prolonged and unnecessary – What do we do meanwhile?
  - An issue of equity – not just the supply of technical parts BUT felt as neglect to the rights of the child for health and well being

### **Support**

The focus of this section of the consultation findings is on ways in which parents would like to be supported through their journey of having a child who is Deaf or has a hearing loss, from the moment of identification of Deafness or hearing loss, and continuing into schooling years. The consultation findings emphasise that parents want and need ongoing sensitive support from (a) other “like” parents and people; and (b) a case-support professional.

The general findings are:

#### *Support from “like” parents / “like” people*

- **Contact with other “like” parents is highly desired as it can bring social / emotional understanding and educative outcomes**
  - To have someone to talk and cry with; to just “be there”
  - To feel less alone and to have the comfort of relating to others who share similar experiences
  - To gain information and seek advice which can’t be found elsewhere
- **Mentor / support parents in an “official” support role, need to be trained**

➤ **Deaf and hearing parents see value in forming connections and relations**

- For getting vital information to “hear all the sides”
- For social inclusion and social experiences
- For seeing hope and opening possibilities for the future
- Concerns of hearing parents when forming connections with Deaf parents

➤ **Parents have been attempting to link and network together, with varied success and with many factors revealed**

- It can be difficult to access parent support groups or individual parent contacts – Where are they? How do I find them? Can I get there? Will it be supportive? What forms could be used to link together? Do I have the energy / time to organise a meeting?
- Efforts to form parent support groups are often met with limited success due to complex issues of group composition, outreach, and personal factors
  - *The children having a similar hearing loss, therefore shared parenting experiences and issues*
  - *Division between communication modes*
  - *Division between schooling systems (public / private)*
  - *Finding “someone like me” to relate to*
  - *Confidentiality of records*
  - *Not wanting the recall of past events*
  - *Getting on with a normal life*
  - *Promotion of groups to attract parents*

*Access to a support professional*

➤ **There is a great desire for parents to have the option of access to a support professional, beginning from the time their child is identified as being Deaf or having a hearing loss, for:-**

- Emotional support and counselling / someone to talk to / follow up
- Timely and sensitive provision of information, advice, referrals, networking
- Assistance with planning, phone calls, research and information
- Accompanying to interviews / visits to centres and schools

➤ **A support professional should have a range of specific characteristics:**

- Suitable professional background e.g. social work, psychology
- Knowledge and experience in the fields of Deafness, hearing loss and disability
- Understands what it’s like to have children and can relate well to children
- Can be open / impartial to methods and philosophies, but also offering advice when needed
- Open, friendly, confident, calm, empathetic personality
- Positive approach to addressing grief and problems; sensitivity to the parents’ needs

➤ **The model for professional support to parents / families should be flexible to each specific family, based around a plan of action, and be open to parent control (of WHEN?, HOW?, WHETHER?, WHO?)**

## **5.4 Information and Resources**

### **Information**

The focus of this section of the consultation findings is on parents' needs, experiences, issues and preferences in terms of gaining information about their child's Deafness or hearing loss and what the Deafness or hearing loss means for the child and the family. Information access, delivery, modes, sources, timing, and content are explored.

The general findings are:

#### **➤ Parents' experiences of accessing and receiving information can be problematic and exhausting**

- Receipt of information can be erratic / incidental / accidental / absent
- Information can come almost solely from self generated research, requiring much effort on the part of the parent
- Information is gained in response to questions parents ask professionals, rather than it being forthcoming
- Information when received can remain unexplained and unsupported by professionals
- Information can come too late or be irrelevant
- Information can be found to be inaccurate or misleading
- When information is received, it can cause overload and de-motivation for parents. Information received may not be immediately processed by parents due to their emotional state

#### **➤ Sources of information for parents are varied, and include:-**

- Various professionals – therapist, audiologist, AVT, ENT
- 'Choices' publication from Australian Hearing
- Other parents with Deaf children or children who have a hearing loss
- Internet – websites, research articles, institutes, associations
- Phone calls and visits to centres and organizations
- Information (and support) more forthcoming when deciding on cochlear implantation

#### **➤ Information needs are very individual. Specific information may be needed but is not easily accessed, can be misleading, too late in coming, or fragmented between systems**

- Information on hearing loss – nature of Deafness or hearing loss, causes, degree, the actual condition
- Information on Deaf culture, Deaf issues, Auslan
- Information about education – communication options, schools and support systems (it's never too early to get this)
- Information on hearing retesting possibilities and procedures
- Information on what is available through the public system
- Information on organisations to contact
- Information on how to access hearing assessment and where to go
- Information from parents and the Deaf community
- Information about the daily things e.g. cleaning hearing aids, interacting with your child
- Technical information e.g. reading test results
- Stories of children's futures – to give hope and direction for the future
- Information on how to be assertive with professionals and an advocate within systems, in order to get needs met

➤ **A preferred mode of receiving information and understanding information is talking to PEOPLE.  
This information should be presented objectively, plainly, openly**

- Professionals / specialists to present, explain and discuss information in a jargon-free, inclusive, friendly fashion
- Professionals to “talk through” information with parents with impartiality and a commitment to a thorough presentation of all perspectives and options
- The opportunity for parents to talk with other parents in a similar situation with first hand experience; including the Deaf community
- The opportunity for information giving and sharing workshops and seminars

**Resources**

This section of the consultation findings focuses on parents’ views and preferences regarding various forms of resources which aim to provide some type of information or support to parents and families who have a child who is Deaf or has a hearing loss. In this consultation, the resource types which are specifically explored are a family file, a general brochure, personal stories, and audio-visual. Parents’ suggestions on a range of other resource types and information-giving strategies are also outlined.

The general findings are:

➤ **Comments on the concept of a Family File (e.g. “Early Support”- UK)**

(-)

- Specialists would not be interested
- No use for it as already have an existing system of files and diaries

(+)

- A good idea
- Keeping such a file would help to deal with grief; encourage acceptance through plotting progress and writing down what you think is best for your child
- Such a file would encourage recording, tracking, and follow-up of valuable information
- The file would be best if completed along with the professionals; wouldn’t do it alone
- An example of a flexible and developmental resource, which gives parents freedom
- The file could be good for sharing information with others (e.g. child care centres, family, friends, babysitters, therapists) and would save repeating yourself

➤ **Comments on the idea of a general brochure at the time of identification of Deafness or hearing loss**

(-)

- Of little value

(+)

- Should be simple and easy to read
- Is something to also give family and friends
- Containing what to expect and do in the future – a timeframe of actions
- Giving an overview of the different options, with phone contacts to centres
- Describing emotions likely to be felt
- Explaining what a child can hear at levels and frequencies – in everyday terms
- Describing other parents’ experiences (but not to overwhelm)

➤ **Comments on reading personal stories of other parents' journeys and experiences**

(-)

- Not overly interested or important
- Everyone is different and should do it their own way
- Can be frustrating if you don't agree with their choices

(+)

- Can relate to other experiences and therefore feel less alone
- Can get different perspectives than my own

➤ **Comments on using audio-visual resources**

- Good for follow-up of information given by professionals; helps information to "click"
- No time or energy to read but can watch and re-watch a video while doing other things
- Useful for supporting regional parents; good to see real parents talking about their experiences

➤ **Other suggestions for resource types to be given at the time of identification of Deafness or hearing loss**

- A kit: pamphlets from all organisations and a list of contacts of parent support groups
- Information sessions and workshops
- Recommended websites for answering specific questions
- Catalogue of books available
- In-depth texts
- Resources at public libraries (especially for regional parents)
- Phone network or panel of experts – list of 2 to 3 parents under each communication option who you can ring and talk with

## **5.5 Daily Life and Personal Relations**

This section of the consultation findings focuses on some of the daily realities of being a parent (in particular, a mother) of a child who is Deaf or has a hearing loss. Parents' experiences and issues around managing their responsibilities of care are explored, including degrees of responsibility, levels of acceptance of the child's Deafness or hearing loss, impacts on time and personal well-being, and the practical daily tasks and problems of parenting. Also, parents' experiences of how others respond to or support them and their child, and the dynamics of family and important social relationships, are described.

Finally, some thoughts are offered from mothers about how they think their child experiences their own life, living with Deafness or a hearing loss.

The general findings are:

➤ **Some mothers can feel the total responsibility for their child's care and development, intervention responses, day to day decision making, and medical / technical program**

- Some mothers can experience that the child's father withdraws emotionally / psychologically; some mothers perceive that the child's father can be slower to accept the Deafness or hearing loss
- Some mothers can feel overloaded and unsupported; there can be reduced opportunity and potential for the mother to have her own time, pursuits, and life
- There can be impacts on marriage and family

- **From the beginning, parents can worry about whether their child will receive social acceptance and quality education**
- **Parents with a child who is Deaf or has a hearing loss can experience a range of social responses from family, friends and the community**
  - Varying levels of understanding and acceptance received from others
  - Creating certain dynamics between siblings
  - Societal responses carrying stigma
  - Impacts on emerging relationships
- **There are daily communication and behavioural challenges when parenting a child who is Deaf or has a hearing loss**
  - Managing hearing aids and cochlear implants
  - Managing behaviour and safety
  - Maintaining and nurturing communication and therapy
- **How the child experiences their Deafness or hearing loss: from a mother's perspective**
  - Feeling or experiencing difference
  - Feeling the same or special
  - Feeling social confidence and success
  - Feeling frustrated
  - Feeling surprise or amazement
  - Feeling peaceful

## 6. POINTS TO NOTE ON THE PRESENTATION AND INTERPRETATION OF FINDINGS

There are several points which should be noted when considering the data presented in this report. These are:

- the findings of this consultation are presented under a series of themes and sub-themes which were identified by the consultant through an analysis of all data sets. For each theme and sub-theme, a series of direct quotations from parents can be found which relate to that idea. The presentation of consultation findings was approached in this way because it was felt that it would best capture and represent the nuances of each parent's contribution, thus adding to the potential of these findings for informing specific change and increasing understanding. All direct quotations are shown in italics and between double quotation marks;
- in the writing of this report, and especially in the construction of the themes and sub-themes which provide its structure, every reasonable effort has been made to use language and terminology which acknowledges and respects cultural diversity and identities. Apologies are extended if any form of expression used in this report offends or excludes;
- all names of individual people have been removed from the data. This includes the identities of the parent, child, family members, friends, and professionals. Specific names are replaced with general descriptors such as 'my child', 'my husband', 'the teacher', 'the therapist';
- at the end of each quote it is indicated in parenthesis whether the parent identifies as being Deaf, having a hearing loss, or hearing. Given the nature of the feedback it was felt that this information was relevant for understanding and responding to the experiences being shared.
- in those cases where it offers an important sense of context and enhances the meaning of the data extract, additional relevant features of the parent (who is being quoted) or their context is indicated in parenthesis after the data extract. For example, 'regional parent', 'single parent' etc.
- specific names of services, centres, organisations, and programs have been retained in the data in order to give the findings their appropriate context and meaning and thus hopefully increase the potential and application of the findings;
- as is indicated in the participant profile (see Section 4), the parents who took part in this consultation have children of various ages, ranging from less than 1 year old, to 21 years old. Therefore the data collected in this consultation represents experiences and journeys of parents that have occurred over a considerable span of time. With the exception of two parents, the parents in this consultation have not had the experience of their child receiving newborn hearing screening through the Healthy Hearing Program as it was not available at the time their child was born. It is recognised that positive service and organisational changes are constantly occurring, and it is acknowledged that some of these changes will have occurred since the period of time that is described by some parents in this consultation;
- illustrative data extracts are presented within each theme and sub-theme of the data findings. The actual number of extracts listed within each theme or sub-theme does not necessarily indicate the number of parents in the consultation who expressed this idea or experience. Several data extracts within the one theme or sub-theme may originate from the same parent. The display of data extracts within each theme or sub-theme is meant to illustrate the NATURE of parents' ideas, experiences, events, and feelings that have been expressed during the consultation, but not to indicate the precise NUMBER of parents who have

made a response which fits under that theme or sub-theme. This is a standard approach used within qualitative research methodology.

## 7. ASSESSMENT AND IDENTIFICATION OF DEAFNESS OR HEARING LOSS

This section of the consultation findings focuses on how parents experience the period of time in which they are seeking and / or receiving identification of their child's Deafness or hearing loss. Interactions and events which occur between parents, family members, various specialists, GPs, and services during this period are described. Parents' emotions, concerns, beliefs, questions, and issues which arise along the way are subsequently also detailed.

The consultation findings for this section are presented under the following main themes:

- 7.1 The process of parents getting effective assessment and identification of Deafness or hearing loss for their child can be a strenuous and confusing process for parents
- 7.2 Parents can experience strong emotions upon being told their child is Deaf or has a hearing loss
- 7.3 The family background or experiences of the parent may be influential on how they feel about having a Deaf child or child with a hearing loss;  
  
Parents who have a family background or experience with Deafness, hearing loss, or disabilities, may have different responses to those who do not
- 7.4 Mothers can feel that a delay in identification of their child as being Deaf or having a hearing loss can have a positive impact on their opportunity to bond with their child because of the period of "worry-free" time prior to concerns arising.

*"...they actually got a social worker in when Mum and I were there, and she spoke to us about the process of grief that people can go through. But I don't recall having that grief. The only anger I had was that it wasn't correctly diagnosed. But there was never any anger that she couldn't hear, never any grief as such." (hearing parent)*

*"... I was relieved in a way, because I had suspected it for so long, and I'd felt that doctors I'd been to just didn't believe me - thought I was a paranoid first time mum - but I just knew I had to know for sure. And being a teacher, I knew how important early intervention was. So it was almost a relief for me to now be able to do something for my child, to help her, and to have picked it up relatively young. It probably wasn't until later that some of those devastation issues hit me." (hearing parent)*

*"...And my child was sitting on my lap having his hearing test, and they didn't have to tell me – I was going into deep shock during the hearing test, with the realisation that he couldn't hear anything. I was just thinking that I wanted to pinch my little boy so that I'd get a reaction from him, but there was just nothing showing in the test." (hearing parent)*

*It's really, really, difficult sometimes with him being deaf, and me being hearing and from a hearing background. But in some ways I'm really glad he's deaf because if he was hearing, he wouldn't be the same kid that he is now. He'd have a totally different personality. And it's because he's deaf that he is the way he is, and he's such a little character. He's really expressive." (hearing parent)*

## **7.1 The process of parents getting effective assessment and identification of Deafness or hearing loss for their child can be a strenuous and confusing process for parents**

- 7.1.a *parents can experience getting a correct and final identification of Deafness or hearing loss for their child as a prolonged process of obstacles, unreliability, and inconsistency. Parents can feel stressed, angry, and frustrated by this*

*"I had asked the nurse at about 6 months if there was something wrong, and she said 'No it's fine!' And we used to see a paediatrician because the twins were premature, and the same thing, he said to us 'Oh, it's fine!'. It went on until we had some work done at our place, and there were nail machine guns, and his twin sister just screamed but he kept on sleeping. So I rang the paediatrician, and I said 'I think the problem is not just the facial nerve. It's deafness as well now.' And he sent me straight to a neurologist." (hearing parent)*

*"And when my child was first diagnosed at the Royal Children's Hospital, they actually got a social worker in when Mum and I were there, and she spoke to us about the process of grief that people can go through. But I don't recall having that grief. The only anger I had was that it wasn't correctly diagnosed. But there was never any anger that she couldn't hear, never any grief as such." (hearing parent)*

*"I've been very lucky, and it's early days. I'm very grateful that my baby has only got a slight loss. When we first found out, in the first few days, we were still in hospital. I was quite ill when they plucked her out in an emergency caesar, and I was quite ill for the first 6 days. So that had more of an impact on the way we dealt with things...When they tested her, they said at first that maybe there's something wrong with the equipment, or she might have a blocked ear, or someone might have a phone on and it might be interfering, but we're picking up that there's a loss in one ear. When we did the referral test, I'd had 4 weeks of a baby that didn't sleep, and doctors telling me that she was colicky, but I'd been exposed to a lot of kids and I knew she wasn't colicky, so I found it a bit stressful. Because all those things are going through the back of your mind, even though you know you have to wait for the professionals to tell me what's happening, you're thinking 'Is she going to be able to hear? Will she be able to develop properly and play with other kids?' So I found the testing stressful in itself, mainly because they sent me an information thing and they said it would be 45 minutes, and we were there at least 4 ½ hours. And because I'd had no sleep and I was still recovering, I went home and was sobbing. I told my husband they think she's got hearing loss, but they can't confirm it, and we have to go back for tests ---- So 4 trips later, they said maybe they should sedate her. And I said 'No, sorry'. But luckily we got moved to a different audiologist, and to be honest this audiologist was a lot more caring and dealt with little babies a lot better. The first one was a bit abrupt, quite rough with my baby. And so we finally got the testing done, thanks to this other patient audiologist, and that in itself took up to a 5 month period. So it was a long time." (hearing parent whose baby's hearing was screened through the Healthy Hearing Program)*

*"It was so tricky to work out what she could actually hear. I had to take her to Australian Hearing and they do the puppet thing, and then I had to do the horrible tests under the general anaesthetic. And poor kid, I think she's had about 8 general anaesthetics. But she's at this age where it's so tricky to test her, and I had to make this decision." (hearing parent)*

*"I think the hardest thing for me was that they were telling me that she could hear people speaking, and I knew that she couldn't. It was just hard getting to the bottom of that - like why? So it was hard about the accuracy of the tests, and that was Australian Hearing - to have my child sit there and trying to listen, and they can't." (hearing parent)*

*"My child was born 16 weeks premature, and he spent 5 months in intensive care. He had lots of different medical procedures and drugs. He was lucky to survive that 5 months, and he didn't have a hearing test in hospital. One of the nurses had mentioned to my husband and I that the antibiotics can have the side effect of hearing loss. I always kept that in the back of mind. When we got him home from hospital, my husband and I used to test his hearing at home, and he was never that responsive. But then there were times when he was.*

Obviously, looking back now, he was picking up on vibrations or movement, like shadows. As far as his paediatrician was concerned, to have a hearing test was definitely something that needed to be done because there was that risk there. So there was never any trouble to convince doctors. Because he hadn't had his hearing test in hospital when he was much smaller, it took 8 months for him to be diagnosed. They didn't have the equipment in our town to test him, so we travelled down to the nearest largest centre. We had to go to a private practice because they didn't have an ABR. The trip there was unsuccessful, and we came back home without a diagnosis because he wouldn't go to sleep for the test. And in between these times, my husband and I were constantly testing him at home, and then having family and friends say to us that he could hear. So it was a very frustrating time. But my husband and I both knew inside. We felt that something was wrong. We finally got the news that there was an ABR machine up north, so we went, and our child was sedated which took about 10 hours because he wouldn't go to sleep. And then finally when they did get to test him, the equipment was playing up and they came up with the diagnosis of a profound hearing loss. And then when we came back home, we got a phone call a few weeks later to tell us that the result was incorrect because the equipment was faulty. So we then went back to Australian Hearing in Brisbane, and they did audiograms, because it was obvious he had a loss. Then they worked out that he had a severe loss. So that was a relief." (hearing parent from regional area)

"Then we started down the cochlear implant road. To us it was a slow process, because we made our decision early on. But it's a long process with a lot of tests, and the poor little bugger had to go under general anaesthetic quite a lot of times, and he had to have some tests twice because the machinery was put out by the slightest environmental factor. Unfortunately they did the CAT scan last, but if they'd done it first we would have known exactly what was wrong. It took us right to the end to find out what was wrong. He's got Mondini's where the cochlear hasn't formed properly in both ears. And fortunately he was implantable." (hearing parent)

"We tried to get a cochlear implant assessment, but unfortunately my child saw a psychologist who sat him in a little chair. And the psychologist stood behind my child and would ask him a question - this was for a deaf child!! Of course he would just keep sitting playing with his toys, he would get up and do whatever he wanted to, and we did this for an hour. And in the end the psychologist then said 'As you can see, your child can't do anything, and so he's autistic. And you can't have a cochlear implant if you are autistic. He is still in the program but we'll have to review him later'. And his teacher, with 30 years experience with the deaf, believed too that my child was not so deaf as the tests were showing. She thought he's not so deaf, he just has an intellectual problem, and she agreed with the psychologist. So I was sent to Melbourne, at our own expense, to prove her point, and Melbourne proved the opposite. But this was at 22 months! And he was implanted a month before he turned 4 because of that." (hearing parent)

#### *7.1.b parents can experience barriers in the process of referrals from one system to another, with feelings of anger and frustration resulting from this*

"It's been a bad journey – like when she was first diagnosed. It was just such a struggle just to get her diagnosed. And I'm just so annoyed that Australian Hearing couldn't refer me to the Royal Children's. The only time I got options from them was, of course, once she was actually diagnosed as deaf, and she got the hearing aids, and we got the Choices booklet." (hearing parent)

"Up to 18 months old, my child was being tested by Australian Hearing who said she had enough hearing for normal development. At 18 months I queried if they could test if she was deaf or partially deaf, and they said 'No we can't do that until she's 3'. So I went 'OK, nothing can be done'. I thought we had done everything that is humanly possible, and we had to wait until she was 3. So it was only my mother-in-law's urging, when she said she would take her to her own ENT for testing, because she believed that our child was deaf. And I said to my husband, 'We have to do something about this'. Because we had a suspicion that she was deaf, but we had done everything we were told we could do. And it wasn't until after we saw an ENT, who looked at her and he said she's fine, and he didn't organise any testing or anything, that we finally found out that children can do an ABR sedation test. Friends of ours had told us about a clinic at the Mater who test everything. So I rang

them, but they said our child wasn't disabled enough to go there. Then I found out that Royal Children's do the ABR test. So we went to the hospital, sat for hours in emergency, waiting for a consultation, and then the next week we were into the Audiology Department and had the test, and we found out she was deaf. So one ENT said she was fine, and a week and a half later she was diagnosed as fully deaf. So we weren't very happy with him. And we weren't actually happy that the federal government doesn't work with the state government in advising people that there is somewhere to go. Because otherwise we would have had her tested at 6 months when the question of her hearing first came up. If we had known about the ABR sedation, we would have gone straight away and got that done. Australian Hearing did not say 'Look, you can go to Royal Children's and have your child tested'. And that's what I'm really angry about - that breakdown between federal and state government. And if we had known that, she wouldn't be struggling. Like at the moment she has her moments when we can't understand her, she can't get across her point, she doesn't know the words. Whereas if we'd got it done at 6 months then she'd probably be in Grade 1 this year. She's repeated preschool because she didn't have enough language and that's the main thing I'm angry about - that they didn't work together and advise us." (hearing parent)

*7.1.c before hearing assessment is undertaken, some parents can feel that their beliefs and intuitions about their child's hearing are disregarded by professionals*

"And it was really hard to accept, to understand how can this happen, that my child's hearing could go from completely deaf to normal, and back again. That was hard to swallow, and for me to agree with the specialists that the tests are showing that he needs to wear the aids. He was saying he can't hear these certain sounds, and I was saying, yes he can, and I would have to prove it to them that he could. And he could. And that's when they realised they needed to check the lowest to highest frequencies." (hearing parent)

"I have to call it mother's intuition. I had a feeling when my child was born that there was a hearing loss. When she was 2 weeks old I mentioned something to my mother, and I followed it up at my 6 week paediatrician appointment. But he said to me, he checked her out, and he said 'No I think she's fine'. She was a very alert child, and he didn't think there was a problem. He told me there was no testing. Anyway, I kept following it up until finally I went to Australian Hearing, and the audiologist there did some testing and said that it's inconclusive until you have the ABR done. She was diagnosed at 5 months as profoundly deaf. And I must say at first it was mixed emotion. I was relieved in a way, because I had suspected it for so long, and I'd felt that doctors I'd been to just didn't believe me - thought I was a paranoid first time mum - but I just knew I had to know for sure. And being a teacher, I knew how important early intervention was. So it was almost a relief for me to now be able to do something for my child, to help her, and to have picked it up relatively young. It probably wasn't until later that some of those devastation issues hit me." (hearing parent)

"I first suspected that my son had a problem with his hearing from approximately 4 months of age. And through my own persistence he was finally diagnosed at 16 months of age. I had mixed emotions because finally it was confirmed what I already knew, and it took me many years to come to terms with why wouldn't anyone listen to me. I found it very distressing and no mother with a new born child should have to go through it at all." (hearing parent)

"I suppose it's always the mother. Like with my child I had a funny feeling that there was something wrong. I had a chat to the doctor about it, and he looked at his ears and he said 'He's fine, there's nothing wrong. Some children don't talk until they're 4'. At that stage my child was 12 months, and his babbling was starting to decrease, and that was what I was getting concerned about. And I found out later that that's what happens. Children talk and babble to start with, whether they can hear or not, but then they don't get that reaffirmation, and that's why at 12 months you get the decrease of babbling. So being a first time parent, I took the doctor's word for it and it gnawed away at me for another 6 months. Then I went back again and I said I want to see somebody else." (hearing parent)

**7.1.d** *parents can experience professionals' communication of their child's Deafness or hearing loss as insensitive and shocking*

*"Where do I start? My twin daughters were born at 26 weeks...They were both very small and sick to start with, so they were in intensive care. One of the twins was very sick, and they said she probably won't make it through the night. But we had her for 2 ½ months, and then finally she passed. By this time, my other twin was making steady progress, although she had a shaky start, being so premature, and she'd been ventilated for a couple of weeks. She finally got into special care after a couple of months, and the doctor would say to me 'Don't worry, she is going to be alright'. She was a very visual happy child, she'd engage everybody, and she was a favourite. And when they did their rounds, she was always looking at them really bright and sparky. Looking back now, you know why. One day in special care, a day or two before we were due to go home, I came in to find a big black box next to her cot, and two people standing over it. I hadn't been told she was going to have a hearing test and I had no idea what was going on. They said to me 'She is having a hearing test, and it doesn't look too good. At least severe to profound hearing loss'. And then they packed up and quickly made an exit, because I probably looked like I would fall on the floor. Then the nurse came up to me and said 'Do you still want to give her a bath then, or not?' I'm thinking 'WHAT?!' I just ran out of the room and drove to my friend's house around the corner, and sat on their couch in deep shock, mumbling." (hearing parent)*

**7.2** *Parents can experience strong emotions upon being told their child is Deaf or has a hearing loss*

**7.2.a** *some parents experience feelings of emotional pain such as loss, fear, devastation, and numbness*

*"I went to my GP. I was just in shock. I felt that I couldn't cope. I didn't want to be a mother anymore. The GP gave me some medication. She was great. I didn't go to the hospital for 2 days – the only days I'd missed in 4 ½ months. When I finally went back to the hospital and saw the paediatrician, he said 'Look, it's probably nothing, these tests aren't accurate', and he basically dismissed it and wouldn't believe it. But my child had had a lot of predisposing factors to hearing loss." (hearing parent)*

*"My child was born hearing, and at 18 months old he came down with a virus...for about a week, in hospital, and then when he was discharged, he was fine. But through that, we didn't know that he'd lost his hearing. We didn't realise for about 3 months. He got tested for his hearing and we found out that he was severely to profoundly deaf. And it was just devastating. I felt like I was thrown into this big pit, because it's something that's never touched us before. I never knew any deaf people. I'd never been involved. So it was all brand new, and it was scary. And because my other child has just sailed through everything, it was just a whole new ball game." (hearing parent)*

*"We had not found out our daughter was hearing impaired until she was 4 ½ years old. We knew our son had a problem but by the time we had him diagnosed properly he was 8 months old. They asked if there were any siblings and I said 'We do, but she's fine'. But we took her in and found out she's NOT fine. So that was a really big shock. So within one week, we found out our son was profoundly deaf and our daughter was moderate to severely deaf." (hearing parent)*

*"I knew nothing about my child's Deafness until the tests. And I was extremely shocked. Mum had gone, she had passed away, and I wanted to ask her for advice, to learn from her experience. And I thought, 'I'm on my own'. I felt very isolated." (Deaf parent)*

*"And my child was sitting on my lap having his hearing test, and they didn't have to tell me – I was going into deep shock during the hearing test, with the realisation that he couldn't hear anything. I was just thinking that I wanted to pinch my little boy so that I'd get a reaction from him, but there was just nothing showing in the test." (hearing parent)*

*“We were very devastated. It was like the end of our lives, like our whole world had come crashing down. My husband took it worse than I did. He was really depressed. And we’d had no experience, like in both families there’s been no disability or illness. And then getting people telling you ‘Oh at least he’s only deaf, it could be worse’. That doesn’t help, because of course we had a lot of behavioural issues as well, and at that time I was very, very, stressed. I wasn’t coping. I would have quite happily rung someone and said ‘Come and take this child away.’ Because it got to that point that I just didn’t want to know about it anymore. And I couldn’t cope with him because he had a total lack of understanding. And of course I didn’t realise that the child doesn’t understand because he can’t hear.” (hearing parent)*

*“The ABR showed nothing, no response, so I knew then that it was worse than I had expected, and I cried all the way home. Because you think ‘Oh I can handle this’, but it was very sad to learn that he had a very big hearing loss.” (hearing parent)*

*“Every night, for about the first 12 months, when I put my child’s hearing mould in my ear to check the hearing aid, I cried. Because when you put it on, it just blows your ears away, and you realise how bad the deafness is, and still to know that it isn’t good enough for him to hear the things that I hear.” (hearing parent)*

*“I was very taken by surprise, and then to have the fact that my child’s hearing loss was going down and down. They said she would have hearing aids and that would help. So I was expecting her to get hearing aids, and it would all be fine. But it didn’t work out like that. Now I just go with the flow. Every time she goes for a hearing test I sort of come out saying ‘Oh, her hearing is gone’, and you feel like crying.” (hearing parent)*

*7.2.b when a child has serious and / or multiple medical problems at the same time they are identified as being Deaf or having a hearing loss, their parents’ emotions about the Deafness or hearing loss may range from despair to relief*

*“This situation was more traumatic for me, as a mum, because my child died at one point; he was in such a critical condition. And to me the hearing loss was nothing. I was just so happy to have him alive, feeling better, and the hearing loss was just so minimal. You have to put it in perspective. I’m not saying it’s not a full on thing, but for me it was not very traumatic at all.” (hearing parent)*

*“We were going through a difficult time anyway with having lost his twin. I think probably for some time we were pretty numb about the whole thing. Although mind you, when we were told initially that he had a moderate hearing loss we were obviously very concerned, but we were told it was possibly just conductive loss, like fluid. And in between then we had to race him to hospital because they thought he had fluid on the brain. And so we just had so much going on, that once we were told he had moderate loss, yes, we were devastated. Here’s another blow. It wasn’t just dealing with a hearing loss.” (hearing parent)*

*“Because he’d been through so much in hospital, and doctors and nurses were telling us that there was a good chance our child would be severely brain damaged, or have severe cerebral palsy, and he nearly went blind at one stage, my husband and I thought ‘We’re going to have a child here who’s got lots and lots of problems.’ But he was developing fine in every other area, so we were relieved that it was only deafness. So we never really went through a huge big mourning or a shock about his deafness, because we were expecting there to be something wrong. And we were relieved that it was deafness, because it was one we would have picked rather than one of the other disabilities. And now he’s running and walking and he’s a normal happy little boy, and a very bright little boy, and it’s only the hearing loss. So I count my blessings everyday that that’s all that’s wrong with him. When I speak with other parents and I listen to their stories - when they’ve had a full term healthy baby, and then they find out that the baby is deaf - it would be a lot more shocking and upsetting. My perspective is more ‘Thank goodness that’s all that’s wrong with him.’ I’ve been lucky in that sense, and I’ve been very accepting of his deafness as a result.” (hearing parent)*

7.2.c *parents can experience a sense of loss when they consider that their child may face limitations:*

○ *in life options*

*“When I first found out he was deaf, it was just devastating. It was just the fact that he was deaf, because I’ve never known any deaf people. I think the thing that made me saddest was thinking that his choices would be limited in life. Because you want your child to be able to do whatever they want to do, and even as far as a job, to do what he wants to do. And you can’t with deafness. His Dad and I are both police officers, but if our child wanted to be a police officer like his parents, he wouldn’t be able to. You just can’t be a deaf police officer unfortunately. So those were the sorts of things I was thinking – that he IS going to be limited in some things.”* (hearing parent)

○ *in experiencing the “beautiful things” of the hearing world*

*“My mum rang me one day and said ‘I was listening to the birds in the trees, and I sat down and cried, because I realised she couldn’t do that’. And I was nearly in tears when Mum told me that, and I said ‘Don’t say that to me’. Because I hadn’t actually got to that point, I hadn’t sat down and thought of everything she couldn’t hear. And I did not want to do that because I knew I would just sit down, or lie down in a ball, and cry my heart out.”* (hearing parent)

*“I live on an acre out here, and there are a lot of birds around. And I used to like going outside, sitting down listening to the birds. And I remember in the beginning thinking how sad it was that my child wouldn’t be able to hear the birds, the rain on the roof, those sorts of things. But I think that now that he’s older, and he’s a happy kid, you can see now that it doesn’t really worry him that much.”* (hearing parent)

7.2.d *parents may question whether they have contributed in some way to their child’s Deafness or hearing loss*

*“I think what was hardest – well, it was hard to believe - because it took me about 10 years of trying to fall pregnant with my child - he was conceived via IVF. So I guess that when you’ve been through all of that, you don’t expect that you’re going to have other problems. And when we went along and had one of the scans, I think at 18 weeks, the measurement that they do at the baby’s neck was a bit thicker, and it could have indicated Down’s syndrome. So we decided to have an amnio just to make sure. But the results of the amnio showed that he didn’t have any of those terrible things that they screen for... But they also said when they did the scan that he might have some problem with his heart, so we had to go to a heart specialist to do a scan, look at his heart, and everything looked alright. So after getting the all-clear from everyone, we just expected that we would have a perfectly normal baby. And to find out that he could have all these things wrong was just really devastating, and you just can’t believe that it would happen to you. And you wonder why it’s happened. And I thought ‘Was it something that I did when I was pregnant?’ Though I couldn’t think of anything, because I didn’t drink any alcohol. I don’t smoke. I tried to do everything so right because I was so afraid of losing the baby after trying so long to have one.”* (hearing parent)

7.2.e *parents’ emotional responses to their child being Deaf or having a hearing loss may include gladness*

*“Of course the first reaction people have is ‘Ohhh I’m so sorry’, or things like that. But now when they do it, I’m thinking, “Well, why are you sorry?” And I just say ‘Well it’s no big deal. He was born that way. He knows no better. And he’s happy’. It’s really, really, difficult sometimes with him being deaf, and me being hearing and from a hearing background. But in some ways I’m really glad he’s deaf because if he was hearing, he wouldn’t*

*be the same kid that he is now. He'd have a totally different personality. And it's because he's deaf that he is the way he is, and he's such a little character. He's really expressive."* (hearing parent)

### **7.2.f for parent, coming to terms with the necessary complex challenges ahead can be overwhelming**

*"Getting the diagnosis wasn't actually a relief as such – it was still 'My daughter's deaf. We don't have a perfect child as we thought'. Yes, diagnosis is good, but just starting the process of getting into the lessons, play group, day care, explaining to everyone about hearing aids and the FM system. You've got to learn how to change batteries, how to test the aids, how to use the FM, how to put the cochlear in properly. It's just the mass of information that you get, and you just sit there and you think 'Oh my goodness'. It's just overwhelming."* (hearing parent)

### **7.3 The family background or experiences of the parent may influence how they feel about having a Deaf child or child with a hearing loss;**

*Parents who have a family background or experience with Deafness, hearing loss, or disabilities, may have different responses to those who do not*

- *the influence of personal belief systems held about Deafness and hearing loss (as a disability; as normal; as cultural)*
- *differing hearing status and background between parents and family members can result in unmet emotional needs, or conflicts in reactions and hopes*

*"But I guess I've grown up with other disabilities around me. My brother is intellectually disabled, and my mum's best friend – her son was intellectually disabled too. So for me deafness hasn't felt like a disability because of the disabilities around me. And that really helped me to deal with it better. I just see my child as a person who is deaf, and we just go through life. And the cochlear implant has done wonders."* (hearing parent)

*"And I'm not worried about my child being Deaf because I have the experience of being a Deaf person. I know that I need to teach my child about the hearing world as well; because it's very difficult, the hearing and Deaf worlds are like opposites. And I want my children to be aware that there are lots of hearing people around us. So I'm trying to be open to all issues. But it's not that difficult for me. I feel that I'm the same as you, but I just can't hear. But I have excellent peripheral vision, and I'm very visual. So it's important to share and talk, and not to feel left out as well."* (Deaf parent, from a hearing family)

*"And I felt very frustrated. I was asking my husband's family, and they had different points of view, because my husband came from a Deaf family. So I felt that we both had different points of view. And they agreed that a Deaf child should go to a hearing school because it's so much better, and they were there to support me, so that made me feel a lot happier. But for myself, I wish sometimes that my children weren't Deaf. But I have to accept that they are, and just move on with my life."* (Deaf parent, from a hearing family)

*"I've got 4 children. I'm married to a Deaf man. The first 2 children are both hearing, and the last 2 children are both Deaf. My 3<sup>rd</sup> child, I didn't know she was Deaf until she was 2 years old. I was very shocked. I didn't know how to cope. I was panicking. I was very disappointed..... and I was very depressed and very shocked. And I thought 'Goodness what do I do here?...When I found out...I drove to my husband's work after the hospital appointment. And I was crying and upset. And my husband said to me 'What's wrong? What's wrong?' I said to him 'Our daughter is Deaf'. And my husband - BIG smile on his face!! I said 'WHAT?!' And he was saying 'Oh! It's a new member of the Deaf community'. And then I became more depressed. 'Why are you upset, because you are Deaf yourself?' he said to me. I said 'Well, you don't understand.'" (Deaf parent, from a hearing family)*

*“It was a shocking time for me and my parents to find out.... It was horrible. I cried, as I was hoping he would be a hearing child. I knew my child would have a great chance of being deaf since I found out the father’s side had such a great chance of deafness in the family. It was horrible, shocking.... My child’s father, he was so happy and dancing proud to have a Deaf son....He said ‘Don’t worry, be happy, he is a fine healthy boy’. But there was more risk in his family history gene, which worried me for my child’s future... I was too upset to do anything, just had to find out all I could so I’d know what to expect. Which was very upsetting for me but I had to get to the bottom of it.” (parent who is profoundly deaf, from a hearing family, with a cochlear implant, who identifies with both the Deaf and the hearing community)*

**7.4 Mothers can feel that a delay in identification of their child as being Deaf or having a hearing loss can have a positive impact on their opportunity to bond with their child because of the period of “worry-free” time prior to concerns arising**

*“I have to say though, that I’m glad I didn’t know my child was deaf for that time. So even though it’s great that the Healthy Hearing is providing screening, I was glad I didn’t know because I didn’t have to worry about it! Once you find out, you worry about it. And I know that professionally it’s very important to start those hearing aids soon. But 12 years now down the track, this lack of 12 months, I don’t think it’s so important. Maybe his speech could be a little better. Maybe he could have heard a little bit before. But I was glad, because then I could be just a mother. I enjoyed him without having to worry. I didn’t feel sad about the delay in diagnosis. I’ve never changed my mind about that.” (hearing parent)*

*“But my choice would be to find out at 4 weeks, not at birth. Because you have 4 weeks to bond with your baby before you find out that there’s a problem.” (hearing parent)*



## 8. DECISION MAKING

This section of the consultation findings focuses on the decision making processes and experiences of parents as they select the communication options and early intervention centres / organisations for meeting the needs of their child and family. The factors that influence parents' decision making, as well as the impacts and consequences of making particular choices, are explored.

The consultation findings for this section are presented under the following main themes:

- 8.1 Parent choice of early intervention centre and communication development options is made around a range of factors
- 8.2 Parent choice of early intervention centre and communication development options can involve decisions to relocate place of residence for better / easier / wider access
- 8.3 Parents can see value in seeking multiple communication development options / a combination of communication development options;

Parents want to be able to change early intervention centre and / or communication development option within a supportive environment;

Parents who change centre early intervention centre and / or communication development option can experience unsupportive responses from others

*"Probably within 3 minutes of walking in that door, I knew that I was going there. My child just took to the woman there, it was so clear that this was where we were coming. She was not only super professional, but her body language, the way my child just took to her - so I knew immediately that she had that rapport with children."* (hearing parent)

*"I'm definitely going to move to Brisbane because I could not live with myself knowing 'What if? Would he have been better off?' I have to at least give this a go for my own peace of mind too."* (hearing parent from a regional area)

*"Parents have to feel that they have the power and that they shouldn't have to keep quiet about choices so they are not upsetting any professional groups. And that's not right."* (hearing parent)

## **8.1 Parent choice of early intervention centre and communication development options is made around a range of factors**

### **8.1.a competent professional standards and expertise are observed**

*“And it was the best that my child could get there – a beautiful lady who really got him going and helped me a lot, even after I left the Unit. She came to my place.” (hearing parent)*

*“So I went about going for interviews. The first place I went to I wasn’t impressed with straight away. I went to Yeerongpilly then, and I just thought ‘Yes this is it. This is what we’re going to do’. So I wrote copious notes about it, they were just lovely... I was fairly adamant that I would go to Yeerongpilly, but then I thought I’d go to an interview at the early intervention centre, with Auditory-Verbal. Probably within 3 minutes of walking in that door, I knew that I was going there. My child just took to the woman there, it was so clear that this was where we were coming. She was not only super professional, but her body language, the way my child just took to her - so I knew immediately that she had that rapport with children. She said for me to come for a trial lesson. So we did that, and I couldn’t believe it, he was just a totally different child. And even at that time I thought I’d give it 6 to 8 months, and if it’s not working, then I’ll think about going somewhere else. But he’s just gone beautifully since he’s had the implant. He’s zoomed along fabulously.” (hearing parent)*

*“My child’s teacher, now for about 3 years, is a Deaf person as well, so I really value her opinion. Because she’s a Deaf person, so she knows, I think, better than I do, what is better for my child in some areas. I think I’ve been really lucky to get some good advice from them.” (hearing parent)*

*“And we’re moving into preschool next year and so that’s going to be another new concept for us. I’ll be going through Catholic Education and we’re pretty confident with the visiting teacher we’ll be having.” (hearing parent)*

### **8.1.b an open professional attitude about options and choices is found**

*“It was important to me that the professional didn’t tell me that you must stop signing. She said ‘You have to do what you feel is right’. She said ‘I will give him Auditory-Verbal, but you must do whatever you must do’. She knew I was not going to give up signing. But at Hear & Say, they tell you if you want to try us, you stop signing.” (hearing parent)*

*“She was the only professional who ever accepted me carrying on with the signing. And my child and her sat at that table and it was almost like they were dancing together. This professional was wonderful, and I thought ‘This is the lady I want working with my child’. And so we shifted and the teacher at the place I was leaving was very hurt that I was leaving her.” (hearing parent)*

### **8.1.c a friendly and helpful atmosphere is experienced at the centre, including a good rapport with and attention to the child**

*“And it’s a friendly welcoming place. They couldn’t do enough for us, and we were just given so much information.” (hearing parent)*

*“I never forget going for my first interview at Hear & Say, and mid sentence, the therapist wasn’t even listening to me because my child started to make a babble. And the therapist was talking back to him, and she said to me ‘I’m really sorry, but when a child talks to me, I’ve got to listen and talk back’. And I was so WOW!! That really jumped out at me. They weren’t just talking to me and my husband; they were talking to my child. They were supporting us, but they were primarily there for helping my child. He was number 1 and that was the best thing.” (hearing parent)*

*"I visited the early intervention centre at Hear & Say, and at Yeerongpilly, within the first 6 or 8 weeks of diagnosis. And I thought the teachers at Yeerongpilly were wonderful and very nurturing, and they seemed to bond with my baby. So I made that early decision just based on who seemed friendly and supportive, not anything to do with communication choices. And in hindsight it was the best decision for us. We started signing straight away to my child, and signed pretty intensely for the first few years."* (hearing parent)

#### *8.1.d a family member or partner expresses a preference*

*"But my husband said 'We are not signing. And I could see his point of view, like we would have had to learn it. But I'd be learning with him so that would be okay.'" (hearing parent)*

*"If I knew that my child had verbal dyspraxia then I would have forced the Total Communication on my husband, so that my child's frustrations would have been less, and communication would have started a lot earlier. But I don't think I could have known this earlier. It's not until he's going to speech therapy, and they try to practice the sounds, can you know about the problem."* (hearing parent)

*"So I really thank my mother because she gave me a lot of value for life. And now I'm assertive enough to do whatever I want to do. And Mum said to me just before she passed away 'What will you do if you have Deaf children?' And I went 'Just exactly what you did'. And so I don't like putting Deaf children into a Deaf school because they have very different curriculum to a normal hearing school. There's not much opportunity there to learn. So I would prefer to have my children involved in a hearing curriculum as long as they have the support such as interpreters or note takers."* (Deaf parent)

*"My husband decided: No Signing - let's go with Oral-Auditory approach. And so I picked a centre, but I wasn't 100% happy. I was happy with Total Communication, listening, signing - EVERYTHING. But I went with my husband's way because that's what he wanted to do. He felt more comfortable that way."* (hearing parent)

*"My husband never liked the signing issue because it was to him: 'My son's different'. Coming from a hearing family and not knowing anybody who was deaf or hearing impaired before, it was just an issue my husband has of: 'My son will be different.'" (hearing parent)*

*"Mum didn't want to learn to sign; she didn't want my child to live in a world of deafness. And I think the family's ideas were really what swayed it. We've got a normal child. She just can't hear. Her ears don't work. As simple as that."* (hearing parent)

#### *8.1.e the centre appears able / not able to provide the required approach or supports*

*"I took my child up to Yeerongpilly and they just laughed at me, and said 'Well he's going to sit here with no language at all around him, and he needs language because he's mild to moderate. And it's a nerve loss and he'll never have a cochlear, and this wouldn't benefit him here, with no language.'" (hearing parent)*

*"I chose Yeerongpilly because they were able to provide both speech and Sign Language."* (Deaf parent)

*"We went through Catholic Education. We chose that because we were thinking of the future, going to school, that he'd have the teacher aides at the Catholic school. And he's done so well with the early intervention. They'd come to the house once a week, and they'd visit him at preschool. And they still visit him at school now, twice a week."* (hearing parent)

*8.1.f dissatisfaction is experienced with a previous early intervention centre and / or communication development option; the parent searches for something better*

*“So when I went to look for the other place, was when I realised that the teacher was not trying to do anything with my child, because she couldn’t. She was happy to keep him there as someone who wasn’t going to perform well..... And when I left, the teacher said ‘I know why you left. I’m so glad that you’ve left because you don’t see half of the things that happen here’. A lot of parents were very happy to have the kids go there in a taxi, come home in a taxi, and they don’t even see the place. For those parents, they have no idea what’s going on. And we had a really bad experience, and I know we were not the only ones.” (hearing parent)*

*“I thought I did not want my child there because I was already feeling very uncomfortable. And towards the end, my child was supposed to be there for 2 hours, and I would stay for an hour pretending to have a coffee, and I would be back half an hour before the time. I was beginning to feel that my child was not being very well looked after. Neither were some of the other children. The ones like my child, who could be a little assertive, they really didn’t like them. They liked the ones who sat and did nothing. And one of the teachers was so rude to me! They all found out I was with the early intervention centre. The teacher said to me ‘Are you going to St Gabriel’s? He’ll never do anything there!! It’s obvious there’s something wrong with his brain!’ This woman has been with my son for 2 years! And St Gabriel’s is wonderful. It was my choice to go there. My child went to a regular kindy and they would visit a couple of times a year; she would make sure they were doing the right thing. And for the next few years we had a good time.” (hearing parent)*

*8.1.g the convenience of multiple services at one centre*

*“And we could actually have his hearing test done there which is a really big thing when you live out of town. Because when I fly to Brisbane every 8 weeks, for me to have his hearing test AND his therapy lessons at the one place was amazing. Not having to take him from appointment to appointment, and parking, and finding places, and just the stress...And that meant a heck of a lot to us when we live out of town.” (hearing parent from a regional area)*

*“A few months later, I still wanted my child to access the S.E.U. (Education Queensland) because he was having physiotherapy there too.” (hearing parent)*

*8.1.h observation of / information received from other parents and their children*

*“We spoke to other parents, we were given phone numbers of other parents that had walked the walk that we were about to, to get their advice and to give us a run down on Auditory-Verbal therapy and the work of the Hear and Say Centre. And also people who were remote as well. That certainly helped us to make the decision to go that way as well..... And their (Hear & Say) playgroups, too, were a big help.” (hearing parent from a regional area)*

*8.1.i a convincing direction is gained from self-research or the opinion of a professional*

*“And after reading different studies on the internet, I decided I didn’t want to go orally.” (hearing parent)*

*“So then I went to Hear & Say, and from your first contact with them they are saying ‘Auditory Verbal is the way to go, NO SIGNING!! SIGNING IS OUT!!’ But that is the way they go. And with the ‘Choices’ magazine, it is really good, but at the same time, when I got on the phone to Hear & Say, they’re just saying ‘Auditory Verbal is the way to go. That’s it’. And that was it, my child was there from 11 months, and that’s it!!” (hearing parent)*

*“After my child was diagnosed, we went to Australian Hearing, got the hearing aids...She had hearing aids from 2 years and 2 months, and she got the cochlear at 3 and a half. When it got to 12 months with the hearing aids, Hear & Say seemed to think that her hearing was going down, so they suggested the implant. And she was finding it hard to talk and hear on the telephone with my mum, and they said that’s one of the first speech things that goes when they start to lose their hearing. Almost straight away, my husband and I thought we didn’t want the implant, and we thought ‘It’s a major operation. Does she really need it?’...And it took us 6 months to actually decide to have it done because she was our little girl and it’s a big operation. We thought ‘Is this going to really be effective?’ And the ENT said to us that she’s going to need it at some stage, whether it’s done now or later. So we made the decision, and we don’t regret that decision at all. And with her getting the implant, that gave us the opportunity to have another child, because I wasn’t having another child. So once we saw what an implant could do, it was a case of ‘OK, yep, that’s fine, we can do it.’” (hearing parent)*

*“The cochlear got mentioned to us at the beginning, but my child’s hearing loss was fine. So it was always in the back of your mind, but I never thought she’d be getting it. So basically this decision was made for us, which was quite good...her hearing loss is profound now so that is really the only option. So they told us it was probably the only thing if she wants to hear one day. So hopefully it works. So that part was fine.” (hearing parent)*

#### *8.1.j the child’s previous hearing background*

*“I think because my child wasn’t born deaf - he’d had that 18 months of hearing and he’d started to build his vocabulary - so when he had the hearing aids put on, he just loved it. He never took them off, we never had the flushing down the toilet, or anything like that. And then afterwards we went on to the cochlear implant, and he just loved it. He loves showing it off. And he wants to learn, he’s into everything, and he’s done wonders with the implant. So it was a decision made quite easy because he had heard before, and he’d just been cut off. He must have thought ‘What’s going on?!’ And the kids accept him at school and he’s just a regular little boy.” (hearing parent)*

*“And we didn’t do signing. He’s got a few signs, and we made up a few of our own, just to get through, but I think because he’d been hearing before, and already started to speak, I wanted him to continue with that.” (hearing parent)*

#### *8.1.k the child’s medical background*

*“I chose to go with signing because it felt right at the time. And the school was very close to us, so I visited and was welcomed. I didn’t call anybody else at that time. We went with signing and I felt comfortable, and within a week or two of signing to him he was signing back, like ‘milk’ or ‘Mum’. And I had no guarantees that my child would speak because of his facial nerve, and signing is good for hearing kids who can’t speak, so it must be good for deaf children as well. And for the 2 years that I was deciding about cochlear implants or not, I really didn’t see another choice but to go on with signing. Still trying to make him listen a little bit, but most important thing was that my child could understand me. At that time education was a long way away.” (hearing parent)*

*“We’ve come to realise now that he has to have signing. He has speech dyspraxia, and he’s not speaking though he can hear everything with the implant. So we are now currently signing and have been for about 18 months. And his understanding and communication is a lot better. The frustrations are nowhere near as severe as they were.” (hearing parent)*

*“My child is profoundly deaf and we do Auslan Sign Language. He has got a hearing aid. He only has a middle ear in one ear, the other ear has nothing at all basically – no inner ear. We had him checked out for a cochlear implant, but because he has an abnormal cochlear, and he only has the one cochlear, then it wouldn’t help him with his speech, it would only amplify the noise. And he has one hearing aid, but that basically only does the same thing – it just amplifies the noise. There’s nothing they can do that can make my child hear speech.*

*The hearing aid helps him only with situations where he's out around traffic, or something. But he doesn't like his hearing aid on. As soon as he gets home, he takes it off...I know that we had a couple of choices. We could learn Signed English or we could learn Auslan. But really Signed English wasn't an option for me.*" (hearing parent)

*"In hindsight it was a good thing that I decided not to go orally, because my child had really bad fluid in his middle ears for 12 months after his hearing aids were put on. And so for this time he was not wearing his hearing aids. That was a terrible time. I had to keep his hearing aids in, and me feeling guilty trying to make him wear them. So really 2 years after his diagnosis he did not have access to amplification. But with signing he developed a really good vocabulary by the age of 2."* (hearing parent)

#### *8.1.1 the geographic accessibility, financial imperatives, and religious orientation of the centre*

*"We thought about Taigum, but it was too far away."* (hearing parent)

*"I think I was extremely lucky to get onto Yeerongpilly Special Education Unit. I think that's probably the best thing I've ever done in relation to decisions I've made for my child.....I don't know why I chose it. I think it was because it was the closest one, and it was an Education Department one and so it didn't require money, and it wasn't religious. Not being Catholic, I didn't want to send him to a Catholic one. So we went to them and from there on, just basically gone with their advice."* (hearing parent)

#### *8.1.m parent desire for the child to have speech as the fundamental mode of communication*

*"And when we got the 'Choices' booklet, and we read about all the different programs, and when we looked at Hear & Say where our child would learn to listen and speak like a normal person, we just said 'That's the one we want'. And it has been so good, because if you think about it, all my aunts and uncles, my parents, my grandparents, would all have had to learn Sign Language, and my mum struggles at the best of times with new things, and I thought trying to teach them Sign Language would be so hard. And now my child talks to everyone, she hears things, and that's how we forget she's deaf because she can do everything that a normal child does."* (hearing parent)

*"And I remember being at Mum's place reading through this booklet, and looking at Hear & Say. I'd obviously heard about Hear & Say but I had no idea what it did, but I HAD heard the name. So when I got the booklet, I was just looking through it, and I was looking at Taigum and Yeerongpilly for example, and they teach everything, like sign and everything. And then I looked at Hear & Say and went 'Well this Auditory-Verbal therapy sounds good, in that she'll learn to speak'. And so I phoned up and made an appointment, and we were just happy with the interview."* (hearing parent)

*"I actually did speak to one mother, she's got 2 deaf kids, and her oldest son went to Taigum where they teach Total Communication. And she actually said to me that in the afternoon when he gets home from school he was that tired that he wouldn't talk, he would just sign. And I thought 'I don't want that for my child. I don't want her to come home from wherever she's been, and be that tired that all she wants to do is sign. I want her to speak permanently'. And I thought 'Well, that's where the difference is'. And when I was talking to Mum about it, that was one of her fears, that if we taught her sign as well as speech, then she'd revert to sign when she was too tired. Like when she couldn't think enough about the words, she'd just rattle them off on her hands. And I've seen people signing when we're out and about, and I look at them, and you sort of can't take your eyes off them. And with a little child it's twice as bad because they're way down on the ground, and if they can't talk they have to tug you to get your attention. Whereas with my child being able to speak, I just have to look down at her to listen to her, and she can say it clear enough. I don't have to stop what I'm doing, like if I'm holding the baby I couldn't sign. So that's where I'm glad that she's learnt to talk."* (hearing parent)

*“I was talking to Hear & Say, but also talking with the family about the different programs. Mum felt that it was most important for her to speak. Her idea was that she’s a normal child, she just can’t hear, but she needs to be able to speak.” (hearing parent)*

#### *8.1.n avoiding negative responses from others*

*“And I didn’t know any deaf people beforehand, so I didn’t have that situation of: she’s deaf, she should remain deaf. And my mum said to me ‘Don’t get involved with the Deaf community because they don’t agree with learning how to speak, and hearing aids, and cochlears, and everything. Don’t get involved with them because you will be ostracised for giving your child speech.” (hearing parent)*

#### *8.1.o personal perspectives on the potentials of identifying predominantly with the Deaf or hearing community*

- creating opportunities for the future*
- enhancing family relations / sharing the same culture*
- access to a new culture*
- enhancing social opportunities*
- maintaining personal identity*
- seeking physical comfort*

*“I made the key decision that my child should have cochlear implants if he’s suitable for it, as I had my child wearing hearing aids at the age of 3 months old, straight away, everyday. All waking hours he would wear them and hear noises. And I noticed he reacts well, and I thought him having a cochlear implant would be a bonus, and great opportunity in life. He would have a better life than I have in the world. I knew about cochlear implants for a long time, since I was around 20 years old. I did lots of research for myself before, so I was very interested in it....But my child’s father refused...He (his father)...wanted him left naturally Deaf and dumb: ‘As God made him so’, he said. I argued and discussed it with my family and....they agreed with me. I wanted my child to have cochlear implants to give him better opportunities in the future,...But he still can mix with Deaf communities, while he has great opportunities in the hearing world out there. I have my parents supporting me 100% and I know how it feels out in the hearing world, not being able to have better opportunities, as I have mixed with the hearing world and it was so frustrating and so hard, so tiring, annoying, when they can’t understand or hear me...With a cochlear implant it will be much easier and better for my child as there’s not many Deaf schools with teachers of the deaf left around. They’re shutting and cutting back slowly. I want him to go to the local school up the road, rather than travel further to go to the Deaf school, so he can have friends up the road not far away from home. I went to a Deaf school but couldn’t hang out with friends until the weekend, which is no fun through the week.” (parent with a hearing loss)*

*“I also found it really hard when my child was first diagnosed and we were going through the decisions on the cochlear implant. I always felt very strongly that I wanted her to still be part of the Deaf community....And there was so much going on with appointments, speech therapy, ENTs, operations, the Deaf schools – that I probably lost that perspective along the way because my first few attempts I just couldn’t get anywhere. And I still wonder if I’m robbing my child of something because she is really just involved in my hearing world, and goes to the regular school which I went to. And I sometimes think that I should have pursued that further. But I almost feel it’s too late because she’s totally oral now, and she’s happy, and she’s got her friends. But maybe I’m taking the easy road because it’s easy for our family. But I was very strong about that at the beginning, and I somehow lost my way with it. How to do it? How to meet Deaf people? How to involve her in groups with children of the Deaf?...I would have loved to have waited and let her decide if she wanted the cochlear implant or not. But obviously you can’t do that because it doesn’t work as well unless she has it young. And we do live primarily in a hearing world. And I have no regrets about having the cochlear implant now because I’m seeing how well she’s doing...And my experiences are with hearing people. Even through Yeerongpilly, and the*

speech therapists - they're all hearing, and so their perspective is from a hearing perspective, and they are the only perspectives I've had." (hearing parent)

"I struggled a little bit with whether to have my child implanted with the cochlear implant, or not, because I had done reading about Deaf culture...and so someone that was Deaf would see us signing, and they would talk to us – not that our signing was really good enough. And they would express their views on the cochlear implant, and people we met were quite against it. And so I struggled with the idea of accepting our child for who she is – a deaf person – but having her involved in our family and our hearing culture. And so I opted for the cochlear implant because I thought 'Well if I was a Deaf person and my husband was Deaf, well I probably wouldn't have my child implanted, because that would be our culture. But I am hearing, my husband is hearing, all our family is hearing, and I want our child to be part of that'...I thought my feelings about our child are the same as a Deaf person's – because I'd read that most Deaf parents want their child to be Deaf. And my daughter - she usually takes her implant off in the afternoon after school and at night, and she says 'I'll just have some peace and quiet for awhile'. And she's very happy to wear it, or not wear it, both ways. And I have always tried to encourage that, not make it a big issue about whether she wears it or not... But she wears it at school because she's at a regular school, and she knows she needs it, but at home she's very comfortable without it – although that frustrates me at times because I don't have good enough signing!!" (hearing parent)

"I was thinking of the options - What would their future be like? Should we let them be a Deaf person without the implant? Or have an implant? And I've been Deaf all my life, and I've never had a cochlear implant. But I was thinking with my own children - What will their future be like? What's the best thing for THEM? So I've been to numerous appointments to see the specialists and doctors. And I just held off on that, and I waited to see what happened with my 2<sup>nd</sup> child, to see if we could make a decision at the same time, rather than have a decision separately. And with my 2<sup>nd</sup> child being severely Deaf, he wouldn't actually need to have a cochlear implant because he's able to hear enough....So actually if my 1<sup>st</sup> child was implanted they would both have the same hearing. Then they could have a chat together, or have a conversation, or share things together. But when I first looked at the cochlear implant, I thought initially that 'No I can't do it, no way, this is impossible'. Because I thought a cochlear implant would change my life. I would never be the same person, because I've been wearing hearing aids myself for 23 years, and I've never been happy with hearing aids, and I'm not the same person with them because hearing aids give me a headache, there's all this noise, it's very annoying, and it's not me, it's not the real me. So I take them off for a while and I think 'This is the real me. It's where I come from. This is how I am. This is me'...And I think the Deaf community is focussed very narrowly on the idea of cochlear implant. But after lots of discussions and chats, I thought to myself 'Well maybe it'll be good for the children, who are quite intelligent, and they're such quick learners, and they could benefit from them'. And thinking about the population in the future, numbers will dwindle, there's so many kids having cochlear implants now." (Deaf parent)

"I try keeping a foot in all camps because my vision for my child is that she grows up knowing that she's deaf, feeling okay about that, being fully able to mix in the hearing world, and if it's all too much and she wants to take her implant off and just go and have a chat to a Deaf person where she doesn't have to concentrate and think and get a headache, then she can sign. I'd like her to be able to mix in both worlds. And she was so little, I felt I had to make that choice for her, because you can't wait until they're adults and say 'Do you want to have a bash at speaking and here's a cochlear implant?' I just want to give her options." (hearing parent)

## **8.2 Parent choice of early intervention centre and communication development options can involve decisions to relocate place of residence for better / easier / wider access**

- *emotionally, socially, professionally disruptive*
- *financially disadvantageous*
- *breaking family and parent ties*
- *life restricting*
- *issues of equity*

*“Unfortunately my child is the only child in this town his age, who has a hearing loss, and so he would have to sit in a classroom where there is no signing support. I feel extremely furious that this little boy that I love so much, I value him, and the education system treats him as just another number. And it’s all about money and their convenience for their resources. And what makes me really really mad is that I don’t get any financial support to move to Brisbane. I’m a sole parent on a pension and trying to do the best for my son, and I feel like I’m being driven away from here. What choice do I have?...I’m not confident about this move. I don’t have any family or friends down there except for one other mother. But it doesn’t feel fair, but at the same time, to be able to cope, I have to have a level of acceptance of why it’s this way. And it comes down to the fact that he’s in a minority in Australia, and this is even more reason why parents need to band together regardless of what options or educational approach is chosen for their child. I know I can always come back, but I don’t want to come back here just because I can’t cope. I know my child is going to be in his element down there in Brisbane. He’s already enrolled into the Bi-lingual Program, and I’ve met the teachers, and I’m really happy about that. And I know I’m doing the right thing when I imagine him being there, and having the signing around him, and it being possible for him to sign to his peers. And I’m hoping I’ll find contact there with other parents too who I can establish friendships with.” (hearing parent from a regional area)*

*“It’s going to be terrible. I’m not looking forward to this move to Brisbane at all. Because I love it in this town. I just love living here. It’s going to be tricky because I’ll have to start all over again with finding a new paediatrician, and finding a new teacher for my child, another day care or whatever they have there, I don’t even know. Hopefully the teachers here can help me with finding someone in Brisbane..... But I’m not looking forward to it. And I’m counting on the services being there in Brisbane.” (hearing parent from a regional area)*

*“I would like to think I wouldn’t have to relocate. I would be contacting members of parliament before that happens. This is the only home that my child knows. And I think it’s a better place for him to be - not hearing - in a place with lots of space, unlike where there are lots of cars. I would have to get rid of all my animals, and I’d like to think that that wouldn’t be an option. I don’t think it’s fair that someone would have to be uprooted from somewhere they’ve lived for 10 years, because of a lack of facilities in a capital city. So I would probably consider transferring with my work somewhere closer to the city, so that I would drive my child to school and to work, somewhere close by. That would be what I’d do before considering leaving this house.” (parent in outer region of a capital city, hearing parent)*

*“I would never be able to leave the capital city because of my child....The Bi-Lingual Program is the only one in Australia. And so I’m limited to where I can live.” (parent in outer region of a capital city, hearing parent)*

*“I’m hoping that I’ve made the right decision but I’m not overly confident. As a parent I never feel confident that it’s the right way to go. You’ve always got in the back of your head at least once a day ‘Oh, am I doing the right thing here?’ But because I’ve given myself 100% to this, I don’t think I’ll ever come to a point when my child is older, where I’ll look back, and I’ll have guilt that I didn’t try hard enough. That’s why I decided I’m definitely going to move to Brisbane because I could not live with myself knowing ‘What if? Would he have been better off?’ I have to at least give this a go for my own peace of mind too.” (hearing parent from a regional area)*

### **8.3 Parents can see value in seeking multiple communication development options / a combination of communication development options**

- open access wanted to more than one early intervention centre / organisation at any time
- options are seen on a continuum, rather than as separate entities

*Parents want to be able to change early intervention centre and / or communication development options within a supportive environment*

- respect for parents as knowing what is best for their child
- the intervention to fit the child rather than the child to fit the intervention

*Parents who change early intervention centre and / or communication development options can experience unsupportive responses from others*

- pressure from professionals
- alienation from centres
- closed reactions from parents and communities
- requires individual resolve to follow your own choice
- creates 'the keeping of secrets'

*"I was asked by the teacher in charge at the Special Education Unit to make a choice. Even though she shouldn't have, she said 'You have to make a choice. Are you going to go Auditory-Verbal, or still come to the Unit?' I said 'Well I could do both. Because the Early Intervention Centre hasn't said that if I go there, then I had to give up the Unit. I'm entitled to access the Unit'. And that day was the last day I saw the teacher at the Unit." (hearing parent)*

*"But I think you need a positive image of all of the communication methods right early on, just for the reason that if the one you choose doesn't seem to fit right after a year or two, then you feel 'Hey, it's okay if I go and check out things. But we have to change the thinking of the professionals and the early intervention centres. They have got a lot invested in their systems.'" (hearing parent)*

*"And I think all these professionals have to understand that it is the parent's choice and if they want to change their mind, well, we have that right. If it's not working for your child then you should change. You're making a choice for what's best for your child, not what's best for them, the professionals." (hearing parent)*

*"I was always told that whatever decision you made, wasn't set in concrete, that you are always able to change at any time. And I HAVE changed, dramatically. I decided that I was going to change, and because I was the main carer for the children, I decided that this is what we're going to do, and that's what we're doing. I didn't feel that anything hindered me, because I've always been a strong person." (hearing parent)*

*"I wanted the cochlear done before she was 2, because the research shows - the earlier the better. And I quoted studies at the ENT. So my child was done, and the surgery went well, and because my child had all that signing, she started talking and responding very quickly. So we kept on with Total Communication, signing, for about another year, and then I really felt that I needed to look at these other options again. So I visited an Auditory-Verbal teacher, and thought 'Yes, that's what she needs now'. So I feel both choices were really good for her. The hospital said 'Well, you can't come here for speech therapy anymore'. And the Total Communication people were too upset to talk to me. And I kept saying 'It's not that I don't think that Total Communication hasn't worked for my child. But it's a continuum. I feel that children should be able to move back and forward for whatever they need'. And this is the big thing - too much professional pride invested in these early intervention centres. So it's not so much what the child needs, but the therapy is more important than the child it serves. And I was alienated from both sides. I now feel that I can't talk about how great I think*

*signing has been for my child, because she's talking well. And the Auditory-Verbal people say 'Oh, isn't she doing well!' And I don't feel that I can say 'Yes, all that early signing was great'. And the Total Communication people will think 'Oh, there's another one that we lost'. But I would do the same thing again. You need to find the method to fit the child, not the other way around. So there's been lots of dilemmas and stress."* (hearing parent)

*"The parent knows what's best for their child. Early intervention therapists see your child for one and a half hours a week, for 2 years, and that's it...It takes a few years to get a handle on the Deafness politics and issues, and I'd think this way for a while, then I would change. But once you know the direction for your child, I really feel as if parents' concerns should be given priority.*

*"Parents have to feel that they have the power, and that they shouldn't have to keep quiet about choices so they are not upsetting any professional groups. And that's not right."* (hearing parent)

*"Some of the Deaf community were against me and my son having cochlear implants. I don't see them anymore. But I said 'It's my choice! I have the right to do this for my son. He's my son!' And they said 'No no no. God made you this way for a reason. There's nothing wrong with being deaf.' But I think, what's wrong with giving my son better opportunities? Being able to hear gives him more opportunities."* (parent with a hearing loss)



## 9. SERVICES AND SUPPORT FROM PARENTS AND PROFESSIONALS

### 9.1 Services

This section of the consultation findings focuses on parents' views and issues concerning the provision of services which they use for meeting the needs of their child and family. Services which are addressed within the findings include child care, transport, education, information support, hearing assessment, and provision of hearing devices. Service access, availability, timing, approach, adequacy and standards are explored.

The consultation findings for this section on SERVICES are presented under the following main themes:

- 9.1.1 Parents can experience an uncomfortable lapse of time between identification of their child being Deaf or having a hearing loss and receiving of service support and information
- 9.1.2 Lack of appropriate child care can be a severe hindrance to families, and parents can feel this compromises their child's development
- 9.1.3 There are large variations in parent satisfaction levels with the schooling options available and educational services received
- 9.1.4 Transport to education facilities can be a major concern for parents and is seen by some as a major equity issue
- 9.1.5 Hearing parents who want their child and family to learn Signed English or Auslan can experience barriers to doing so
- 9.1.6 Access to services can be problematic for families in regional areas
- 9.1.7 Parents need professionals to work alongside them – cooperatively, inclusively, sensitively
- 9.1.8 Mothers want to be mothers, with a balance between parenting and doing therapy / teaching in the home
- 9.1.9 Issues around hearing aid supply and care can frustrate parents and increase concern for their child's development

*"The key is having someone who can communicate with my child. Like they say, communication is every person's basic right, and my child has a right to be able to have someone to communicate with him when he's in their care." (hearing parent)*

*"You have to have good professional people. And we have meetings together at the school, and it's a team effort. Like it takes a bit of an army to carry my child. And we're all batting for him, and heading for that same finishing line." (hearing parent)*

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### **9.1.1 Parents can experience an uncomfortable lapse of time between identification of their child being Deaf or having a hearing loss and receiving of service support and information**

- *delayed attention to the needs of the child and family*
- *sense of no follow-through*
- *feeling lost and without direction*
- *experiencing emotional / mental anguish*

*“My child was diagnosed at 12 months. When we did the tests we thought he was profoundly deaf and he started wearing hearing aids, and I started signing because, from the bit of information we received, I thought that he needed signing because he wasn’t hearing. Looking back, that was the first time I had a bit of trouble, because there was no real follow-through between what happened at the diagnosis, and me contacting Australian Hearing, and then from Australian Hearing making a choice. I was sort of left a little bit lost, and later on I thought that there’s not a lot of connection.” (hearing parent)*

*“And then when the girl at the hearing centre told me my child had hearing loss, I was floored. We weren’t given any information really at that stage, and it’s actually a bit hazy because it was very traumatic..... Then we were referred to Australian Hearing, and there was a time between that when we were given no information, we were given basically nothing. At that stage he was moderate to severe in one ear, and severe to profound in the other ear. And then when we finally went to Australian Hearing he had to have hearing aids. It was a long process. He got his hearing aids at 2, so there was a 6 months lapse without our child receiving anything. And of course, we’re being told now ‘Oh he’s a bit old to be diagnosed at 2.’ (hearing parent)*

*“And we didn’t get anyone sitting down with us to tell us the options, to talk with us, until we went to Hear & Say. But in between finding out about his hearing loss and going to Hear & Say, it was hell.” (hearing parent)*

*“Then we had more tests on the day of her discharge, via the audiology department. Luckily I had a lovely audiologist, but I felt really disconnected because I knew what was happening – my baby wasn’t responding to anything. The audiologist was very empathetic, she talked to me. It’s all a bit blurry what happened next. I think it was quite a few weeks before we had an appointment at Australian Hearing. There was this no-man’s land, this big gap, for about a month.”*

*“So it took us 6 months before we got to Australian Hearing. This visit to Australian Hearing was quite strange because the whole point of us going there was to find more information, and they said to us ‘Well, we don’t know if your child is going to need a hearing aid, but if she’s going to have one, she’ll need one soon. What do you want?’ And we said ‘Well YOU’RE the professionals, you’re supposed to advise US. And they said ‘Well we’re going to do this behavioural test’, which she didn’t respond to because she’s only 6 months old, and so they said ‘Just bring her back in 6 weeks and we’ll see what to do then’. So that’s where we are up to now.” (hearing parent)*

### **9.1.2 Lack of appropriate child care can be a severe hindrance to families, and parents can feel this compromises their child’s development**

- 9.1.2.a *no coordinated system of listed child care centres that can cater for Deaf children or children with a hearing loss; lack of child care workers who are competent in using Signed English or Auslan; time consuming and disillusioning for parents to search endlessly*

*“It’s so frustrating. I have made so many phone calls, I’ve gone through the phone book, and rung all the child care centres around where I live, and around where I work, and I’m asking if anyone knows some Sign Language. Well, some of them know Makaton which is the very basic one they use for more severely handicapped children who can’t really communicate. And that’s not good enough for my child..... So I have found, now, a child care centre where they do have a young assistant who does have some Sign Language,*

*but it's the only one I know of and I've only just found out about them through word-of-mouth, this year..."*  
(hearing parent)

*"I phoned Deaf Children Australia and tried to find out from them if they knew of any child care centres where I could send my child, and they found a guy who's deaf who lives at Forest Lake, who was prepared to look after my child free of charge on the days I had to go to work. So that was very nice of him to do that, but I didn't know him, and it's still a fair way away,...and it's pretty bad if you have to resort to something like that."*  
(hearing parent)

*"The key is having someone who can communicate with my child. Like they say, communication is every person's basic right, and my child has a right to be able to have someone to communicate with him when he's in their care."* (hearing parent)

*9.1.2.b significant impacts on family finances as the child's mother chooses not go to work in order to support their child; or long distances are travelled each day; especially significant for single mothers and mothers in regional areas*

*"It would be very very helpful if I could work and have an income on those 2 days my child goes to Toowong. Even if I could work for 6 hours on those days...And I've gone part-time so I can stay home and look after my child, and that is because there's no family day care carers that know sign language, and there's no child care centres that know sign language, so there really aren't any facilities..... So it's been very difficult because it means that during the school holidays, I can't put him into care because there is none, so I'm using all my holidays to look after him."* (hearing parent)

*"And after-school-care and before-school-care, that also causes a difficulty because I live so far away from Toowong, it would mean I have to drive over there and pick him up, and I don't think they know signing either. Also the government doesn't subsidise you for after-school-care like they do for child care."* (hearing parent)

*"Especially being a single mother, there's no-one else here to look after my child. It's working as well. It makes me mad that the government wants single mum's to go out there and work, yet if you are a single mum with a child with a disability, well how are you expected to work when they don't provide the facilities that you need to go out and work?"* (hearing parent)

*9.1.2.c lack of precise attention to the basic daily needs of the child within the child care centre e.g. care of hearing aids and cochlear implants*

*"And in this age of the working parent, I wanted my child to go to day care one day a week when he was 2, just to socialise him with other children. Now, day care centres are all 21 or 22 year old girls, and I'd go from one day care centre to another and another, to try to make them understand what he needed, how he needed his hearing aids in at all times. I told them that if he was in the play area and sand pit, then I don't expect him to have them on because I would be looking for them buried, and everything like that. And it was very difficult. And in the end I was happy, he was in a day care centre for 2 years, but I have to say I really don't think he had his hearing aids in for very much of the time at all. Just because it's too hard for them to be chasing him around. Now imagine if I was working full time! And then if the child is in day care 5 days a week, what are they going to get from it?"* (hearing parent)

### **9.1.3 There are large variations in parent satisfaction levels with the schooling options available and educational services received**

#### **9.1.3.a parent concern that public state education / schooling is not accommodating the needs of their child**

- **signing support**

*“There’s one school here that I was told that my child would go to, because that’s where all the deaf kids in the town go. So I relaxed and I wasn’t too concerned about it. But then just before he started kindergarten I started questioning how’s he going to go in the classroom, and I ended up finding out that he had to go to a private kindergarten to get an interpreter through Commonwealth funding. So then I started to think, well, what happens when he goes to a public school – he won’t get the funding for an interpreter. So I went down to the school one day and they weren’t very helpful, they were like ‘Well, what do you want?’ I said I was just trying to work out what would be in store for my child when he starts preschool. And she said to me ‘Well what do you mean, like what type of things? What exactly are you after?’ I said ‘Well, will there be someone signing in his classroom?’ And she turned around to me and said ‘No, because if there was someone signing all the time in the classroom with him, then he wouldn’t learn to speak’. And alarm bells went off in my head then, and I just thought ‘I can’t stay in this town’. Because what she said is a huge big statement, when there’s no research to back up what she’s said.” (hearing parent from a regional area)*

*“After his diagnosis, Australian Hearing referred me to his advisory visiting teacher, and we received a visit from her..... it made me annoyed that she didn’t know how to sign properly, and that she couldn’t teach me different signs. She was learning herself and that was frustrating.” (hearing parent)*

*“So I went to see the head of the special needs at Education Queensland, to try to find out what was going on. And what it basically comes down to is the factor that unfortunately my child is the only child in this town his age, who has a hearing loss. And so he would have to sit in a classroom where there is no signing support. I feel extremely furious that this little boy that I love so much, I value him, and the education system treats him as just another number. And it’s all about money and their convenience for their resources.” (hearing parent from a regional area)*

- **social / behavioural support**

*“I’m finding that a lot of the times kids who are full signing are put into the too-hard-basket...and a lot of the time they are sent to the office for unacceptable behaviour. And I think that’s more for the teacher to have a break, than anything. The deaf kids are straight to the office, whereas the other kids have several steps before that happens. Like in the playground, my son had shouldered someone in the line, so he was straight to the office. Whereas the hearing children would have been talked to about it.” (hearing parent)*

- **educational standards**

*“I’m feeling that education now is excellent. We go to Yeerongpilly one day a week, and my child’s language is really improving, and he knows everything and what things are, and we just communicate all the time. And with his hearing it’s actually getting worse and worse, but still signing is fine and that’s how we communicate, and he doesn’t miss out on anything because of signing.” (Deaf parent)*

*“I’m fighting all the time for people to understand that because my children are deaf, doesn’t mean that they are intellectually impaired. And they can learn as much as any other hearing child. Basically they have the right to do it; they have the right to learn!! Education is a real worry, it’s a real concern, it’s so important, and we feel that it’s a little sub-standard.” (hearing parent)*

*“And Queensland Education seems to be well behind all the other states. And there are a lot of people who are moving from Queensland to interstate, to get a better education for their children, and we shouldn’t have to move to get the same education for our children as the kids in the other states get. Why is it like that? In other states they get a lot more support, more visiting advisory teacher time, more teachers of the deaf. We don’t get very much support.” (hearing parent)*

*“And I’m finding that it’s difficult for people to understand that the deaf children have the right to the same education as everybody else, and it’s hard to get that across to a lot of people.” (hearing parent)*

*“So I thought I was fine with the little kids, but then when it came to teaching the kids, that was a huge worry for me, because in Queensland it’s very different to other states. Here in Queensland the education was very hard to get the services that you need for your Deaf child in a normal school.” (Deaf parent)*

*“I’m really FOR education access for Deaf children, no matter where you are. As long as they’re getting the same learning opportunities as any other children are. That’s what I’m trying to fight for. I want them to be included with every other child, and so please could the Education Department accept what our needs are. And I think there’s a lack of experience in the remote areas in Queensland, not enough people who can support...If they were reflecting on what’s happening in other states, and they can then change what’s happening here, and modify it.” (Deaf parent)*

*“I am amazed that 12 years after I had all these dramas with my own deaf son, that young mothers of deaf children who I speak to now, are still having the same problems.” (hearing parent)*

- *diversity in / access to education / communication options*

*“I’ve had to send my Deaf child interstate to be educated because of Education Queensland’s inappropriate method of teaching Deaf children (Total Communication using Signed English). Initially I was advised to learn Signed English along with my son, which I did for approximately 7 years. As my son’s language was not developing I had to adopt a different approach of communication with him. An interstate organisation called Deaf Children Australia have been most helpful and supportive with their advice in the area of my son’s education.” (hearing parent)*

*“My child started Grade 1 this year. We’re finding education very hard. He is integrated. Where we live there’s only one school that has anything to do with deaf children.” (hearing parent)*

*“Earlier in his schooling, it became obvious that Education Queensland’s method of communication with deaf children was not appropriate for our son’s needs.” (hearing parent)*

*“Some sections of the ‘Deaf Industry’ ..... would have parents believe that if their deaf child is allowed to use Sign Language as a communicator, then it will hinder their ability to learn to speak. We feel from our experience with our own deaf child, and many others we know, that this is completely wrong. Even children with cochlear implants can benefit from early exposure to visual language - Auslan. From our experience we have found most children, both deaf and hearing, love to learn sign language, and do so easily.” (hearing parent)*

9.1.3.b *classroom teachers require further specific training in order to accommodate the needs of a child who is Deaf or has a hearing loss; parent vigilance and presence at the school is sometimes deemed / predicted to be necessary*

*“I’ve tried ringing lots of other schools in my region, to get my children to go to different schools, because we have a teacher of the deaf for my Grade 1 son, and everything that she’s learned about deafness is out of a book, she doesn’t understand deaf behaviours. I got a note home the other day to say that the teacher is not happy when my son touches other children...He is told that if he wants to touch them he must sit with his hands in his lap and count to 5. I mean, that is a deaf thing!!! Deaf children and deaf people touch each other, for goodness sake!!...And she is a teacher of the deaf, for heaven’s sake!! So maybe these teachers of the deaf need to be in the Deaf community, and learn these issues, not just out of a book.” (hearing parent)*

*“We have found it totally frustrating with education attitudes in Queensland because of lack of appropriate training for teachers. And experts who do not understand Deaf culture and Deaf issues, in most cases do not even know the language – so once again the deaf child has to come to the hearing world. What we feel hindered us, was getting information from people who regarded themselves as experts, although in hindsight I feel they were not sufficiently trained to understand deafness and deaf issues in children.” (hearing parent)*

*“Every now and then you see the other children go through their stages, normally, that our children are delayed in. And as the children get older you can see the differences are getting wider and wider. When the children are young, as babies or toddlers, it’s not such a big difference because they can get away with so much, that people don’t notice the difference as much...and my daughter, now at 9.5 years old, is socially struggling for friends. Both my children are integrated, but socially is where we’re finding it very hard. I try to spend as much time at the school as I can, helping the teachers out. I shouldn’t have to...but I feel like I have to spend time helping the teacher as much as possible, doing their job. And I need to be me. I haven’t been me since before the children were born....” (hearing parent)*

*“So I think it’s important for parents to drop in unannounced into the Centre, because I came behind one of the teacher aides screaming at my child, ‘You are the naughtiest child in the world, and that’s why no-one likes you!’ I thought ‘Thank god he’s deaf; he’s not hearing you’. But mum heard!! That these places get all the support from the government, and there’s no checks, no-one comes in to see if these people are doing their job properly, if the right work is being done.” (hearing parent)*

*“Because aside from his hearing loss, he’s doing great, so I think it’s joyous for us and the family to know that he is going to a regular school. But the concerns that you have are ‘Is he going to get the support that he would get if he was in a special needs class or school? Is he going to cope with children teasing him?’ I will stand on top of the teachers, stand on top of the support staff, ensure that he gets funding, getting parent help, making the school and the class aware of his hearing loss and aware of certain things like sounds which can impact on his hearing like air-conditioners and moving chairs. Also making teachers aware that if there’s a day with a lot of background noise, then he might be out of sorts, and perhaps he’ll get a bit cranky, and so then they shouldn’t put it down to him being a naughty boy – there’s a reason for it - he’s got a headache because it’s hard to concentrate for a child, and they get tired. I think I’ll need to keep the school on their toes.” (hearing parent)*

*“And one day the hospital rang the teacher about my child’s cochlear implant, and asked how he was going with his hearing. And the teacher complained to me ‘You know the hospital just asked me all those questions, and how am I supposed to know!’ And I thought ‘You’re supposed to know!’ I didn’t even make a comment, I went home, I rang other places...” (hearing parent)*

**9.1.3.c** support and awareness-raising systems can be lacking in the school environment and community

*“Sometimes I want to go to schools and make presentations at assembly, to explain to all the other children about the Deaf issues. Make all the hearing kids realise what’s happening and learn from that. And talk to the principals of schools because they are responsible to make sure that things are okay with all children, and make Deaf children inclusive.” (Deaf parent)*

*“And it’s been very upsetting, terrible, mostly with ignorant people. I had one woman (a parent) say that she didn’t want a deaf and dumb child in her daughter’s class, which is really sad. But then I realised that she’s ignorant, and it’s sad that people like that are still in this world.” (hearing parent)*

*“And the division between the deaf and the hearing – that’s what it’s like at school as well. My daughter will approach people and say ‘Can I play with you?’ But when they keep saying no, you don’t get taught to deal with rejection. And maybe if she is playing with a group, they say ‘Let’s go and do such-and-such’, off they go, but she hasn’t heard, so she thinks they don’t like her. They’re not thoughtful enough to say ‘Hey, we’re going here now, come with us’. It’s just growing up, maturity, I suppose. But also, this school is supposed to cater for deaf and hearing impaired children...So you would think that they’d be more understanding or have it in place that somebody come along and talk about how it is to be deaf, or have a buddy system for the children, because they are all struggling, all 8 of them.” (hearing parent)*

**9.1.3.d** advisory visiting teachers are an invaluable support, and are needed as early as possible

*“The advisory visiting teacher is lovely and she’s taught me a lot. I only wished I had it earlier...maybe after he had his hearing aids put in, or when he was about 4 months old, because he was home by then. It didn’t start earlier because...we never quite caught up with each other for months. And I was just too busy for her to come out with all my child’s appointments, or with school for my daughter. It wasn’t a lack of being able to access it, it was more trying to find the right time to do it.” (hearing parent from a regional area)*

**9.1.4** Transport to education facilities can be a major concern for parents and is seen by some as a major equity issue

- *rights of the child to receive the most appropriate schooling*
- *concern about possible future cutbacks to taxis*
- *geographic boundaries which decide taxi access can be inflexible and limiting*
- *limited options in mainstream schooling can mean excessive time spent in driving children to school*

*“I think the transport problem is because too many children go mainstream, and that makes the taxis very expensive. But bad luck for Queensland Transport, they have to do this. The child has the right to receive the education that they need, and we have to respect the rights of the child to go to the school that they need to go to, no matter what.” (Deaf parent)*

*“Queensland Transport have decided to cut back on the taxis. The taxi has been great. I travel 30 mins to and from school every day, because I don’t have a choice of schools in this area. There’s only one that will cater to the hearing impaired children. And Queensland Transport will cut that out at the end of this year. We’re advocating already for every single thing in these kid’s lives as it is, it’s so frustrating, really hard.” (hearing parent)*

“So the closest school to us is Yeerongpilly where my child goes 2 days a week – a taxi takes him there, which is subsidised from the government – and the other 2 days a week he goes to Toowong – for which the government won’t subsidise the taxi because it’s not his nearest school, and it’s only free if you live within a 25km radius and we’re just outside of that. It’s the same program but it’s held at 2 different venues, so we have to drive him, it’s about 40 kilometres one way, it takes me an hour to get there in the mornings, and about 35 minutes to get home, then about 35 minutes to get there in the afternoon and 35 minutes back again. So a big part of my day is spent just driving him to and from. And there’s nothing I can do in between...So I can’t work on the days that he goes there...Whereas on the days where he catches the taxi, I can go to work..... but I can’t do that if I have to drive him to school, but I can’t survive if I don’t.” (hearing parent)

### **9.1.5 Hearing parents who want their child and family to learn Signed English or Auslan can experience barriers to doing so**

#### **9.1.5.a families and children need easy access to teachers and courses for learning Auslan or Signed English**

“As in our case, if the parents decided to embrace their child’s Deafness, a fluent Auslan teacher could be made available to teach the family and the Deaf child Auslan – the native language of the Deaf – as early as possible. We cannot emphasise the importance of exposing the Deaf child to accessible language as early as possible. The hearing child hears language from as early as birth, so it is vitally important for the Deaf child to have access to language just as soon. In the case of a Deaf child, it has to be a visual language for them to have full access to it. This is to avoid the inevitable language delay experienced by most Deaf children which then carries on to their schooling, which means that they are always behind their hearing peers. This does not have to be the case if the child is exposed to Auslan as soon as possible. This is not only our opinion; it is the opinion of world renowned experts in Deaf education.” (hearing parent)

“I’ve gone to TAFE and done a signing course. That was very difficult, but I guess that’s another thing that I think the government could probably do to help deaf children, and that’s to pay for them to go to signing classes. And perhaps if they were extremely generous, also to pay for the immediate family, like the grandparents, because my parents now have a hard time talking to their grandchild. Mum and my sister did a basic Sign Language class, I think at Yeerongpilly SEU, years ago when my child was a baby, and it was Signed English. So they know a few signs. My child is now quite good at showing you what he wants, so if he needs to show Mum, he’ll grab her hand and take her to whatever it is he wants.” (hearing parent)

“Because of the lack of resources in this town, I’m not able to keep up with the signing, and we are struggling now. He wants to say more to me, and I want to learn sign, but I’m not able to access a course in this town. And we’ve been making a transition to Auslan at the moment. Before that we only had a 6 week course in Signed English, only the basics. It was a matter of getting the book down and looking up the word and remembering the sign. And that’s frustrating in itself too, when you want to tell him a new word, he points to something and you’ve got to go and look up the book, and by the time you’ve worked out how to do the sign, he’s lost interest. That was a very frustrating time. They do have courses on Auslan running here, but the last 10 months the teacher has been on maternity leave, and so it’s bad timing when I’m making the transition. And it’s been tough, too, making the transition from Signed English to Auslan, extremely. It could have actually been prevented. It was due to the choices I had to make about education.” (hearing parent from a regional area)

**9.1.5.b** *parents can experience stress when they can't keep up with their child's growing need to communicate*

*"My minute to minute daily interactions with my child are harrowing. There's a lot of anxiety involved with what I feel on a daily basis. My ability to be able to communicate with him the last 18 months more so, him wanting to communicate more, and it's heart breaking. I mean he's a very happy little boy and he doesn't get easily frustrated, but the concern of being a parent for him does play on your mind constantly when you compare him to normal children. Just the frustrating daily task where I need to look at him more to communicate, and get down at his level, and I can't have anything in my hands because we sign together. I started learning Signed English when he was 12 months old and he picked up the signing really well, so he's been able to communicate which I'm really grateful for. Initially I was leaps and bounds ahead of him, but as he's getting older I'm not able to keep up."* (hearing parent)

**9.1.5.c** *there are difficulties accessing the current Signed English dictionary*

*"And it also frustrated me that the Signed English dictionary was out of publication, you couldn't purchase a copy. There was 6 months where I wanted to learn Signed English, as this is what they teach in the schools in this town or all the schools in Queensland, but the parent cannot buy a dictionary."* (hearing parent from a regional area)

**9.1.6** *Access to services can be problematic for families in regional areas*

- *extended travelling*
- *unstable connection to professionals*
- *unavailability of some essential technical or medical testing procedures*

*"Up north it was fine when I got there. They had an ENT surgeon and my child just got set up with her hearing advisory teacher. Because we just figured out that she was deaf a few weeks before we moved, which was very difficult. So we quickly went to Australian Hearing, got the moulds done, and then it got sent from Tweed Heads up north to us. And she had the ENT there, but then the ENT left, and then they got another ENT, and I don't think he was qualified or something so he had to leave, and then they had another one, and now they're not getting another one, so that went down the drain. They've got the audiology department still there, but they can't do the mapping for the cochlear now that there's no ENT. So they told me all this, because I did have the cochlear in the back of my mind this whole time, but I thought 'Oh if they can do the mapping here it's just the actual surgery that you have to go to Brisbane for. But they can do everything else here'. But now that they can't, it's really hard that there's no-one there. It's hard."* (hearing parent from a regional area)

*"It's a lot harder when there's only one car in the family and the partner works. Access would really be limited in that situation, because you have to drive down to the main town – there's nothing here in this town for hearing impaired facilities. Although, the AVT does come to us, which is good. But everything else I have to go to the main centre for. It's not difficult for me though, you just do it."* (hearing parent from a regional area)

*"Talking to different professionals - his speech therapists, his audiologist, his teacher, his AVT – and when I had questions, they would honestly sit back and say to me 'I'm really sorry, but I don't know'. There are no experts here in this town on deafness. Like the speech therapists would say to me that my child is the first child with a hearing loss that they've worked with."* (hearing parent from a regional area)

*"Australian Hearing gave me booklets with lots of information about the service supports, which helped us find where to take my child. The only trouble was, most of the places to go were in Brisbane and I lived in another region. The location was limited, which is hard."* (parent with a hearing loss)

### **9.1.7 Parents need professionals to work alongside them – cooperatively, inclusively, sensitively**

9.1.7.a *a team effort between all – parents, child, therapist, audiologist, AVT, school, social worker – with common goals*

*“Because I’ve been extremely fortunate that my speech therapist, my audiologist at Australian Hearing and Mater, and the visiting teachers at Cath Ed, have all been so wonderful. And I think that’s the bottom line. You have to have good professional people. And we have meetings together at the school, and it’s a team effort. Like it takes a bit of an army to carry my child. And we’re all batting for him, and heading for that same finishing line.” (hearing parent)*

*My child is at kindy this year and he’s got an awesome teacher and an awesome aid, and his advisory visiting teacher (state) comes to visit him regularly, and they all meet regularly to sort out his funding etc. My biggest concern is will that carry on into primary school? I always worry - me as a parent sitting down at a table with specialists or a teacher - and I say ‘This is his hearing loss, these are his needs, and this is what hinders and helps him’ and I sometimes wonder if they think I’m just an overprotective parent. But I think if we have the evidence there, and the support there, and his teachers and his x-teachers, and his advisory teacher, and they’re all supporting what works for him – then I think we can’t go wrong.” (hearing parent)*

9.1.7.b *understanding the WHOLE family – beyond the clinical*

*“And maybe a little bit more training of professionals such as audiologists, to consider the outside factors of the parents and the child - Have they have a bad night? or, Are they sick? or, Have they got a death in the family? And if they don’t seem to react or respond very well to you, maybe there’s other factors. Professionals probably need a little bit more training. For example, they consistently have to attend workshops for how to liaise with families and relate to little children.” (hearing parent)*

9.1.7.c *understanding Deaf issues, culture and language*

*“Would be great to have an advisory visiting teacher who understood Auslan and Deaf issues.” (hearing parent)*

*“It wasn’t until he started kindy this year, and I had to really look into what was available to have an interpreter at the kindergarten. Like if I hadn’t gone ahead and looked into that, then he would be at kindergarten without an interpreter. But now he has an interpreter and she knew how to do Signed English and Auslan.” (hearing parent from a regional area)*

### **9.1.8 Mothers want to be mothers, with a balance between parenting and doing therapy / teaching in the home**

- *an over expectation from professionals regarding the amount of therapy parents (mothers) will do at home i.e. the therapy as a lifestyle*
- *over emphasis on therapy and teaching in the home can be impoverishing to the bonding and enjoyment between parent and child; the child can become “work” rather than “joy”*
- *there can be child resistance to the amounts of therapy expected beyond actual appointments – causing stress for the mother*
- *there should be an emphasis on helping parents to be parents – to build loving relations*

*"I did find that the professionals are always about "teach teach teach". And a lot of the times you feel like you're the child's teacher, and it's hard then being the parent. Because all the time you are trying to put so much information and communication in for the child, that you forget to be the mum. I'd like to enjoy my children more, but I find it hard."* (hearing parent)

*"Yes I am always feeling that I become teacher to my children, all the time. The teacher, to make the language and speech okay, and try to make sure the hearing aid is okay. And sometimes I feel like she's my student, not my daughter. But last night it was beautiful, I sat down because I had such a headache, and my 3<sup>rd</sup> Deaf daughter said to me 'Mummy you don't look well. You are sick. I love you. I'll take care of you, you have a headache. I'll be kind'. And when she said that language I thought 'WOW!! Lovely!!' And lots of sentences were coming out, and I've never seen her do that before."* (Deaf parent)

*"And it's important to help parents to be parents to their children. Because sometimes the child can become just work to the mother, for years...I play with her, and I talk to her, and I do all of that, but I am NOT her therapist, I am her MUM, and I have to build a loving relationship with her. And I kept working part time when my child was a baby because I think parents can focus their whole attention on this child who is deaf, and they forget about everything else that's happening around them. And I think parents need to feel that it doesn't have to be hard work, this is still your little baby that you love and cherish."* (hearing parent)

### **9.1.9 Issues around hearing aid supply and care can frustrate parents and increase concern for their child's development**

#### **9.1.9.a waiting times for replacements, repairs and parts can feel prolonged and unnecessary – What do we do meanwhile?**

*"With regard to services, I felt okay in that area, but I'm not really happy with the timeframe because it took such a long time for waiting. And if the hearing aids were lost, or the batteries had run out, because they were such cheap quality they would obviously be destroyed very quickly and therefore the kids would miss out on their hearing time."* (Deaf parent)

*"When the hearing aid breaks, or when the wires in the implant break, you want it now, you can't wait 6 weeks."* (hearing parent)

*"I'd like that Australian Hearing have a bigger supply of the parts. You may have to wait weeks to get those parts in. Instead of having a pile of those parts, and then when you go in, it's there, and it's fixed."* (hearing parent)

#### **9.1.9.b an issue of equity – not just the supply of technical parts BUT felt as neglect to the rights of the child for health and well being**

*"It's vital, the time we need to get the hearing aids fixed or fitted, rather than wait for so long. To have a quicker process and a more effective timeframe. When hearing children hurt themselves, they can be seen to straight away, so why not Deaf kids, why can't we see to their needs straight away too?"* (Deaf parent)



## 9.2 Support from “like” Parents / “like” People

The focus of this section of the consultation findings is on ways in which parents would like to be supported through their journey of having a child who is Deaf or has a hearing loss, from the moment of identification of Deafness or a hearing loss, and continuing into schooling years. The consultation findings emphasise that parents want and need ongoing sensitive support from (a) other “like” parents and people; and (b) a case-support professional.

The consultation findings for this section on SUPPORT are presented under the following main themes:

- 9.2.1 Contact with other “like” parents is highly desired as it can bring social / emotional understanding and educative outcomes
- 9.2.2 Mentor / support parents in an “official” support role need to be trained
- 9.2.3 Deaf and hearing parents see value in forming connections and relations
- 9.2.4 Parents have been attempting to link and network together, with varied success and with many factors revealed

## 9.3 Support from Professionals

- 9.3.1 There is a great desire for parents to have the option of access to a support professional, beginning from the time their child is identified as being Deaf or having a hearing loss
- 9.3.2 The support professional should have a range of specific characteristics
- 9.3.3 The model for professional support to parents / families should be flexible to each specific case, based around a plan of action, and be open to parent control (of WHEN?, HOW?, WHETHER?, WHO?)

*“We really need to look after the primary care givers because if they’re not looked after the whole thing falls apart” (hearing parent)*

*“Someone to support you, because mothers need to be strong to help the little one. You can’t be a blubbing mess 24 hours a day like I was the first month!!” (hearing parent)*

*“Just someone to bounce off. They listen to what your problems are. You need a shoulder” (hearing parent)*

*“Someone different to tell, outside the family, where you can cry and let it all out. There’s nobody” (hearing parent)*

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## SUPPORT FROM “LIKE” PARENTS / “LIKE” PEOPLE

### 9.2.1 Contact with other “like” parents is highly desired as it can bring social / emotional understanding and educative outcomes

#### 9.2.1.a to have someone to talk and cry with; to just “be there”

*“And maybe through a parent support group we can actually contact the parents, and if they don’t want to talk, then that’s fine, but probably most parents are just DYING to have someone listen to them, give them a tissue, and just be there.” (hearing parent)*

*“I did not have any contact with any other parents at all. And that was so detrimental to me. Phone networking or support groups would be great.” (hearing parent from a regional area)*

*“Even just to have another parent to walk with the other person, that is something that would probably make life simpler.” (hearing parent)*

*“I’d get an answer to one problem, but then I would worry about the next problem. What about when he goes to preschool? What’s going to happen when he goes to school? And you’d just like to have someone to talk to about the future.” (hearing parent)*

#### 9.2.1.b to feel less alone and to have the comfort of relating to others who share similar experiences

*“And I would have liked some more support with other mum’s and their experiences, maybe in a group. I think that would help you not to feel so alone, more of a feeling that my child isn’t the only one. When I go shopping with his hearing aids in, people look and say ‘Oh my god look at his hearing aids!!’ They feel so sorry for me and him, and to me it’s nothing. Even though I’m busy, I would find the time to go to a group. I think it’s because they know what you’re going through. Any tragedy in your life, you will turn to people with the same tragedy, because you know they understand and they can feel for you.” (hearing parent from a regional area)*

*“To speak to someone else that can understand what you’re going through is a massive help. Because they understood where I was at that time, and I could see that there was light at the end of the tunnel from where they were standing. Because they had done the walk that we were about to do. So it was a big deal.” (hearing parent)*

#### 9.2.1.c to gain information and seek advice which can’t be found elsewhere

*“What would be terrific is if parents could have the case worker help the parents to make decisions as far as finding out where to get the information, and once they’ve made the decision of communication option, to have a parent to call on who has a child that is grown up now, but has chosen that particular option.” (hearing parent)*

*“Having someone who you can talk to. It’s one thing talking to your family, but they say ‘Oh you should do this’. But you think ‘Well, fair enough, but we’re the one’s making the decision, like how are we supposed to decide which one is better?’ So just someone who explains things. Even just someone who’s walked through the system and they can say ‘Well we went this way and that’s our experience’. And have another person too, who went another way. Then at least you can listen to different experiences, think about what can happen with the different ways,...and it can help you work out sometimes what you DON’T want. So someone who’s been through it, or an impartial person who knows the systems and knows what all the options and therapies are.*

*It's one thing to see it written down, but until you actually experience it, you don't know, you don't actually know how it's done and how they do it."* (hearing parent)

*"Contact with other parents in a similar situation would be great.....And I don't know of anyone except for one other mother, who is in the same situation, who's a hearing mother from a hearing family with a deaf child, and she's a single mother too. Because everyone else, at least one of the parents are deaf. I think it would have been really helpful to have someone who's aware of the difficulties we face as hearing people with deaf children. Advice on how to put them off to sleep without sound. Just a phone number to be able to ring someone if you were having a hard time. I know I ring this other mother if I'm having a really hard time."* (hearing parent)

*"My mum was really helpful. But I found it difficult, even when I went to the health care nurse and got together there with a mothers' group. It was hard because if I was having problems, say with getting my child going to sleep, the first thing that most mothers naturally say is 'Have you tried music or a ticking clock?' or something like that. And then they go 'Ohhh sorry, I forgot'. But soooo much of that sort of advice seems to be involving sound, for hearing children. So I found it really difficult because no-one really knows, except for other parents of deaf children, what works for deaf children...I probably didn't meet other mothers like me until my child started going to Yeerongpilly Special Education Unit, round about kindy."* (hearing parent)

*"But I can't underestimate how important it is to speak to people who have had that experience. I have met a few parents whose children have grown up and it's been really helpful speaking with them, and a couple of things they've said to me where they felt they went wrong. And like one mother said to me that one thing she regrets is not concentrating more on explaining emotions to her 2 deaf sons. So that was terrific because now it's a main focus of mine so that I don't make the same mistake."* (hearing parent)

### **9.2.2 Mentor / support parents in an "official" support role need to be trained**

*"We all have a preference or a bias, but if you're not able to put that aside, and say 'There's all these different ways of doing it, and they can all have good outcomes, but you have to find what's best, and what you feel you can go with'. If someone can't do that then they shouldn't be in a support role. We need to explore the whole language of what it means to be unbiased."* (hearing parent)

*"These parents would have to be trained to do this, not just anyone,...just because I'm a parent of a deaf child doesn't mean that I can listen. Because over the years I've had parents almost pushing me to do things, and you think 'I have to be able to make a choice, but if I don't do what this parent is saying, then I'm going to hurt their feelings'. So that obviously wouldn't be the right person to go and ring up new parents."* (hearing parent)

### **9.2.3 Deaf and hearing parents see value in forming connections and relations**

#### **9.2.3.a for getting vital information to "hear all the sides"**

*"One example of support would be this type of group (the focus group). Where we can get together and talk about all the issues, to hear all the sides, the Deaf community side and the hearing community side, whether a child is implanted or not implanted, and talk about each different perspective, and give each other ideas."* (Deaf parent)

*"And sometimes you want to ask a Deaf person what it's like to be Deaf, but you feel bad, and think they might think you're being too personal. And it's hard when you don't have great communication with your child because they can't express it, and so it's helpful if someone else tells you what they went through, so you know what your child may go through, or how they may feel, because your child can't express that to you."* (hearing parent)

### 9.2.3.b for social inclusion and social experiences

*“Recently I went to see a Deaf play and I took the children with me, and the club accepted the children straight away, I was accepted straight away. I have felt more accepted with this Deaf community than I had in my hearing world and my hearing friends and family. For the first time in years I actually felt really comfortable, and people said ‘Let the children be their normal selves, let them go, let them be free’, because I was all the time saying to them ‘Quiet, quiet, don’t do that’. Whereas the hearing community that I’m in expect so much more of the children and they don’t understand the social differences. People just don’t understand.” (hearing parent)*

*“My daughter knows she’s deaf, she’s fine with that. I’ve always brought them up to have self esteem and confidence. But her lack of social friends at the moment is bringing her self esteem right down. I asked her to draw a picture the other day of something that made her happy, and she thought for a minute and then she said to me ‘I can’t think of anything that makes me happy’. And that’s really sad. And I know most of it is because she’s struggling socially, so I’m trying to be a bit more involved in the Deaf community so that she sees other children with hearing aids, and that are signing. She likes to sign, and we have a lot of fun with signing. I’m not proficient at it, but I’m trying.” (hearing parent)*

### 9.2.3.c for seeing hope and opening possibilities for the future

*“And just somebody, like a Deaf parent, who can show me that they’re not going to die. Apart from giving parents magazines on intervention, I think you need to deal with how they are feeling in their head and their heart, and particularly for the mothers. And I was feeling sorry for my child too, and that affected my mothering in that first year.” (hearing parent)*

*“And I’d like to be more involved with other Deaf families because maybe later on in his life my son might want to be in the Deaf community. But I would like to be more integrated with them now, so the children are more accepted. But it’s really hard to find anybody in the Deaf community who accepts the cochlear, because they think ‘There’s nothing wrong with me, why fix it, Deaf is normal and who I am’. But realistically my son is deaf in a hearing family and this is the real world for him. And if this is not the path he wants to go on he can chose later on in life what he wants. But I’d like to be involved in the Deaf community now, for him to be able to make that choice, and so that the choice won’t be so hard later on in life.” (hearing parent)*

*“And to have contacts in the Deaf community who have open arms. It would be good to be able to go to a social group where they’ve got parents of deaf children. Like when my child was first diagnosed, I would have loved to meet some teenagers that were deaf, and see that they are all okay, they are coping. I’m still looking forward to have that happen, because I haven’t really yet.” (hearing parent from a regional area)*

*“I think now, since I’ve met some Deaf people, and I realise that there is so much that they can do, that they do have good lives, and that they can do lots of things – it’s much easier now, but back then when I didn’t know any Deaf people, I thought ‘What’s my child’s life going to be like? Awful.’ But especially now, when you see Deaf people who are teachers, and there’s a lot of them that do labouring type jobs, but there are also people who go on to do better, and that’s really great, I think.” (hearing parent)*

### 9.2.3.d concerns of hearing parents when forming connections with Deaf parents

*“...And because I couldn’t use Sign Language I didn’t feel very comfortable, I couldn’t communicate with other parents with Deaf children, because a lot of them are Deaf themselves. I didn’t know of other people in my situation that came from a hearing background and had a deaf child. So it was probably not until I started learning some Sign Language, and when my child was a little bit older, that I started having more to do with Deaf parents. And even now when I talk to them I feel stupid – I’m always doing the Sign all wrong - and I feel*

*horrible when I have to ask them to repeat themselves. But I don't feel so strange about it now, not so uncomfortable around Deaf people."* (hearing parent)

*"But not to have contact with Deaf parents straight away, because I would have been very scared I think, not ready for it straight away. Maybe when my child was about 2 to 3, when I had accepted it a bit more. Because you are scared of things that are different. For me, I remember once having to deal with a Deaf person in my job, and as soon as they come it's a bit scary because you don't know what to do. But then again it's hard to communicate with Deaf people, and you can't always have an interpreter."* (hearing parent)

*"I don't think contact with Deaf people because that's all a bit scary and overwhelming straight up."* (hearing parent)

#### **9.2.4 Parents have been attempting to link and network together, with varied success and with many factors revealed**

9.2.4.a *it can be difficult to access parent support groups or individual parent contacts – Where are they? How do I find them? Can I get there? Will it be supportive? What forms could be used to link together? Do I have the energy / time to organise a meeting?*

*"I find there's lots of different groups all around but they're all fragmented. I guess it's not a bad thing that there's lots of groups, but it's accessing them, knowing where they are."* (hearing parent)

*"In a regional area though, a parent group probably won't work very well because I haven't met anyone else up here with a child with a hearing impairment. I think if my only choice was a phone network, then I'd take it."* (hearing parent from a regional area)

*"I've got no-one who I could ring and say 'Oh can I just come over for a cup of coffee?' And I've found that really really difficult, and I still do. Like there was a friend who has a hearing impaired child, and we had been getting together on a Friday night once every couple of months, and her daughter has many other complications as well as her hearing, and I found that that's been really good. We chat for hours, and she's local too. But it's taken a long time to get that. But I still can't just ring her and say let's have a coffee, because she's got other children."* (hearing parent)

*"But I have sought out support groups before, but most of them were on the Northside and I'm way over on the Southside. It's difficult to form any friendships and get over there and socialise with them. And when you're not working you can't afford to be driving all over the place. I met this other mother through Deaf Children Australia at the Hands & Voices meeting. I met her then, and she's the only person I know who's in the same situation as me, and it's just so good to know someone who's in my situation."* (hearing parent)

*"We have a play group in this town but there are a lot of young mum's from the 16 to 25 age range. They dump their kids off and have a gossip. I'm interested to take him there but I'm not interested in looking after everybody's child while they gossip and I try to interact with my child. I'm left there looking after all the kids...That's my choice though. I could probably go down to the next major town if I wanted too, I'm sure there would be a few play groups down there that I could join. But it's a matter of petrol being priced so high, the actual money. So yes I guess I feel a bit isolated."* (hearing parent from a regional area)

*"We have 14 deaf children that live in my local area. And I have bumped into only 2 parents in our local area, but not the others as yet because we are so busy, because of our kid's special needs and that takes away our time. And I feel that other parents will be in the same boat, that they would have the same issues. But I'm trying to find some time to set up a parent support group, maybe organise a BBQ of some sort, but lately it's just been impossible."* (Deaf parent)

9.2.4.b *efforts to form parent support groups are often met with limited success due to complex issues of group composition, outreach, and personal factors*

- *the children having a similar hearing loss, therefore shared parenting experiences and issues*

*“It was important for me to find this mother who has the same situation as me, who I can really relate to. I believe that she fully understands what my problems are,...And I think if you have a child with cochlear implants or they can hear and speak even though they were hearing impaired, that’s totally different to having a profoundly deaf child who doesn’t have any chance of hearing and speaking. It’s totally different because they don’t have to learn Sign Language, they don’t have to run after their child when their child is only 6 feet in front of them, and they are not as limited in options as I am. So to me, getting in touch with a parent who has a child who doesn’t sign wouldn’t be beneficial at all for me.” (hearing parent)*

- *division between communication modes*
- *division between schooling systems (public / private)*

*“I go to the Hear & Say playgroup, even though we don’t go to the Hear & Say Centre. And that’s really nice, my child gets to see and play with other kids with implants and hearing aids. But I do feel that I can’t be open there, I can’t talk about the communication decisions I’ve made.” (hearing parent)*

*“I went to a meeting and there were parents of children who are either totally signing or signing plus verbal, and there was a very anti cochlear group, and a very anti-whatever out there. So I’m aware that this is out there, but as far as I’m concerned that’s their problem and I’ve made the best choice for my child.” (hearing parent)*

*“And getting parents together has also got something to do with the communication modes that you choose. When I tried to do the second attempt at my support group, I put on my flier that all communication options and education approaches are welcome. Because in the story in the paper they mentioned about my signing, and how I wasn’t in contact with other signing families, and I think that deterred people. And it’s a real shame that people across the communication options don’t communicate well with each other, because no matter what option you choose it’s still hard, and I think parents should still be able to lean on each other.” (hearing parent from a regional area)*

*“I tried to start a parent support ..., and I had Deaf people come, and a professional from Deaf Children Australia. No other parents of deaf children came. And I had put on the flier – a parent support group for parents, grandparents, carers, anybody of deaf and hard of hearing children, no matter which mode of communication they use – I made it broad so it included everybody. I know there are quite a few deaf children in this area, but they’re oral so they don’t like signing, so they’ll have nothing to do with me because we are signing, Total Communication. And they send their children to private Catholic Education, whereas my children are public. I don’t know if that makes a difference.” (hearing parent)*

- *finding “someone like me” to relate to*

*“I tried to start my own support group when my child got to the toilet training stage. I was having so much trouble I just wanted to talk with other parents of deaf children – I hadn’t met any.....But I tried to start up this support group which had a story in the paper, and the first group had about 2 or 3 families turn up for that, but the second one, no-one turned up again. I don’t know why, but I can only relate to how I am, and I have met 2 other mothers here in this town who have deaf children, but we don’t have as much in common. Like one is working and the other one has trouble with being confident enough to be proactive and communicating. So, just because you’re a parent with a deaf child, doesn’t mean you’ll relate to each other. And when I went down to Brisbane and I met other parents who were like me, they were more proactive and wanting to make*

*changes and help out where they can. But some parents have 2 or 3 or 4 other children where they can't put so much energy into this.*" (hearing parent from a regional area)

*"But I wasn't one to go out to groups, I just didn't want to do that. I just wanted to deal with it myself, I'm that sort of person."* (hearing parent)

- *confidentiality of records*
- *not wanting the recall of past events*
- *getting on with a normal life*

*"I thought the advisory visiting teacher could have done a better job at getting parents in my town together, because there are 40 families here. There is such a lack of networking, and because of the confidentiality issue I wasn't able to get access to anyone's phone number. All the AVT could do was actually ring someone for me, and say can you ring this mother, and people wouldn't for whatever reason, like it brings up things from the past. And it could be because of the lack of support in this town, which in the first place puts people up to the point where they just want to get on with their normal lives and not focus too much on it."* (hearing parent from a regional area)

- *promotion of groups to attract parents*

*"And I was friends with a reporter of the local paper, and he did an article about my child, and wrote that I was asking for other people of deaf children to contact me. It was a full page thing in the local paper and I put in my mobile phone number. But I didn't get any contacts."* (hearing parent)

*"And also, you have to get the information out there too, to the different people, to let them know that there is a group."* (hearing parent)

*"Maybe if the parent groups could be more self-promoting. And if the government can help to promote them as well. Like if the parents want to come, then here they are."* (hearing parent)

## SUPPORT FROM A CASE WORKER/PROFESSIONAL

### 9.3.1 *There is a great desire for parents to have the option of access to a support professional, beginning from the time their child has been identified as being Deaf or having a hearing loss, for:-*

#### 9.3.1.a *emotional support and counselling / someone to talk to / follow up*

*“Places to go for support, like social workers, and how you’re handling it all. Because people deal with it in all different ways, and I know personally, because I didn’t get a lot of support from my in-laws, I would have loved to have gone to someone to vent how I felt.” (hearing parent)*

*“That you be referred straight away to a social worker, because they don’t know the journey that’s ahead of them, and they’re devastated, and they need to just be able to talk with somebody... Because I just thought ‘Oh woe is me. Why have I got this child? What sort of life is he going to have?’ That’s honestly how I felt.” (hearing parent)*

*“I suggest counselling, that is optional of course. But if the person doesn’t agree for a counsellor to come and see them, then to have someone that’s not identified as a counsellor. Because as a parent you try to cope, and you try to be strong, you try to do everything the right way, but we are still needing support.” (hearing parent)*

*“And someone like a case manager, like a social worker, someone who can follow these cases up, yes that’s another resource that they need as the kids get older, to follow them right through....It’s lovely to have that social worker backup.” (hearing parent)*

*“When my daughter went to school many years ago, there wasn’t much available then. You were more or less told that’s where you go, that’s what you do, and there was no-one to talk to... And there were never any social workers...And in between the appointments you are just left hanging there. I found that really difficult. And you’re always thinking to yourself ‘Am I doing the right thing? They said to do this, but should I be doing that?’ (hearing parent)*

#### 9.3.1.b *timely and sensitive provision of information, advice, referrals, networking*

*“Having a person, or a role model, or a consultant, to be provided and be available to a person. We’re getting all this information and if we can then have the possibility to contact this person...And that is better than ‘This is your problem, go away, deal with it’. At the moment it’s a struggle to try to get through our lives, it makes the grief longer, it’s very frustrating...And that person can then advise us, be more verbal rather than getting documents, and I’d like to talk to a person not a book. Face to face conversation is more useful to give parents options to their decision. It’s easier to know where they can then go. And then they can move on from there, rather than just hitting brick walls – Have I got the right place? Where do I go? If this doesn’t work, what will I do?” (Deaf parent)*

*“We need someone like a case manager. Someone that you come to and say ‘These are my concerns, and this is what I’m thinking, this is research that I’ve done, or talking to parents, or watching my child.” (hearing parent)*

*“There would be someone there to walk you through all the things that are out there, to help you, so you don’t always have to learn the hard way, and not go over everything again and again with other people. It would be like a short cut course, saving some of the frustrations.” (parent with a hearing loss)*

*“Not a piece of paper, but someone who can talk to you. Sit you down and say these are your options. And here is where you can go to get support, or depending on his loss, this is what these organisations can do for you. And this is what we are doing for the hearing impaired children in the world today. Because you have no idea if you’ve never had a hearing impaired child before. We don’t know anyone who’s got a hearing impaired child. You may have heard of hearing aids, and you may have heard of cochlear implants, but you’ve got no idea what can be done, and the fact that it may not be as bad as you think.”* (hearing parent)

*“I think a case worker would have been great because then at least you don’t have to think – Where do you go? and Where do you start? That would be a really great starting point, to answer all those questions that you have, and to give you the support that you need, or put you into contact with someone who does know, right from the start, instead of you taking a few weeks to find out anything yourself, and in those few weeks you’re going crazy. And knowing that someone is there if you are having a hard time, to call them.”* (hearing parent)

*“Because we’d go one step forward and two steps backwards with his respiratory problems, and then another hurdle. So to have someone be able to sit down and say ‘I’m really sorry that this has happened, and it must be really hard, but this is what is available, this is what you can do, well there’s cochlear implants, and there’s hearing aids and there’s play groups, and there’s this and there’s that.’”* (hearing parent)

#### **9.3.1.c assistance with planning, phone calls, research and information**

*“Because I was having coping issues, behavioural issues, and it would have been really nice to have that sounding board right from the very beginning...Because it’s not that you want to stick your head in the sand – well, sometimes you do!! You don’t want to know about it – but it’s just nice to have someone who would ring up for you and make some enquiries for you, and say ‘I’ll get back to you’. Or they may already have the answers for you. Because it’s so hard to get on the phone, you’ve got a baby; you’ve got all sorts of problems to handle... It’s not a lazy thing, it’s about coping as a parent, and I went through a stage where I just didn’t want to know. Like now I think we’re losing more hearing in the other ear and it’s like “OHHHhhhh!” It’s ongoing, trying to cope.”* (hearing parent)

#### **9.3.1.d accompanying to interviews / visits to centres and schools**

*“And giving parents support when they have to approach schools – about having their child there. I had quite a positive experience with my child going to our local Lutheran school, but I know of parents who approached another private school in the area about their little boy going there, and they said ‘Oh sorry, we won’t have the facilities to cope with a child with a cochlear implant’. Well that was really just a total misunderstanding on the part of the school about what that would involve. And so, help to be able to approach schools, because parents don’t always know what to tell the school what it will involve... And that’s what I find all the time – everything is new with cochlear implants – my child is the first cochlear implant student that the advisory visiting teacher has had, there’s hardly any research on cochlear implant students...Parents need support about knowing what to ask, what to look for, and how to explain their child’s disability to the school.”* (hearing parent)

*“If a support person/parent could go with the parent to visit the early intervention centres, and my feeling is that they would see Auditory-Verbal, Total Communication, and Auslan-Bilingual Bicultural.”* (hearing parent)

### **9.3.2 A support professional should have a range of specific characteristics:**

#### **9.3.2.a suitable professional background e.g. social work, psychology**

*“...counsellors or social workers who specialise in this area, for when the parents first get the diagnosis.”* (hearing parent)

*“Like a counsellor, facilitator, networker. With experience in this area.”*

*“You need someone who can stand back a bit and let the parent talk and someone who has a counselling background, like a social worker. Whereas this lady was a teacher and she really didn’t have any background on counselling or psychology. That would definitely be better.” (hearing parent)*

#### *9.3.2.b knowledge and experience in the fields of Deafness, hearing loss, and disability*

*“As long as this consultant has the experience and knowledge about all kinds of service provision, access, support issues, group support, the whole lot. They need to be prepared and not just have a limited knowledge ....As long as this person has accurate knowledge and understandings about the kinds of disabilities, not just Deafness – I mean Deafness with other disabilities would be important to know too. To know that when you go and see them, about the Deafness, or if we have any other issues, or behavioural problems, then this person could cover a whole range of issues.” (Deaf parent)*

*“Ideally it would be good to have someone with a huge background knowledge in deafness, and the different options that are available, and to remain unbiased.” (hearing parent)*

#### *9.3.2.c understands what it’s like to have children and can relate well to children*

*“And hopefully they would have children too, because people who don’t have children, don’t understand – they say ‘Why do you feel like this? Why are you upset? You’ll be alright.’*

*“I find that my child’s therapist, she doesn’t have children, and she sends me off with all this homework and I look at them and I think ‘Huh, well that ain’t getting done!!’ Because I’ve got a 2 year old and he doesn’t want to stay strapped in a seat for a lesson!! It’s hard enough getting him there once a week for therapy! So a worker who understands about having children.” (hearing parent)*

#### *9.3.2.d can be open / impartial to methods and philosophies, but also offering advice when needed*

*“And I suppose it would be important for the support person to be impartial because I’m sure there are people who believe that if their child is deaf then they should learn sign, and that’s the way it’s going to be.” (hearing parent)*

*“I’m not really sure about the case worker being impartial. Because I think that Yeerongpilly basically gave us all the information but suggested and recommended that Auslan would be the best. So I think sometimes, when you’re really unsure, then maybe you DO need someone who does know and has a direction. I don’t know, I can’t say I’m impartial at all about Sign Language method because I don’t understand why parents send their kids to learn Signed English, it makes me a bit mad even though I try not to, because I KNOW they’ve got a choice.” (hearing parent)*

#### *9.3.2.e open, friendly, confident, calm, empathetic personality*

*“She’s just got that natural way about her and she relates to my child well.” (hearing parent)*

*“I think the professional should have empathy, that they empathise with the situation. Because obviously people are going to be very upset, their dream in a way has been crushed. Confident in what they believe in is going to work, but also not saying that that’s the only way. Also giving you the best and the worst of what is possible to achieve. Someone who is calm and confident. And can sympathise with what you are going through. And someone who wants to pay attention to your child too.” (hearing parent)*

9.3.2.f *positive approach to addressing grief and problems; sensitivity to the parents' needs*

*“More support in the hospital. In an ideal world, you get diagnosed one day, and fitted the next, if that’s what’s needed – quicker follow up. I had a social worker phoning me after the birth and after he was taken to Brisbane away from me. And she’s ringing me up, and she’d say to me ‘How do you feel about this hearing loss? How devastated are you?’ And she was just really emphasising the negative side of it. And I ended up saying to her, ‘Please don’t ring me again because I don’t want to hear it, I’m dealing with it, I don’t find it a very big deal’. And she said ‘Oh, because it is a very tragic thing’. And I said, ‘Well, I don’t feel that way’. She couldn’t seem to accept that I didn’t feel that way. She wasn’t helpful at all, not listening to me at all. I would have preferred a positive approach.”* (hearing parent from a regional area)

**9.3.3 *The model for professional support to parents / families should be flexible to each specific family, based around a plan of action, and be open to parent control (of WHEN?, HOW?, WHETHER?, WHO?)***

*“And maybe some sort of a timetabling of systems, so that you’ve got a few weeks to go away and think about it and just be with your child, but you know you haven’t got months and months of doing nothing. So some sort of framework of doing this, and then this, and then this. And saying to the parent ‘Do you need to see a social worker? Or a group counsellor?’”* (hearing parent)

*“I think it’s important that, whether it be an advisory visiting teacher or a case worker, that it’s up to the parents WHEN they want they want that person coming to their house or to have contact, and WHETHER or not they want it. I mean, I used to feel with the advisory visiting teacher that it was compulsory, that I had to have this woman come into my house once a week, and I didn’t like it. And also WHO, I mean it’s such a shame to be put with someone who you really don’t relate to. It got to the point after 2 years where I was just praying that my advisory visiting teacher would leave town. She eventually did! Because she used to just play with my child and tickle him and carry on, and the very first time that she sat my husband and I down, she said that she was a great believer in the Lord! A very religious lady, she believed in the healing power of the Lord. And I was thinking this is just so unprofessional. And because of the vulnerable situation I was in, I wasn’t that assertive at the time, and I used to avoid her as much as I could. And you don’t need that! So the personality of those case workers – if they are overbearing – that’s really hard.”* (hearing parent from a regional area)

*“And then I guess every parent is different. Some will want information straight away, some people want to go away and mourn, some people want to talk with other parents, some parents don’t want a bar of other parents. So I guess, whatever that person needs, that there be some accommodation for that – if they want some information, if they want to join a parent group, if they want a parent contact, if they want to be left alone.”* (hearing parent)



## 10. INFORMATION AND RESOURCES

### 10.1 Information

The focus of this section of the consultation findings is on parents' needs, experiences, issues and preferences in terms of gaining information about their child's Deafness or hearing loss and what this Deafness or hearing loss means for the child and the family. Information access, delivery, modes, sources, timing, and content are explored.

The consultation findings for this section on INFORMATION are presented under the following main themes:

- 10.1.1 Parents' experiences of accessing and receiving information can be problematic and exhausting
- 10.1.2 Sources of information for parents are varied
- 10.1.3 Information needs are very individual. Specific information may be needed but is not easily accessed, can be misleading, or too late in coming, or fragmented between systems
- 10.1.4 A preferred mode of receiving information and understanding information is talking to PEOPLE. This information should be presented objectively, plainly, openly

*"We had no idea that there were choices. And we thought: Where do we go from here? Who do you talk to? Where do you start? Where on earth can you start that ball rolling? What do you do? Who do you ring?" (hearing parent)*

*"You don't want someone speaking at you with all these big words that you don't understand. And you're thinking 'What are you talking about?'" (hearing parent)*

*"But I got a lot of books and pamphlets – coming out of my ears" (hearing parent)*

## INFORMATION

### 10.1.1 Parents' experiences of accessing and receiving information can be problematic and exhausting

#### 10.1.1.a receipt of information can be erratic / incidental / accidental / absent

*"And then there was a fellow from my work, and his daughter had a cochlear implant, so he was quite good, he gave me some information and he told me the places I could talk to."* (hearing parent)

*"And the only glimmer of hope in that time period – I had no idea what sort of lives deaf children lead, I had no experience of deafness, I didn't know what it would mean having a deaf child, I didn't know that deaf children led wonderful happy full lives – was that a woman I met in Intensive Care said she had a friend with a deaf boy and he's got a cochlear implant, and he goes to a normal school, and he talks."* (hearing parent)

*"And I think if I'd been a younger person, maybe a bit more naïve, then I still wouldn't know that stuff exists out there, and I could have just thought I was the only person out there. It was just from pure chance that things happened."* (hearing parent)

*"And definitely more help as they're getting up to kindy age, like- Where to go? What does the public system offer? What do other people offer? Because I just stumbled across Catholic Education. I would not have known otherwise. And an impartial view, because our state school where we live, all I was told by my child's therapist was that he would be lost in that school, he would sink. But I don't know what the public system has to offer – I have no idea. So that was all I was told."* (hearing parent)

*"I think no-one talked to us about our choices. We were given a pamphlet. I'm not sure what could have been done to improve that, whether a social worker could have been involved. I was shocked that no-one was talking to us, someone to tell me this is the best thing for you to do if you want to go that way, this is the best thing because---. And we already had so much going on, it's like, what can we do now? How do we jump this hurdle?"* (hearing parent)

*"...we were just confused about what do we do now – here's another blow. It wasn't just dealing with a hearing loss....What is life going to be like for this little boy if he can't hear, as well as having lung problems? And we didn't know anyone with a hearing loss. And we were thinking, well - Do we have to learn Sign Language? What do we do? We had no idea that there were choices. And we thought - Where do we go from here? Who do you talk to? Where do you start? Where on earth can you start that ball rolling? What do you do? Who do you ring?"* (hearing parent)

*"Yeerongpilly were able to give me advice, like it was them that suggested my child should learn Auslan rather than Signed English, because Auslan was the main language of the Deaf community. Not having any idea about deafness, I didn't know there were different types of Signed English. I got onto Yeerongpilly SEU through Australian Hearing when we had my child fitted with his hearing aids when he was a few months old. They gave me the book 'Choices' and it listed all the types of educational facilities, and I went through there and chose Yeerongpilly."* (hearing parent)

*10.1.1.b information can come almost solely from self generated research, requiring much effort on the part of the parent*

*“After I found out my husband’s father’s side has the gene to carry deafness in the family, I needed to make sure what to expect. As it’s not that common, most doctors haven’t heard of it, so nearly all my information came from the internet.” (parent with a hearing loss)*

*“And any information we found we found on our own. And I didn’t even know that Deaf Children Australia existed, only this year I found them. I didn’t know any of the organisations.” (hearing parent)*

*“It’s tiring enough just with my daily interactions with my child, then having to sit up late at night on the computer researching. At one point my telephone bill was \$400 a month, from ringing all over the country. I did not want to be kept in the dark. Like I was ringing the Principal at the Victorian Public School for the Deaf, different schools, with teachers in Brisbane, with Education Queensland, trying to work out what to do.” (hearing parent from a regional area)*

*“Over the years I have thought, what if I hadn’t made those phone calls, would I still be waiting for the hearing aids? Would I still be waiting to contact teachers? And I thought, well I had a great support group around me – friends – but some people are quite alone. And there was no-one that knew my son had been diagnosed that contacted me.” (hearing parent)*

*“So then I started investigating the cochlear implant, I rang lots of people, asked lots of questions, went to any conference I could find, lots of research on the internet, and sifting through the misinformation on the internet.” (hearing parent)*

*“And the only organisation I’ve found that is impartial is Deaf Children Australia, and that was such a relief when I found them, and I only found them off my own back. If I had realised that all back then, then I would have learned Auslan.” (hearing parent from a regional area)*

*10.1.1.c information is gained in response to questions parents ask professionals, rather than it being forthcoming*

*“And it’s only with time and experience that you know what questions to ask...So all the time I just ask questions. I intend to ask more questions now. I intend to say ‘What else can I do?’...I advise parents to ask questions – don’t be afraid to ask. But it is hard to know what to ask, you don’t know at times.” (hearing parent)*

*“And if you don’t ask questions, then they won’t tell you. That’s what I’ve found. You really have to question everything. The amount of times I asked questions, then received the answer, and just been so relieved that I actually asked. But it’s extremely exhausting to be doing this all on your own.” (hearing parent from a regional area)*

*10.1.1.d information when received can remain unexplained and unsupported by professionals*

*“At Australian Hearing they just said to me ‘This booklet ‘Choices’ will tell you about different programs that are available, but you have to choose the one that you feel is best for you’. So then it was the case of actually sitting down and going through it.....And I think in the respect that Australian Hearing says just go home and read about it and decide which one you want – I think there could be a bit more intervention. Maybe even like a night or a day time information session, say once a month, where each of the centres come and talk about what they do. Then parents can get a hands-on idea of what they do, like how it’s all done with your child, what is involved.” (hearing parent)*

*"I don't have any questions now, but at the very beginning I did find that when we went to Australian Hearing they just gave me a photocopied thing called 'Choices' to read, and it was all these places listed, and you were just left – go off and read this and do what you think. We just went home with it, and you didn't really know."* (hearing parent)

**10.1.1.e**      *information can come too late or be irrelevant*

*"I feel disappointed that often I got information too late, because that means that my child has missed out on that little bit."* (hearing parent from a regional area)

*"And they did give us a small information book, but a lot of it wasn't applicable to our situation. So we just had to wait. And you think 'Should I be making more of an effort to interact with her? What other things should I be doing?'"* (hearing parent)

**10.1.1.f**      *information can be found to be inaccurate or misleading*

*"The only thing now, with the cochlear, they sent me the consent form but they sent me the previous last model, they didn't send me the new model that my child is actually getting. So I was a bit funny about that. I was reading up on everything, on how long the surgery is going to be, and all things like that, and then I go to the speech pathologist and she says well, no, and she showed me a really lovely booklet of the actual new model and what my child will be getting, and it was lovely glossy little coloured book.....Hopefully with the cochlear, it comes with a booklet like a hearing aid. It would have been nice if the consent forms have the right information, that's really been the only disappointment I've had. Not being able to see it, the new one, and know what my child is getting. And hopefully I get that when my child gets fitted."* (hearing parent)

*"But then you get a book called 'Choices' from Australian Hearing, you get told read through this, make appointments at a couple of places, and make your choice. So that's it – that's all we had. And you find that different organisations are all speech and listening, or all signing. They won't come together and help, and I found that one or two places gave me really misleading information."* (hearing parent)

*"So we went to this Centre and I got a lot of misleading information. They said 'The best thing is cochlear implants, that's the only way he'll listen and speak, because he has no hearing at all'. So we went this way and we were told that to have a cochlear implant we needed \$30 000. Well we didn't have that. As a parent you want to do the best that you can for your child, and of course the earlier that you get the communication into the child, the better, so the earlier they have the implant and learn to listen, the better for the child's communication. So for the next 10 months I spent all my time going out trying to raise this \$30 000. Like knocking on business doors, doing raffles, selling chocolates, doing anything I can to get this money. Which I found out later on – because I was continually told that the public system is really slow, you will have years to wait, you need to get the implant early, push push push you need to get the money, it's the best thing for your child – it's not the truth. By the time he'd had all these tests to say he was able to have an implant, I found out that publicly he could get the operation straight away. So I didn't have to do all of that. So I feel like I missed out on a lot of the proper normal grieving process, because I was so busy fundraising, I missed out on all of that. And I missed out on so much of my child's early childhood. I don't think I actually have grieved yet, if I'm actually over it..... And I think it's wrong, because anybody should be told that you can go either private or public, it doesn't matter which way you go."* (hearing parent)

**10.1.1.g**      *when information is received, it can cause overload and de-motivation for parents. Information received may not be immediately processed by parents due to their emotional state*

*“But I got a lot of books and pamphlets – coming out of my ears.” (hearing parent)*

*“At diagnosis, they didn’t give me a pamphlet. When I went to Australian Hearing - she was wonderful, don’t get me wrong - but she gave me this big thick book, and she says that anything I’ve said now is in the book, and you’ve got this big pack here for his hearing aid, and this goes here, and that goes there. And you get out of there and you think, ‘Okay, okay, what the hell was all that about!’ And when it comes time to doing it all, it’s like, ‘Ohh what did she say again? Ohhh what did I have to do here?’” (hearing parent)*

*“When you receive all this information as a parent, I just put it all aside. But at one time I sat back and I actually opened up this information, and I read it, and I thought ‘Ohhh I should have done this before’. But I just can’t be bothered to contact all the organisations, I don’t have enough energy to do it. I think ‘Should I contact them to make the initial booking?’ It still affects parents emotionally, because there’s so many services, and it makes them think ‘Oh I just can’t be bothered going there and making that contact’. And it’s really hard to be motivated to move on and do this. And because I’m Deaf myself, I do know that there are services around locally, so that’s an advantage. When they give me information, it’s lovely, but I just feel sometimes that I don’t want to know.” (Deaf parent)*

*“I rang the audiologist a few times, she was very good, and she gave me the ‘Choices’ book which I looked at about 2 years later. And I thought then that some of this information is quite useful, but you can’t read it when you’re so shocked, it wasn’t user friendly.” (hearing parent)*

*“I did so much reading on the internet and I realised that I probably did too much - because it was all so controversial, it was also overwhelming trying to decipher what I should be reading and what I shouldn’t, and what was helpful.” (hearing parent)*

**10.1.2 Sources of information for parents are varied, and include:-**

**10.1.2.a**      *various professionals – therapist, audiologist, AVT, ENT*

*“Probably stuff I’ve been borrowing off the hearing advisory teacher, like she’ll give me websites, or I’ve got a book at the moment with all different stories about how children react with a cochlear, and videos and things for my child and nursery rhymes. So she’s like my library that I go to when I need something, or she’ll look it up for me and print it out for me, so it’s been pretty much her. And I’ve also been to Hear & Say and they’ve got the stories.” (hearing parent from a regional area)*

*“I rang the audiologist a few times, she was very good.” (hearing parent)*

*“She’s (the advisory visiting teacher) very professional, she’s very helpful, she’s left me a video which has helped me a lot.” (hearing parent)*

*“If I had any questions, our therapist at Australian Hearing, or the audiologist, I would talk to them. They were a great help with the school side when he got to 4. And the same with his visiting teachers.” (hearing parent)*

*“And if I have questions I can ask our speech pathologist, I’m really close to her, and she’s great to talk to. And I can ask the professionals at Cath Ed or his visiting teacher at the school. So I feel safe. If I’ve got a question, one of them can answer it. Yes I’m really happy with the track we’ve gone.” (hearing parent)*

*“But it is good because not only did we have the social worker come in on one of the visits, she called me – when I was having a really bad day – and I just bawled about everything to her. She was fantastic. They also had a speech pathologist come in on our last visit, and she was very helpful in that she said there are organisations out there that you can contact, although they didn’t actually give us a list. And she said Australian Hearing would sort that out for you.”* (hearing parent)

*“Her paediatrician has been really fabulous. I met him at the end of last year, and he basically pushed me back to Brisbane a lot sooner, just to get things rolling because things weren’t rolling there in Townsville. So he’s been good with booking the flights and he’d get back to me with times and things.”* (hearing parent from a regional area)

*“And the advisory teacher was talking about the cochlear implant from the start and she’s always made sure that I realise that there’s a lot of speech therapy and a lot of this and that. So she sat me down and told me what it all is, and how it works, and a few little stories she knew about children, and that getting a cochlear is not the end like it is portrayed in the media sometimes. Because I wouldn’t have known, well, really anything about the cochlear if it wasn’t for her because I didn’t have any information until she came along.”* (hearing parent from a regional area)

#### **10.1.2.b**      *‘Choices’ publication from Australian Hearing*

*“Once we got the ‘Choices’ booklet, that was fine, that had enough information for us to make up our mind on learning. I suppose for the first 12 months I kept going back to Choices occasionally, and I had a booklet on the different types of equipment that Australian Hearing would supply, and I’d flip through that a few times to see what was available. Other than that I had no other information.”* (hearing parent)

*“And when I had a look at the book ‘Choices’, I found it very useful, as to where to start with contacting schools for education. Like for example, Yeerongpilly or Taigum.”* (Deaf parent)

*“Choices was helpful in pointing me in the right direction, where to get started. I read through the book pretty well.”* (hearing parent)

#### **10.1.2.c**      *other parents with Deaf children or children who have a hearing loss*

*“I actually did speak to one mother, she’s got 2 deaf kids, and her oldest son went to Taigum where they teach Total Communication. And she actually said to me that in the afternoon when he gets home from school he was that tired that he wouldn’t talk, he would just sign.”* (hearing parent)

*“Hearing people’s stories and about the different hearing losses of their child, and sometimes their additional disabilities – it’s worth to meet all those, because my x-neighbour, she has a deaf son and he has ADHD, and I learned so much from her when she interacted with me. So it’s worth having a parent support group.”* (Deaf parent)

*“Initially we tried audio verbal approach for communication with little success. Then Education Queensland’s Total Communication method (using Signed English) with little success also. By this time I’d met and befriended a mother of a Deaf child, as well as Deaf parents of her own, who was fluent in Auslan. By seeing first hand the excellent results she had achieved with her own child by communication in Auslan, this convinced me of the need to teach my deaf child an accessible visual language which is Auslan.”* (hearing parent)

*“And when I think back to the advisory visiting teacher, I used to think if only it was a mother who has a deaf child, who can relate.....But I can’t underestimate how important it is to speak to people who have had that experience. I have met a few parents whose children have grown up and it’s been really helpful speaking with them, and a couple of things they’ve said to me where they felt they went wrong. And like one mother said to me, that one thing she regrets is not concentrating more on explaining emotions to her 2 deaf sons. So that was terrific because now it’s a main focus of mine so that I don’t make the same mistake.” (hearing parent)*

*10.1.2.d internet – websites, research articles, institutes, associations*

*“The internet was a huge resource for me. Looking back now, if I didn’t have the internet, I don’t know where I would be today. Having access to loads of information available on the internet.” (hearing parent from a regional area)*

*10.1.2.e phone calls and visits to centres and organisations*

*“I visited the early intervention centre at Hear & Say, and at Yeerongpilly, within the first 6 or 8 weeks of diagnosis.” (hearing parent)*

*“And because we had no idea where to go – we must have been given a pamphlet from Australian Hearing – but we did read their name, we went and visited both organisations – Hear & Say and St Gabriel’s, and Hear & Say explained to us the options.” (hearing parent)*

*“And I also got onto Yeerongpilly SEU, they helped me along and steered me in the right direction with other decisions. It’s mainly the whole – well, What do we do? Where do we go? Who do we see? What’s his life going to be like? Just the shock of it all and not knowing where to go and who to see.” (hearing parent)*

*10.1.2.f information (and support) more forthcoming when deciding on cochlear implantation*

*“And the time we got the most information was when we started on the cochlear implant road, because the staff here at the Royal Children’s are very very good. They still didn’t give us a lot of general information, but they were very good in giving us information pertaining to the implant in his case. And the social worker was very good.” (hearing parent)*

*“The first time I got a social worker was when we were looking at cochlear implants. So that was a long long way down the track. But finally I could have someone to talk to.” (hearing parent)*

*“Then Hear & Say gave us heaps of information about the implant..... Then before we went to the hospital we were given a colouring booklet which is for the kids to go through about what to take to hospital, you take your special doll to hospital. And that helped us as well as our child. Like we took that to Day Care the day before her operation, and we talked to the kids there about it, we showed them her doll, we showed them the booklet, just explained to the kids about the fact that she would be coming to Day Care on Monday with a bandage on her head, that they should be very careful with her ear. And I think the teachers appreciated it as well because they learned a little bit about it as well. Hear & Say has provided us with heaps of information, they’ve been the best with their information, like a booklet for the preschool about the FM and the hearing aids and the cochlears.” (hearing parent)*

### **10.1.3 Information needs are very individual. Specific information may be needed but is not easily accessed, can be misleading, too late in coming, or fragmented between systems**

#### **10.1.3.a information on deafness and hearing loss – nature of deafness or hearing loss, causes, degree, the actual condition**

*“I wish I had known earlier that my daughter was Deaf, whilst being a baby... Because I missed all this time, so it was so hard to try and catch her up. But now she’s doing well. Because at the hospital they didn’t have the newborn screening testing. I wish I knew earlier, I really regret it, and I’m still frustrated about that.” (Deaf parent)*

*“I don’t know why my children are deaf. Nobody that I know is deaf. Never in my whole life have I had anything to do with deafness. Not knowing why the children are deaf is hard. It’s one of the things that you have to deal with. A lot of the information didn’t sink in, with the audiograms, and those type of things from the audiologist earlier on..... So I could quite easily go back over that to find out. To know more, that would help explain things to other people, like the degrees of deafness.” (hearing parent)*

*“I remember with my daughter, when she was diagnosed with hearing loss, we went to Australian Hearing and they were saying she was severe to profound hearing loss, and just leave her hearing aids on and she’ll be fine with her hearing aids. But with my 4<sup>th</sup> child, she has the same hearing loss as the 3<sup>rd</sup> child, but she hears more. But I thought ‘How does that work?’ It wasn’t very clear as to what they mean by that.....that the 4<sup>th</sup> child hears more than the 3<sup>rd</sup>; that they hear different things but have the same hearing loss. So I’m still puzzled as to how that works. I don’t have much information about that at all.” (Deaf parent)*

*“Will we ever know why this happened? Knowing WHY was important because we were concerned it might be a hereditary thing. Any future children that we might have, is that something that we need to look into?” (hearing parent)*

*“We don’t know why my daughter’s deaf. At about 18 months old we realised something was the matter, so we went to an ENT, and he just said ‘Ohh its just fluid’. So we had a hearing test at St Andrews, and we were told then that my child had a severe to profound hearing loss. And it just breaks your heart...Like even now, it still comes rushing back. And you want something to blame, and you end up blaming yourself, because they can’t give me an actual reason why your child is deaf.” (hearing parent)*

#### **10.1.3.b information on Deaf culture, Deaf issues, Auslan**

*“And I actually wanted to learn Auslan, but I found a lot of brick walls, I just couldn’t get the information I needed to really know how to go about it, because I had no experience with the Deaf community, with sign language, with anything. And I remember ringing the Deaf Society a few times, and talking to people about it, but the reaction was very much ‘Well if he’s getting the cochlear implant, she’ll be part of the hearing world, so why are you bothering?... .But I also know how happy she is with her deafness and how she would respond well to Deaf culture, but I don’t know how to do that, and I don’t think I could learn Auslan unless I was using it all the time with people. And I don’t know anyone to practice with.” (hearing parent)*

*“Learning about Deaf culture and the Deaf language - Auslan. If only I knew Deaf culture then I would have done communication differently. When our son was young, had we been given more information about Deaf culture and Deaf issues, then it would have saved us and our son years of anguish surrounding his education needs.” (hearing parent)*

*“Lack of opportunities to learn the Deaf language (Auslan). When our son was first diagnosed I did not have many questions as I was very naïve and I thought that once he was fitted with his hearing aids he would hear just like us.” (hearing parent)*

*"I would have liked more information on parents' experience, Deaf culture, Deaf issues, and Deaf language."* (hearing parent)

**10.1.3.c** *information about education – communication options, schools and support systems (it's never too early to get this)*

*"I guess my main questions were: Will he be able to speak? Be able to carry a conversation? Will he go to a normal school with hearing children? What is his future going to be? Will everything be alright?"* (hearing parent)

*"I actually went back to uni because I was so interested in it, and I'm now doing my Masters in Special Ed and Hearing Impairment. And that has filled in a lot of the gaps for me, and the study has made me aware, whereas I think if I hadn't done the study I would still have a lot of unanswered questions. I wanted to understand the educational side of it all. It was so difficult when you have this little 6 month old baby and you're trying to choose a philosophy – Total Communication, Auditory Verbal – and I found that really hard. We opted for Yeerongpilly and Total Communication, and I was very happy with that, but it's a lot to have to decide when you're going through this and you don't really understand it."* (hearing parent)

*"I think it's natural that parents look to the future. You can try and focus on the here and now, but you naturally want to have some reassurance about what the future holds and what your options are. And not feeling like I can't ask those questions yet about education, because my child's only 6 months old."* (hearing parent)

**10.1.3.d** *information on hearing retesting possibilities and procedures*

*"I think that people need to be told before they have the hearing test, even just on a leaflet, that if you get bad news you'll be retested, and if your child is found to have a hearing loss, it's really great that we'll be picking it up straight away, because deaf children can have wonderful full lives. Because I didn't get that when I went through. Just some sort of prior preparation so that the bottom of your world doesn't fall out when you are not prepared for it."* (hearing parent)

**10.1.3.e** *information on what is available through the public system*

*"He had started his early intervention when he got his hearing aids at 2, and it was just by chance that we found we can go through the public system!! Australian Hearing just give you the book, that's it."* (hearing parent)

*"I went to a specialist, no information was given to us, we were just sent off to a private specialist. My child was subsequently implanted with grommets because they said he's had too many ear infections, although I wasn't aware he'd had any infections in his life. But I wasn't seeing any change, and I was thinking 'What are these things supposed to do?' So I went back and we were then sent to a private hearing centre. I still didn't know that the public system existed. So that was another couple of hundred dollars."* (hearing parent)

**10.1.3.f** *information on organisations to contact*

*"Give parents the list of organisations, and if you do want to contact them, they are around, you can call them and visit them. Instead of having to search for it. Which is what 90% of the parents do, but there's always that 10% who are in the lower socio-economic group and they don't know to do it, or you don't know that they're there."* (hearing parent)

### 10.1.3.g *information on how to access hearing assessment and where to go*

*“The working of the 2 levels of government, federal and state, together, and the fact that Australian Hearing had information in their Choices booklet about where to go for teaching, but they had no information on what to do to actually have your child diagnosed. They couldn’t tell me that Royal Children’s did testing, Hear & Say does testing, St Gabrielle’s has some things. That was the sort of thing that we really needed - a guide as to where we can go to actually have her diagnosed for good.”* (hearing parent)

*“Talking with other parents, you can see what they’ve learned through their experience, and then you can learn from them. And that way you can alter your preference from what they’ve learned. If professionals are telling you one thing, I’m thinking ‘Well is it believable? Will it work for my child?’ And then you try it for some time, but if it fails it’s a huge impact later on in life if it’s not worked. Whereas if you’re seeing what works and what doesn’t, then you would be more comfortable to go with your preference.”* (hearing parent) (Deaf parent)

### 10.1.3.h *information from parents and the Deaf community*

*“Most of the literature seemed to put an emphasis on bringing the deaf child into the hearing world. What helped us get information we needed was mixing with people directly involved with Deafness and the Deaf community.”* (hearing parent)

*“It’s good to get together with other parents, to talk about things like in this consultation, and share information, and what you’ve been through, and what the children do. It’s good for me as a Deaf parent, to know about your children and also talk about the implants, because I’ve never met any children with a cochlear implant. And I’ve been thinking so much about it, my husband is dead against it, but it’s good to talk with you to see different examples.”* (Deaf parent)

*“I’ve found it really good to have a Deaf mother here (in the consultation group) to speak with. I would like to have more opportunity to have a more mixed group so you can hear different ideas, and a perspective from a person that is Deaf.”* (hearing parent)

*“You don’t have the time to go through all the information you are given. A parent support group is better, seeing what other choices parents have made; I think you would understand the information a lot better.”* (hearing parent)

*“And to talk to parents, and see children who have done well in each communication method, would be a big help, early on. To have positive images of all the different communication methods, early on, so if in 6 or 8 or 10 months or a year into your therapy you’re thinking ‘Oh I’m not really sure about this’, you feel as if you can then say ‘Oh perhaps I should go and investigate this other way’. That ...it’s not the be-all-and-end-all, and that you’re not going to be dumped by one system when you go to another.”* (hearing parent)

*“I did meet a mother once but I didn’t know then that my child would get a cochlear...That was nice, to be able to hear someone else who had a similar story and you’re not the only one. It’s a disappointment that there isn’t a play group anymore in this town, having children in my child’s situation.”* (hearing parent from a regional area)

**10.1.3.i** *information about the daily things e.g. cleaning hearing aids, interacting with your child*

*“Some of the first information I got was about the hearing aids and what sorts there are - how to clean them, how to look after them. I mean I’ve only just found out now – we have a little jar for storing his aids in – it’s got a little block in the bottom that you change when it gets a certain colour – and that actually draws the moisture out during the night, Now, I’ve been putting these things in, thinking I’m doing the right thing, but last time I went to Australian Hearing for a test, she said you know you have to put holes in there!! And that I didn’t know!! It’s just all the little things. How to store them, clean them, check them, look after them. And also, how to interact with your child. Like how to start talking to your baby, and how to do the sounds, when to do the sounds, what to do.” (hearing parent)*

**10.1.3.j** *technical information e.g. reading test results*

*“Sometimes I wish I knew more technically of how to read his results, but in terms of explaining his loss to people, and information that’s been given to me – I’m really happy with that.” (hearing parent)*

**10.1.3.k** *stories of children’s futures – to give hope and direction for the future*

*“The video of those identical girls. Because it helped with hope and joy. That sticks out in my mind all the time as being one of the most memorable. The overwhelming relief and joy and sadness and hope that came with that. It set off a lot of triggers to see that video, to realise that we are doing the right thing.” (hearing parent)*

*“To show them that video of those identical girls – Hear & Say gave that to us the first time we were there, and we showed it to my family. Well it just gives you hope. When I saw that video, I thought ‘Oh my god!!’ (hearing parent)*

*“The ‘Choices’ book has some parent stories in it. But to see further on down the track – if you take this mode, then you can see how the children have grown up as adults, and what they have achieved. Just to have other people’s experiences. Because every child is different, every hearing loss is different, everybody’s home life is different, so you need personal experiences.” (hearing parent)*

**10.1.3.l** *information on how to be assertive with professionals and an advocate within systems, in order to get needs met*

*“And helping parents to be assertive or having workshops available for parents to advocate for their children. And educating parents about common misconceptions, so that parents can decipher or know about it when they hear those misconceptions. Because even though it’s all controversial, there are still things that are said by people which are just incorrect. And parents need to be aware of myths or old school ways. And more so, parents in rural and regional areas.” (hearing parent from a regional area)*

**10.1.4 A preferred mode of receiving information and understanding information is talking to PEOPLE. This information should be presented objectively, plainly, openly**

**10.1.4.a** *professionals / specialists to present, explain and discuss information in a jargon-free, inclusive, friendly fashion*

*“I’d prefer it if professionals don’t use the professional terms when they speak to you about your child. The way that they say things, makes it sound a lot worse than it is.” (hearing parent)*

*“Sometimes the professionals should tell me what’s going on when my children are having their tests. They give me such limited information. And they are doing all the talking, and I miss out on what’s going on. I want to know what’s going on, so they should also include me in that type of talk. More involvement, so the parents can then learn more about what the professionals know, and that way we can do more practice at home with our children.” (Deaf parent)*

*“What I found hard, and even still now, is that the audiologists use terms that are very hard to grasp – the general terminology to do with your child’s hearing loss. I found that very hard to grasp, because you read and read and read the terminology, and you’d ask the questions, but it just wouldn’t sink in. And up until I went to that Cath Ed in-service in February, that was probably the best presentation I had seen to make me understand what it is that my child can and can’t hear, what it all sounds like to him. Over the years I’ve struggled with that, and I get on well with my child’s audiologist, but I still find it very hard.” (hearing parent)*

*“You don’t want someone speaking at you with all these big words that you don’t understand. And you’re thinking ‘What are you talking about?’ (hearing parent)*

*“But the ENTs aren’t real helpful. They don’t sit there and take the time to explain anything to you. Like the last time I went to the ENT in the public system, I waited for two and a half hours and saw him for five minutes. And when I asked him a question he said to me ‘You’re not listening to me!’ You feel like you are asking too much. That’s happened a few times now. That’s the only negative thing I have to say about the medical side of things. You are a concerned parent, and you want to help your child, and to me, those questions I asked weren’t silly, but that’s how you are made to feel. The ENTs could be a little bit more gentle.” (hearing parent)*

**10.1.4.b** *professionals to “talk through” information with parents with impartiality and a commitment to a thorough presentation of all perspectives and options*

*“I think the book ‘Choices’ was really good BUT I think parents need to be able to talk it out as well. Yes, the specialist would say ‘This is your decision, we can’t make it for you’, but it is a really hard decision to make. And sometimes parents aren’t well informed ..... and I think a parent has to choose what they think is right for their child, but sometimes parents think that there is only the one choice. And they don’t always have the background to understand language development and how that’s all acquired, and they get given this information ‘If your child signs, they won’t talk, blah blah blah’. And I think for the parent who doesn’t have a background to draw on, that is the obvious choice. But I think that parents just don’t get the full picture.” (hearing parent)*

*“I think you shouldn’t just be given that book ‘Choices’. Someone should be there to explain it to the parents, the differences in the choices. But then also, the professionals should remain unbiased. The parent should be able to go around and look at different settings, be spoken to about that setting, but not being pulled over here and over there. And just sit down with the parent and explain, and answer questions, and someone to talk to.” (hearing parent)*

*“To receive accurate information about the pros and cons that is IMPARTIAL. Obviously when you go to Hear & Say you get their views, and when you go to Yeerongpilly you get their views. But you need an impartial view on both, and what it has to offer your family, and what the negatives are. And that needs to be laid out.” (hearing parent)*

*“And also they could also have a person who is experienced with the different philosophies, for example in signing and cochlear, somebody impartial. Therefore they can talk to parents and help that person make a decision, but without being biased. And it’s really important to have that. You’ve got the individual philosophies, but you need one central contact person. Because parents really need to have a good talk with someone who is impartial. We don’t want that person to be biased towards any one philosophy. Like for example, this contact I had in Deaf Children Australia – she was very impartial, she had no bias against any*

*philosophy, she worked with parents, with the medical model, she worked with the Deaf community, so she was a very good person to talk with.” (Deaf parent)*

*“When I got my ‘Choices’ magazine, I went to Catholic Education – the Mater Audiology Department put me on to them. And the professional person came to me and went through the book with my husband and I. Which I thought was great because she didn’t have any bias, she didn’t say ‘Oh Catholic Education is the best. Come with us!’ She said ‘I’ll go through it with you, and it’s your choice’. Everyone needs someone like that to come and sit down with you, and go through it, and answer questions that the parents ask.” (hearing parent)*

*“Somebody who is able to be neutral in their opinion of deafness and give you unbiased information.” (hearing parent)*

*“And I think parents should learn about the Deaf community as well as the hearing community. That way they can see the two variances, and they can choose what they are more comfortable with for their children. If they go straight to the cochlear implant choice, they miss out seeing what’s on the other side. So I would like the choices to be combined and integrated in one appointment. They can both offer great experiences, regardless of whether it’s a Deaf or hearing culture.” (Deaf parent)*

*“I prefer talking to someone because that way you can find out exactly what it is that you want to know.” (hearing parent)*

*“I started going to ENT appointments. And this was the first appointment I’d ever gone to. And I was really unhappy with that particular visit because a lot of the ideas I was against, because I didn’t think they knew anything about the Deaf community, all they talked about was how fantastic cochlear implants are, and how it’s great to integrate, and they were very firm on that one point only. And I thought ‘Well hold on! What about my Deaf community that I’m involved in?’ And they never knew anything about the Deaf community. And we have fantastic choices in the Deaf community!! So I was very disappointed and a lot of people know nothing about the Deaf community.” (Deaf parent)*

*“And I was horrified that the advisory visiting teacher said that Auslan wasn’t really an option – not that she said it in those words – but she had said that if you want your child to learn to read and write, then they will need to learn Signed English, which I realise now is not true because you can learn English as a second language. She would actually say that ‘It’s not for me to give you an opinion on what is best’, but then turn around and say the misconception that if you want your child to read and write then he has to learn Signed English. I suppose it’s not her fault that she didn’t know. I am a strong believer that there is no right way to chose for a particular family, it’s up to them to feel their way and work out what’s best for them.” (hearing parent)*

**10.1.4.c** *the opportunity for parents to talk with other parents in a similar situation with first hand experience, including the Deaf community*

*“We would prefer to be told from people who have experiences in deafness first hand, that is, parents, Deaf people, and CODA’s (Children of Deaf Adults). We think people who are involved with the Deaf community are the only one’s who fully understand Deaf issues. In hindsight, very few of the brochures and booklets were much use at all. Most of the literature seemed to put an emphasis on bringing the deaf child into the hearing world. What helped us get information we needed was mixing with people directly involved with deafness and the Deaf community.” (hearing parent)*

*“I would find other parents very helpful. I wish I had that...A shared hint even would be good, like how do you keep the aids in? Like a video of other parents, because you don’t always get the time on the phone. You can sit down with a video at your own leisure and listen to what these mums have got to say today. Little hints of what you can do.” (hearing parent from a regional area)*

*“I think if there’s possibly a parent support group that the people can contact, then it’s easier to get more information and understanding from a parent who’s been through it, rather than just go to one of these institutions, talk to professionals.” (hearing parent)*

*10.1.4.d      the opportunity for information giving and sharing workshops and seminars*

*“Recently I went to a teaching workshop run by Education Queensland on hearing impairment. And as a teacher, I went. But also as a parent. And that was one of the best information sessions I’ve had. And the parents should be going to those things, because I just got so much out of it as a parent. But they offer it for the teachers for children coming into their class, but not for the parents.” (hearing parent)*

## 10.2 Resources

This section of the consultation findings focuses on parents' views and preferences regarding various forms of resources which aim to provide information or support to parents and families who have a child who is Deaf or has a hearing loss. In this consultation, the resource types which are specifically explored are a family file, a general brochure, personal stories, and audio-visual. Parents' suggestions on a range of other resource types and information-giving strategies are also outlined.

The consultation findings for this section on RESOURCES are presented under the following main themes:

- 10.2.1 Comments on the concept of a Family File (e.g. "Early Support"- UK)
- 10.2.2 Comments on the idea of a general brochure at the time of identification of Deafness or hearing loss
- 10.2.3 Comments on reading personal stories of other parents' journeys and experiences
- 10.2.4 Comments on using audio-visual resources
- 10.2.5 Other suggestions for resource types to be given at the time of identification of Deafness or a hearing loss

*"But I got this video and it shows you how to interact with your child and do these different games and different sounds. And everything that people have been telling me for the past few months has just clicked into place – 'Oh is that what they want!' They need to make more of those videos"* (hearing parent)

*"Something like that – if you read 12 months after diagnosis – you realise 'Ohhh my god, how far your child has come in that 12 months!'" Because you forget. And unless you get reminded, you can get bogged down and think you're getting nowhere"* (hearing parent)

*"That's when I mentioned to them about the lack of resources in the library.....Now they've got 74 different items. I have a pile of 10 books now that I'm reading! It was like Christmas when they came"* (hearing parent from a regional area)

## 10.2.1 Comments on the concept of a Family File (e.g. “Early Support”- UK)

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### 10.2.1.a *specialists would not be interested*

*“I don’t know if you would go to your ENT with this big folder. Would he care less? To be honest, would he sit down and read it? And any GP, or audiologists, I don’t know if they would sit and read about that? How often I’ve been in to specialists and they’ve said to me ‘How did you pick his hearing loss up so early?’ And how many times I’ve had to tell them the same story!! And it’s the same ENT since he was born!!...Would they care less what my child likes to do?” (hearing parent)*

### 10.2.1.b *no use for it as already have an existing system of files and diaries*

*“I’ve got my own files with all my medical stuff that you can refer to, and my photo album, your baby book. I don’t think I would have any use for it.”*

(+)

### 10.2.1.c *a good idea*

*“Great idea.”*

*“That sounds like something really useful...for parents who have trouble organising themselves.” (hearing parent)*

*“And they’ve (the developers of the UK resource) done a lot of work to get it together. Obviously their problems are our problems.” (hearing parent)*

### 10.2.1.d *keeping such a file would help to deal with grief; encourage acceptance through plotting progress and writing down what you think is best for your child*

*“I think it’s excellent because when the family first have a Deaf child or hearing impaired child, and they don’t know where to go, and they feel grief, it could be part of the grieving process to be putting all this down on paper. It could help to reduce the grief time, and they can learn from reading the file, like ‘Yes I remember this’. It’s like a record and to reflect back. And that way it’s more positive, it’s about acceptance, and moving on.” (Deaf parent)*

*“Something like that – if you read 12 months after diagnosis – you realise ‘Ohhh my god, how far your child has come in that 12 months!’ Because you forget. And unless you get reminded, you can get bogged down and think you’re getting nowhere.” (hearing parent)*

*“If you can find 5 minutes to write in it, I think it’s an excellent idea. And it wouldn’t be time consuming because you have kept it up to date. And just to look back on it would be great.” (hearing parent)*

### 10.2.1.e *such a file would encourage recording, tracking and follow-up of valuable information*

*“As a parent we could write in it on our own time. You don’t want to avoid it because your child really does need the support services, and they do need assistance, and they can’t really ignore stuff like this. They need to know what’s happening, and this resource would be really good. And sometimes I want to know things, ask things, but I forget to ask when I’m out. And even writing important things that you need to know about the education, the hearing aids, because you have so many appointments that you have to go to, it’s quite impossible to remember everything.” (Deaf parent)*

*“It’s great, practical, because a few years down the track I thought I wish I had all those early files, letters, and that information. Keeping track of all the information so you’re not having to get the same letters written over and over again.” (hearing parent)*

*“My AVT has just dropped off a book, it’s really really thick, and it’s got lots of lessons in it. I’ve flicked through the first lesson this morning and then had to do the washing. But in the back of it you’ve got a section for your child’s progress and development, like when did he do this and that. A bit like those baby books you can get. That I would have liked earlier on, because I could have written down the dates – it’s important to know that apparently, when he hears this, and when he doesn’t hear that.” (hearing parent)*

*10.2.1.f the file would be best if completed along with the professionals; some families may not do it alone*

*10.2.1.g an example of a flexible and developmental resource, which gives parents freedom*

*“I’d hope a resource is flexible, so the parent can have a choice. And until they can find an appropriate service that they like and need, the parent shouldn’t feel forced into doing something, feel bound by the book. So writing things down that you think is right for your child, that’s good.” (Deaf parent)*

*10.2.1.h the file could be good for sharing information with others (e.g. child care centres, family, friends, babysitters, therapists) and would save repeating yourself*

*“When meeting someone who is new, it would be valuable to help explain. It would be really lovely to have that to show people who are accepting of you and your child.” (Deaf parent)*

*“That would be good for the simple fact of, my child has just changed day care centres, and so we’ve had to go through AGAIN about the FM system, and the implant. And if we had something like that file we could have given it to them and left it with them for a week. Instead of spending so much time explaining everything to them, like what my child needs to do, like she needs to use it during reading time and even outside play occasionally, to call her you need to use it. Well it would certainly make it easier if the child was being babysat by someone, and they have to take them to school, like my mother. And to give it to the rest of the family to read.” (hearing parent)*

## **10.2.2 Comments on the idea of a general brochure at the time of identification of Deafness or a hearing loss**

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*10.2.2.a of little value*

*“In hindsight, very few of the brochures and booklets (which I’ve been given) were much use at all.” (hearing parent)*

**(+)**

*10.2.2.b should be simple and easy to read*

*“A pamphlet when you get the diagnosis, that would be great. Something easy to read.” (hearing parent)*

*“Yes, something simple that says you can teach your child to speak and listen, or you can teach your child to speak and listen plus sign and gestures.” (hearing parent)*

10.2.2.c *is something to also give family and friends*

*“So not just for the parents, something for all the family and your friends. Anyone who is saying to you ‘Oh I’ve thought about what they can’t hear’ or something like that, that’s when you need something to give them.”* (hearing parent)

10.2.2.d *containing what to expect and do in the future – a timeframe of actions*

*“Yes, a brochure with a time span of what you can expect in the next few months in terms of the systems. How you can access support.”* (hearing parent)

10.2.2.e *giving an overview of the different options, with phone contacts to centres*

*“If there was something that says these are the different options, to look at these ring so and so. And if you wanted more information they can give you the ‘Choices’ booklet that says: this is what we do, we have this program, we do this, we do that.”* (hearing parent)

*“Yes that would have been helpful. It could have information about your options of what you can do now; some expectations for the future.”*

10.2.2.f *describing emotions likely to be felt*

*“And something about emotions that you can have and something also for the immediate family.”* (hearing parent)

10.2.2.g *explaining what a child can hear at levels and frequencies – in everyday terms*

*“About what you can hear and not hear at the various levels of loss – make it real, like if it’s a moderate loss you would hear the plane fly over but you won’t hear the leaves rustle in the wind; to explain that you can have loss at different frequencies; that you can have loss at different levels.”* (hearing parent)

10.2.2.h *describing other parents’ experiences (but not to overwhelm)*

*“With comments from parents about their experiences – but for some people they might find that a bit overwhelming to read emotional statements.”* (hearing parent)

10.2.3 *Comments on reading personal stories of other parents’ journeys and experiences*

(-)

10.2.3.a *not overly interested or important*

*“I read a few stories, I was interested in other people’s experiences, but I wasn’t overly interested. It wasn’t a case that I needed to know of anyone else’s stories. I just read a couple of them to get an idea, and then that was it.”* (hearing parent)

10.2.3.b *everyone is different and should do it their own way*

*“Everyone’s experience is different. The stories are not the same. They’re good just to get the idea. But you have to go through it YOUR way. Not to compare, but just get the idea.”* (parent with a hearing loss)

10.2.3.c *can be frustrating if you don't agree with their choices*

*"I like it but I don't... I get frustrated with reading some of them, just some of their decisions, some of them were deciding not to do it (have a cochlear implant). But then you read on and the children are 7 or 8 now and they are fine. So I probably shouldn't have read so much."* (hearing parent)

(+)

10.2.3.d *can relate to other experiences and therefore feel less alone*

*"I like reading about other people's experiences, and you can relate to it. And you don't feel like you're the only one in the whole wide world."*

*"Choices' was helpful in pointing me in the right direction, where to get started. I read through the book pretty well, and it also had stories in it from other parents with deaf children which you could relate to. I always find that helpful. It helps when you're going through a really hard situation, to know that other people are experiencing the same thing, because you feel like you're on your own. You think 'Wow!' that's just how I feel and you don't feel so alone, and you don't feel like the things you're thinking are not normal."* (hearing parent)

10.2.3.e *can get different perspectives than my own*

*"And not just one parent's story, but lots of different views."*

10.2.4 *Comments on using audio-visual resources*

10.2.4.a *good for follow-up of information given by professionals; helps information to "click"*

*"She's (the AVT) very professional, she's very helpful, she's left me a video which has helped me a lot. But you know how some people can explain something until they are blue in the face, and you don't really get it, because there were a few times that I didn't know what they wanted..... But I got this video and it shows you how to interact with your child and do these different games and different sounds. And everything that people have been telling me for the past few months has just clicked into place – 'Oh is that what they want!! They need to make more of those videos.'" (hearing parent)*

*"This is where another video would be good. What sorts of communication do you need once the hearing aids are in? Like you have to do these little interactions, 20 minutes each day, you just don't put in the aids and then do nothing."* (hearing parent from a regional area)

10.2.4.b *no time or energy to read but can watch and re-watch a video while doing other things*

*"You don't get time to read books. They give you a book, and like, it's THICK! And it's full on anyway with a baby, but when you have a hearing impaired baby it's more full on. And when they say, 'Oh have you read the book?', and you feel bad because you think 'Oh what am I doing? Am I doing enough? Oh my god, I haven't read this book!' And not that they make you feel that way, but you DO as a mum.....and it's not a bible! So give us some websites that we can have a look at, or get us more videos. That's what I would prefer. It's so much easier. I can sit down and watch the video and interact with my child at the same time. I can do that, and there are other duties like housework, so you are just bugged, and with a video you can watch it in bits and pieces. And you need time out for yourself as well, and you can veg out a bit as you watch the video."* (hearing parent)

10.2.4.c *useful for supporting regional parents; good to see real parents talking about their experiences*

*“Videos are good, especially if they are real, parents talking about their experiences, something realistic, and it’s easier to re-watch a video than to reread a book.” (hearing parent from a regional area)*

10.2.5 *Other suggestions for resource types to be given at the time of identification of Deafness or a hearing loss*

10.2.5.a *a kit: pamphlets from all organisations and a list of contacts of parent support groups*

*“A pamphlet from Deaf Children Australia, from each of the organisations, and about parent support groups. Like a kit with concise information.” (hearing parent)*

10.2.5.b *information sessions and workshops*

*“We mostly get information via mail because we live remote, so we don’t really get to any seminars. I guess it would be helpful if there were some in regional areas. I’ve been to one that was delivered by Australian Hearing and the AVT – I went to a workshop once which was really helpful and fantastic. And I wish every teacher in every school was there.” (hearing parent from a regional area)*

10.2.5.c *recommended websites for answering specific questions*

*“I’ve never used websites, I’m not big on the internet, but if I was told this is a great website, then I’d go to it, but I won’t surf to find something. If there was a list of good websites, then I would use it.” (hearing parent)*

*“Or recommended websites that would answer certain questions.” (hearing parent)*

10.2.5.d *catalogue of books available*

*“And like a catalogue of all the different books that I realised were out there for me to read. But I could never afford to purchase them.” (hearing parent)*

10.2.5.e *in-depth texts*

*“A book like ‘Choices’. Something that’s more in-depth. Like when I finally did get my hands on ‘Choices’, it was really terrific, but not enough information. Like just the section they had on communication options was just so small.” (hearing parent)*

10.2.5.f *resources at public libraries (especially for regional parents)*

*“Another thing that needs to change, and I helped to make a change here in this town, was the library. I was forever going into the library trying to find books to read, and went down to Education Queensland one day and then to different places. I was thinking ‘There’s got to be books in this town that I can read!’ And there were none or they were really old. So I ended up getting Quota International, who contacted me when I had my story in the paper about my support group. There’s a clause in their Mission Statement that they raise funds for hearing impaired children, and they’d been sending the money down to the Hear & Say Centre. And they were asking me if they could do something more locally with that money. That’s when I mentioned to them about the lack of resources of books in the library. So they ended up raising about \$500, and then with me talking to the Community Officer at the library, they ended up getting \$2000 worth of books. Now they’ve got 74 different items. I have a pile of 10 books now that I’m reading! It was like Christmas when they came.” (hearing parent from a regional area)*

10.2.5.g *phone network or panel of experts – list of 2 to 3 parents under each communication option who you can ring and talk with*

*“Or like a panel of people that are doing it full time – that they can say ‘Well our child did it this way’. Or a list of parents who you can ring, like they could list where you live and they can actually ring, and the parent could know they are on stand-by to speak to someone. We knew no-one with a deaf child and we didn’t know what to expect. So when you don’t know what to expect, it’s really really hard.” (hearing parent)*

*“Having a list of 2 or 3 parents under each communication option who you can contact through a phone network.” (hearing parent from a regional area)*



## 11. DAILY LIFE AND PERSONAL RELATIONS

This section of the consultation findings focuses on some of the daily realities of being a parent (in particular, a mother) of a child who is Deaf or has a hearing loss. Parents' experiences and issues around managing their responsibilities of care are explored, including degrees of responsibility, levels of acceptance of the child's Deafness or hearing loss, impacts on time and personal well-being, and the practical daily tasks and problems of parenting. Also, parents' experiences of how others respond to or support them and their child, and the dynamics of family and important social relationships, are described. Finally, some thoughts are offered from mothers about how they think their child experiences their own life, living with Deafness or a hearing loss.

The consultation findings for this section are presented under the following main themes:

- 11.1 Some mothers can feel the total responsibility for their child's care and development, intervention programs, day to day decision making, and medical / technical program
- 11.2 From the beginning, parents can worry if their child will receive social acceptance and quality education
- 11.3 Parents with a child who is Deaf or has a hearing loss can experience a range of social responses from family, friends and the community
- 11.4 There are daily communication and behavioural challenges when parenting a child who is Deaf or has a hearing loss
- 11.5 How the child experiences their Deafness or hearing loss: from a mother's perspective

*"I probably haven't dealt with my own personal stuff, because I have been so focussed on the children, I have lived my life for the children, that I haven't stepped back yet. And it's probably only the last couple of weeks that I've realised I need to step back and lead my life as well. I need to be a whole person for the children..."*  
(hearing parent)

*"...but there was many a time I left a shopping trolley full of groceries at Woolworths, because I'd see an older child saying to his mother 'What are those things in that baby's ear?' And the mother would stare but not answer to their child. And I'd be so upset and leave."* (hearing parent)

*"But we've had ear infections, and the biggest challenge is just keeping the aids in. If they could invent something for toddlers to keep their aids in, that would be great! The dog has eaten them and things like that!"* (hearing parent)

*"My child is very comfortable with her deafness. Like she loves it. But she's just as comfortable in the hearing world, with her implant on at school. She participates in everything. She has this whole little life at school that I have no idea about. There's nothing she feels she can't do."* (hearing parent)

## **11.1 Some mothers can feel the total responsibility for their child's care and development, intervention programs, day to day decision making, and medical / technical program**

11.1.a *some mothers can experience that the child's father withdraws emotionally / psychologically;*

*some mothers perceive that the child's father can be slower to accept the Deafness of hearing loss*

*"It did make it really hard because my husband was really angry and he withdrew really for a few months. And it really made it tough for me, being a first time mother, not really knowing what to do and not having his help and support."* (hearing parent)

*"You have to push all your feelings to the back. I got depressed for awhile there, but I thought if I'm not here for the children then nobody else will do the same job as me. Nobody else can look after the children as well as I can. So I have to be here for them. Not so much my husband. I suppose men more or less live in their own world in a way. Because he sort of removed himself a little bit – I mean, we're still together as a family – but he stood back, as in working longer hours, doing more of this own thing, and leaving me to raise the children and to deal with all of these issues."* (hearing parent)

*"I spend my time doing things with my children... He's (my husband) taking it hard. He's always been really sporty and physical...and suddenly he's had this child that he's always wanted – his son – and realised that he's deaf and won't be able to do all these things. I think he thought he wasn't going to be able to do any of these sports with his son, he won't hear it all, he can't do all these sports. I figured it would take a while for him to accept it, so I've stood back and I've let him have his time to learn to come to terms with it all. It's been really hard and I did not think it would take this long. But he is starting to accept it now."* (hearing parent)

*"My partner is...away a lot. So it is really just me. And I think just in the last few trips I've been down here in Brisbane; this whole thing has just really hit my husband. I think he's just thought 'Oh, she'll be right'. But it's just sort of hit him."* (hearing parent from a regional area)

*"And I know that my husband had a really hard time accepting it. He felt like every time we went for an appointment at the hospital, that it was more and more bad news. And he got to the stage where he said that he couldn't handle coming to the hospital with me because he couldn't handle hearing bad news continuously....He stopped coming to appointments with me, so basically I had to do everything on my own."* (hearing parent)

*"It's very tough on your own. Not to be able to sit down at the end of the day and talk to someone about your concerns. Which I tried to do with my now ex-husband, but he just clammed up and didn't want to talk about it. And he's quite happy to baby sit our child as such, without actually being involved in the decision making. And so we're not making decisions together, and with the type of decision making involved, you don't get any validation because the issues are so controversial. And it would be nice to get some validation at least from family and partner. I need to be strong."* (hearing parent)

*"He (my husband) really withdrew and blamed himself, and blamed me, and took it out on the whole world, hated everybody. So that made it hard too, because I think, as a mother, you want to withdraw and run away but you can't because it's your child, and you just have to look after your child, and that's that. So that was very tough on me because I didn't really have his support because he didn't know how to handle it."* (hearing parent)

11.1.b *some mothers can feel overloaded and unsupported;*

*there can be reduced opportunity and potential for the mother to have her own time, pursuits, and life*

*“I probably haven’t dealt with my own personal stuff, because I have been so focussed on the children, I have lived my life for the children, that I haven’t stepped back yet. And it’s probably only the last couple of weeks that I’ve realised I need to step back and lead my life as well. I need to be a whole person for the children.”* (hearing parent)

*“When you’ve got a Deaf child, and then a second one, it just takes a lot of your time, to go to appointments, hearing aids, doctors, ENT specialists – back and forth. And my other 2 hearing kids, they say ‘Oh Mum, where are you going now? I want to do such-and such’. I feel trapped. I feel right in the middle, between my 2 hearing kids and my 2 Deaf kids. And I try to make the most of my life with the kids, for all the kids, to make things equal, but the 2 Deaf kids are a lot of work. The time is very drawn from you, and the energy. And I’m trying to study at university and I have to stay up late every night to finish my assignments and research, and then I’ve got the kids needs, to go to different appointments. I’m trapped with it 24 hours a day. And my family is not here in Brisbane. And you spend so much money too, for travel, for petrol, for expenses here and there, and your money just goes down, and that’s quite stressful. But I have to keep moving. I have to keep going.”* (Deaf parent)

11.1.c *there can be impacts on marriage and family*

*“And we’ve been a bit distant sometimes. It feels like I have a flat mate. He goes out, comes home, he eats the meals, and goes off and does his own thing. I’ve spoken to other people, and it seems that men have found it harder to deal with it than the women.”* (hearing parent)

*“I have a huge responsibility for my daughters because my husband - he doesn’t mind sharing the roles with me - but sometimes I have to say to him ‘Can you take her to the early intervention program?’ And he’s like ‘Why?’ And I say ‘Well I have other things to do’. He says ‘Ok’. But it’s like he doesn’t want to do it because it’s a woman’s job. And I say to him ‘Just go’. Because I want a break as well. Sometimes that happens. Other times, I just get sick of telling him what to do, and I just do everything myself. And I’m worried that that can affect our relationship.”* (Deaf parent)

*“My child sees his father on a regular basis. That’s extremely hard, having a child with deafness, and having the 2 households. You need to be consistent with the children as it is, and I don’t have a good communication rapport with my ex-husband, and there’s a great need for him and I to be able to communicate for our child’s benefit....He was diagnosed with his hearing loss. Then men deal with things differently. He really didn’t want to about things openly. He would get quite aggressive and angry, and I packed up and left. And I’ve been a lot happier since. So to me it was one of the best things I’ve ever done....but then it has been hard not having a family. It would have been good to be able to communicate better with him, and stay together as a family, and to have had that support.”* (hearing parent)

**11.2 From the beginning, parents can worry about whether their child will receive social acceptance and quality education**

*“I just hope he won’t get teased at school because of his hearing aids. Kids can be very cruel. That’s all I hope for. And that he will grow up to be a doctor or something.....And I’ll probably have to keep a close eye about his schooling. I’m not really sure because I’ve not been through this before, but I’d want him up the front of the classroom to be able to hear better.”* (hearing parent)

*“His image for himself later – I worry about that now. Like whether he will get teased at school. I worry about: Is he hearing enough to learn to read? Is he going to be okay at school? Is he going to be okay in life?”* (hearing parent)

### **11.3 Parents with a child who is Deaf or has a hearing loss can experience a range of social responses from family, friends, and the community**

#### *11.3.a varying levels of understanding and acceptance from others*

*“I’m not one for wanting sympathy. They (my partner’s family) have accepted him fine. They think he’s just beautiful and treat him as such. There are no negative reactions at all.”* (hearing parent)

*“My girlfriends are accepting it, and we saw one of them yesterday and her kids accept my child as she is. Like a lot of the kids used to say to her ‘What’s that on your ear?’ And I explain to them that she’s got a special ear, and they just accept her as she is. And all the kids at preschool, they might look at it the first few days, and ask what it is, but after that no problems at all. And my whole family is accepting of it, and I haven’t lost any friends over it.”* (hearing parent or a child with a cochlear implant)

*“We have found that having a deaf child does not have a negative impact on relationships or friendships. Most people we know and meet seem to have a genuine interest in deafness. Telling our family and friends about our son’s deafness was never a big issue with us because we loved and accepted him as he was.”* (hearing parent)

*“I’ve had a really positive experience with family and friends. I think that in my circle it has demystified deafness and most of my family and friends now would not think of deafness as a disability either.”* (hearing parent)

*“My friends and family have been excellent, very supportive, and the children just don’t realise that my child is a little bit different, and they just accept him as he is. There’s no difference the way they play with him, and they play with each other. Which is wonderful. And he speaks quite well, so we have little steps forward, and I’m really proud of him, and he’s doing really well at school.”* (hearing parent)

*“But now that he’s five and he speaks so well, and of course he’s a very good listener, and he’s very visual, I think that my family are happy with how he is. And my friends are impressed by how my child progresses and talks so well. And I think they thought he’d go to a special school, and how would he sound? And now that he’s started preschool at Cath Ed they were very impressed with him because he’d had all the early intervention. And that’s made me really proud, and it’s been really hard, but it’s good now. And I’ve belonged to the same play group since my child was 8 weeks old, so I’ve made friends since he was a baby, and they’ve been through all the appointments, and it’s funny that the kids now don’t even notice that he’s any different, they don’t ask anymore about his hearing aids”* (hearing parent)

*“And lack of understanding and support from family has been really hard. Family and friends, they quite often relate any problems back to it being the same as if he was a hearing child. And to start off with, I thought that was fair enough. Because he’s my only child and I haven’t got any other children to compare him to, and I realised that there ARE times when it is just a developmental stage. But as time goes on now, and the more I see other parents with their children, the grievances I do have being a parent with a deaf child, is that people write it off too easily as saying ‘Oh all kids do that’. I mean lots of kids don’t listen to their parents, but when other children are having a tantrum, or you need to explain something to them, their parents can get their attention for a longer period of time, and you can use your voice and different tones of voice. You are very limited when you’re only communicating with sign and you’re not fluent. You feel very alone and extremely frightened, fearful of being able to cope.”* (hearing parent)

*“The sympathy thing is the first thing that you go through, which is really annoying. Like ‘Ohhh you poor thing’. But it’s not a tragedy or anything, it’s not life threatening. Okay, my son’s deaf! I’m fine with that. I’ll deal with that. That’s what I’ve been dealt in life, that’s what I’ll do in the best way that I can. Friends thought that they will support and help me in any way that they can. They said ‘Just tell us what to do’. But I found myself drawing back from them because they expect the children to behave in particular ways, like they expect them to be perfect and quiet. Socially they expect them to do all the same social aspects as what we do.” (hearing parent)*

### **11.3.b**            *dynamics between siblings*

*“While I was breastfeeding my 4<sup>th</sup> baby, I was watching how my children are socialising at home. My 2 hearing children were talking to each other, and the 3<sup>rd</sup> Deaf daughter was just very alone, I noticed. She was just enjoying playing on her own, with her own things. And now I’ve got the 4<sup>th</sup> Deaf daughter, so it’s 2 and 2. They have different social skills - the 2 hearing and the 2 Deaf children. I’m trying to encourage the 3<sup>rd</sup> one to be involved with the first 2, with the hearing world. Trying to encourage her to get with the 2 hearing sisters, and for the 2 hearing ones to get with the Deaf sister. But it’s not easy. When I look back now on my life, I didn’t care about being Deaf. I thought ‘If you don’t accept me for who I am, then I will just do what I want, enjoy myself’. My parents were very good role models and gave me confidence to do whatever I wanted to do. But now I’m looking at my 3<sup>rd</sup> daughter – will she have the confidence to do like I did?...I want my child to...go out into the general community, and roam where they want to roam to. I don’t know what her future will be like, but at the moment I can see the boundaries, the barriers, between the Deaf and the hearing. The 2 hearing are always together, and the 2 Deaf are always together. The 2 hearing are more comfortable to talk talk talk verbally, and they can’t be bothered moving their hands to sign, and then repeat and repeat to make sure they understand – they can’t be bothered. And I say ‘Oh come on kids, go back, help your sister please’. But no. It’s not easy.” (Deaf parent)*

### **11.3.c**            *societal responses carrying stigma*

*“At first when my child was a baby and had his hearing aids on - and I was still very upset – but there was many a time I left a shopping trolley full of groceries at Woolworths, because I’d see an older child saying to his mother ‘What are those things in that baby’s ear?’ And the mother would stare but not answer to their child. And I’d be so upset and leave.” (hearing parent)*

*“And people staring at him on a day to day basis. And you go to the shops or kindy, and people are just looking at him, and I think ‘I know he’s got them in his ears, but he doesn’t look any different to any other child.’ That’s a really difficult thing, as a parent, having to see other people stare at your child and wonder what’s wrong with them. I think we’re very fortunate that he’s such a confident lively little boy. And I think sometimes, oh, should I grow his hair or put a hat on him. Just because I didn’t want it to upset him when he got older. But it doesn’t bother him at all. If people say ‘What are they?’ he tells them ‘They’re hearing aids so I can hear it when you talk to me.’ (hearing parent)*

### **11.3.d**            *impacts on emerging relationships*

*“It does impact on my other relationships too because my ex-fiancé was having to learn Sign Language, so any man you go out with, and they’re going to be seriously involved in your life, they have to learn Sign and they have to understand kids that can’t speak.” (hearing parent)*

## **11.4 There are daily communication and behavioural challenges when parenting a child who is Deaf or has a hearing loss**

### **11.4.a managing hearing aids and cochlear implants**

*“My child learned to communicate early on. When she was 8 months old, she started signing. Then we started trying to keep the hearing aids in, which was a nightmare, absolute nightmare!! And the lying to all the therapists ‘Oh yes!! She has them in for a couple of hours a day.’ Because you just felt so guilty that you couldn’t get them in. Trying to make out it was better than it was, because it was really only 10 minutes here and there. She hated them.” (hearing parent)*

*“My child has an implant in one ear and an aid in the other. And now she’s wearing her implant more than her hearing aid. And sometimes when we go to preschool we forget about putting it on because you don’t think of your child as deaf!! (hearing parent)*

*“But we’ve had ear infections, and the biggest challenge is just keeping the aids in. If they could invent something for toddlers to keep their aids in, that would be great! The dog has eaten them and things like that!” (hearing parent)*

*“He is very good with keeping in his hearing aids now, but sometimes that was difficult because he wouldn’t keep them in. And that was a pretty stressful time when I’m constantly having to put hearing aids in his ears, and he pulls them out and throws them, then I put them back in again. That was a bit tricky.” (hearing parent)*

### **11.4.b managing behaviour and safety**

*“It’s very, very, hard. We’re just looking into whether she has a behavioural problem. She’s just so hyperactive. It is rather hard, and she’s a runaway as well, so I’ve got all the alarms on the doors. It makes it hard when you just want to have a shower. And it’s hard when you can’t call out to her too, because of her hearing. It’s a horrible feeling. Just losing her, and seeing what’s she getting into. So it’s very, very, tiring.” (hearing parent)*

### **11.4.c maintaining and nurturing communication and therapy**

*“With my child and showers, we forget that she’s deaf, and we talk to her, and then we remember ‘Oh, we have to tap her on the shoulder, because she doesn’t have her implant in.’ She can lip-read alright but we have to remember to tap her. And my parents do it, my mum just talks to her and she goes ‘Oh that’s right, she can’t hear’...When she takes her ears out, she talks in a very high pitch voice, she squeals sometimes, and you say ‘Stop’ but she can’t hear. Then you tap her on the shoulder and say ‘Be quiet, shhhhhh’. And she doesn’t understand what we’ve said, so you have to enunciate clearly.” (hearing parent)*

*“The impact of the hearing loss hasn’t hit me. It’s not something that I feel grief over or stress. It’s just more demanding. You have to be more full on with him, and I’m learning a lot too, as the process goes on. What I find hard is that I have a hearing teacher coming around once a week to see him, and what I find hard is explaining to him - because of all the different noises that he needs to hear - telling him everything that I’m doing - like ‘Mummy is washing up now’ or ‘Do you want to do that now?’ – constantly talking to him, getting him used to those sounds. That’s what I find hard. But it’s just something that you do, talking in short sentences and stuff like that. Whereas with a baby without hearing loss, they will hear those sounds normally.” (hearing parent)*

*“My hearing daughter is such a big help and she doesn’t even realise that she is. Just teaching him the sounds, and by interacting with him and playing with him. I teach her what to do and she does it with him. Then we’ll both do it. And then Dad gets in. It’s a big family thing. The majority of it is up to me, because Dad’s working, but when he’s home he’ll help for sure.” (hearing parent)*

*“We’ve been going to Hear & Say since he was 11 months old, and this is our last year. This year has been very difficult because he doesn’t enjoy the therapy. It’ll come around and he’ll say ‘I don’t want to go there Mum. It’s boring. It’s an hour of sitting in a chair.’ And we have done the same thing for 4 years, so it has been hard.” (hearing parent)*

## **11.5 How the child experiences their Deafness or hearing loss: from a mother’s perspective**

### **11.5.a feeling or experiencing difference**

*“My son seems quite happy. My daughter, she’s a bit more reserved. In Grades 1 and 2, the kids don’t care about differences, they’re happy just to play. But when they get to Grade 3 the other children, as they’re maturing, they’ve realised that this child is different, and they don’t want anything to do with that child. So it’s a maturing process, and they push them to the side.” (hearing parent)*

*“But she is a little bit aware of the support that she gets. And when they’ve been on excursions, they would take the teacher aide, and she said to me ‘When will you come on the excursion? Because I never get to go with the parents. I always have to go with the teacher aide. It’s just because I’m deaf, but I don’t need her, I can go with a parent. I’m just deaf, I don’t need this. What’s the big deal?’” (hearing parent)*

### **11.5.b feeling the same or special**

*“I really don’t think that my child feels or thinks that he’s any different. He’s got this pretty little red thing on the side of his head, and he’s real proud of it. And he can do everything else that other kids do. The only difference is, at school he gets taken out to work with a special teacher, but it’s not made a big deal of. And all the other kids know that he goes. He’s been very adaptive to all the changes, like going to hospital, the hearing aids, the grommets, the this and the that.” (hearing parent)*

### **11.5.c feeling social confidence and success**

*“My child is very comfortable with her deafness. Like she loves it. But she’s just as comfortable in the hearing world, with her implant on at school. She participates in everything. She has this whole little life at school that I have no idea about. There’s nothing she feels she can’t do.” (hearing parent)*

*“But she lip-reads very well, especially that she’s older. And she has a full time job. And it’s very lucky, these days you have email and text messages on the phone. And she has some speech, but she’s fantastic in society. She’s learned over the years that: ‘I’m deaf, too bad!’ She’s quite proud of herself.” (hearing parent)*

### **11.5.d feeling frustrated**

*“I know he gets very frustrated. I think he’s only just now starting to understand that not everybody is like him. And there’s still a lot of times when he just goes to naturally sign to other children, and if they are hearing, they don’t know what he’s saying. And other children don’t understand the whole concept of being deaf. They don’t understand that he’s deaf. They just want to yell louder. And also, other children, when he goes up and taps them to talk to them to get their attention, they think that he’s hitting them. And they say ‘Mummy, he’s hitting me!’ I think he gets really frustrated, because if I’m not around - like he likes the 2 little girls next door, but they don’t sign. When he’s talking to them at the fence, and I’m not around, then they don’t know what he’s saying, and he doesn’t know what they’re saying. So I think he is starting to notice that people are different, because he’s starting to ask me now if people are deaf or hearing. Sometimes we go through a whole big list of people. He’ll say ‘Is so-and-so hearing?’ Just about all of them are hearing, and then when he says someone from his school who is deaf, and I say ‘Yes, they’re deaf’, then he gets all excited!! He even gets frustrated with ME now when he’s signing something to me, and I don’t understand him. And when he gets frustrated, then he starts overemphasising it and it makes it even harder to understand what he’s saying.” (hearing parent)*

11.5.e *feeling surprise or amazement*

*“I wonder what he hears, what depth he can hear to. He can hear to a certain extent. There’s a different response from when his aids are on, to when they are not. I often look at him, just the expressions on his face, like ‘Ohhhh what’s that?’”* (hearing parent)

*“We put her switch-on on video, and just watching that, just the way her eyes lit up when she heard, just the amazement that they can hear.”* (hearing parent)

11.5.f *feeling peaceful*

*“And I asked her once ‘What’s it like to be deaf?’ Because I have no idea. I look at her in the playground, because you have to take the cochlear implants off for plastic play equipment because of static electricity. So she’ll go out in the playground and I think ‘What is it like to be out on a noisy playground with no sound?’ I just can’t comprehend it. And she said to me ‘It’s very peaceful.’”* (hearing parent)

## APPENDICES

**Appendix 1** Information package to parents for gaining participants' informed consent

**Appendix 2** Question schedule for guiding the consultation discussions

## APPENDIX 1      Information package to parents for gaining participants' informed consent

### (a) CONSULTATION BY FOCUS GROUP

#### RESOURCE DEVELOPMENT CONSULTATION FOR INFORMING THE QUEENSLAND HEALTHY HEARING PROGRAM QUEENSLAND HEALTH

#### *Personal Experiences & Information and Service Needs of Parents who have a Child with a Hearing Loss*

### **INFORMATION SHEET**

#### **1. Who is conducting this consultation for resource development?**

This consultation is being conducted on behalf of the Queensland Healthy Hearing Program, Queensland Health.

The key contact person for the Queensland Healthy Hearing Program is:

Shirley Glennon  
Statewide Coordinator  
Queensland Healthy Hearing Program  
Statewide Health Services  
Statewide Health & Community Services Branch  
Queensland Health  
Ph: 07 3131 6814  
Em: shirley\_glennon@health.qld.gov.au

#### **2. Why is this consultation being done?**

The Queensland Healthy Hearing Program, Queensland Health, is currently introducing Universal Newborn Hearing Screening to Queensland. The aim of Universal Newborn Screening is to identify children with a permanent hearing loss by the time they are 3 months old and to commence early intervention services by 6 months of age. The first stage in this process is to provide hearing screening to all newborn infants within the first few days of their life.

For most families, receiving the news that their baby has a hearing loss can be a very challenging time. The Queensland Healthy Hearing Program wants to provide a range of supports to parents and families as they make many important decisions for their child's future.

One way to support parents and families is to provide them with information and resources, such as brochures, booklets, videos etc. The Queensland Healthy Hearing Program is in the process of developing such resources.

The Queensland Healthy Hearing Program wants to make these resources as appropriate and responsive to the needs of parents and families as possible. Talking directly with parents who have already experienced this time of finding out that their child has a hearing loss, can be a very effective way to find out what resources and information parents most need at this time. Therefore, the Queensland Healthy Hearing Program would like to invite a number of parents to discuss their ideas and views on this, as well as the types of support services that parents most need.

In the near future, the Queensland Healthy Hearing Program will run a number of focus groups in Brisbane so that parents who have a child with hearing loss can come together for a shared discussion about their experiences, including their information, resource, and service needs.

This information sheet gives you the specific details about these focus groups, so that you can decide if you would like to participate.

### **3. What is a focus group?**

A focus group is a bit like a group interview. It is a specific technique for exploring a topic or issue by discussing it within a group of people who share similar experiences or who have something in common. Usually a focus group has about 6 participants, plus a facilitator who guides the group through the discussion process. A focus group can be a very powerful tool for learning about a topic or issue, because it allows ideas and viewpoints to grow and expand as they are bounced around the various people in the group. Typically, the participants in a focus group discuss a set of preset questions, but other associated issues and questions which arise naturally will also be encouraged and included.

### **4. If you decide to participate, what will you be asked to do?**

- Read this information sheet carefully and make sure you fully understand all the aspects of participating in this consultation project;
- Sign a consent form to show if you agree with the terms of your participation;
- Attend ONE focus group session, 90 minutes in duration;
- Share your experiences, needs, knowledge, opinions within the focus group setting – by responding personally to a set of interview questions (please find a guide to these questions in section 5 of this information sheet), as well as discussing the questions with other parents participating in the group;
- Share your ideas and views within a focus group which will have 6 to 8 parents participating;
- Allow your dialogue to be video and/or audio taped during the focus group. Taping is needed so that your ideas can be accurately and fully captured. The tapes will only be viewed by the focus group consultant. Your ideas will be documented into a report, and some of your actual quotations (word for word) may be printed in the resource. Your name will not be identified with any of your ideas or words unless you give your permission for this (all data is kept confidential);
- Maintain the privacy of other participating parents, by not revealing personal issues that are discussed within the focus group, to anyone outside the focus group.

## 5. What types of questions will I be asked during the focus group?

During the focus group, the consultant will ask a range of questions to the group and invite discussion on them. These questions will be about (a) your experiences of being a parent to a child with hearing loss; (b) your information requirements; (c) the decision making process you go through; and (d) your service and support needs.

Listed below are some examples of the types of questions you will be asked. These examples are only a guide, because other associated issues and questions which arise naturally from the group discussion may be included too.

### (a) Your Experiences

“How did you find out that your child has a hearing loss?”

“What were your first reactions to your child’s diagnosis?”

“What other reactions have you had since?”

“What are the key times that you have felt the greatest stress or anxiety?”

### (b) Your Information Requirements

“How did you develop your understanding of your child’s hearing loss?”

“What has been the most crucial piece of information that has helped you?”

“At what points have you needed specific pieces of information?”

“What information resources have you liked and found useful? What would you have ideally liked?”

### (c) Your Decision Making

“What have been the key decisions you have made?”

“How did you make these decisions?”

“What has helped and hindered you in making these decisions?”

“Have you modified your key decisions along the way? How? Why?”

### (d) Your Service and Support Needs

“During the first 12 months after diagnosis, what information would you have liked about the various service organisations?”

“What has been the most helpful aspect of service support? Why?”

“Have you needed to rethink your decisions about service choice?”

“In an ideal world, what supports would be provided to parents?”

## 6. What are the expected benefits of the consultation?

It is intended that this consultation with parents, such as yourself, will inform the Queensland Healthy Hearing Program about the information, resource and service needs of parents and families, in order to:

- develop resources which are responsive to the real and daily needs of parents and families, and which are in the most useable form and mode;
- develop early intervention services which directly meet the needs of parents and families.

## 7. What are the risks to you of participating in the consultation?

There are 2 main areas of potential risk which you should be aware of.

### 1. STRESS

If you decide to participate, this consultation project will ask you to share and discuss your past and present needs, your experiences, your feelings, and your problems concerning having your child diagnosed as having a hearing loss. Therefore, it is possible that you may experience some levels of personal emotional stress as a result of your participation.

This project will provide the following supports to you so that personal emotional impacts be minimised:

- (a) A qualified professional will be on call in the centre during the conduct of the focus group for any required personal and emotional support;*
- (b) A qualified professional, who is familiar to you from your service organisation, will make phone contact with you on the day following the focus group for any follow-up support that you may require;*
- (c) the focus group will be conducted within a friendly, relaxed, supportive and open environment.*

## 2. PRIVACY

If you decide to participate, you will be discussing your needs, experiences, feelings and problems within a group setting. Therefore other parents and the group facilitator will be privy to the things that you say.

This project will provide the following mechanisms to you so that your privacy is maximised:

- (a) Prior to the focus group, each parent will be required to sign a confidentiality agreement that asks that matters discussed in the group setting will not be revealed to anyone outside the group;*
- (b) The group facilitator and the support professional are bound by ethical guidelines to keep all your information private at all times and for all participants;*
- (c) your name will not be identified with any of your ideas or words (unless your permission is given to do so);*
- (d) you have control over what you choose to say or not say in the focus group – there is no pressure to answer every question or to participate in all aspects of discussions.*

## **8. What will happen to the information you give?**

The information which you, and other participating parents, give during the project will be:

- collected and documented in a written report. This report will be made available to:
  - a) various management and advisory groups associated with the Queensland Healthy Hearing Program, to assist in their decision making and planning roles;
  - b) other associated organisations;
  - c) parents who have participated in the project.
- used to advise the development of various educational and supporting resources for parents and families who have a child with a hearing loss.

Some of your direct speech (in word-for-word quotation) may be used in the resource. This would provide parents who are reading the resource, with “real and personal” experiences of others who have shared similar experiences. Often personal statements of others can be very supportive, comforting, empowering and therapeutic.

## **9. What about confidentiality?**

This project makes sure that all the information you offer in the consultation will remain anonymous. This means that your name will not be connected in any way to the information that you give (unless your permission is given to do so).

The following things will be done to protect your rights to confidentiality:

- Names will not be identified with ideas and words – complete anonymity is ensured;
- If, in a special case, it is thought useful that your name accompany your specific information and words, then this would be done only with your formal permission;
- While in the process of transcription (writing down word-for-word what is recorded on the tape), video and audio tapes will be stored in a locked secure place – names of participants will not be kept in the same location as the tapes;
- Video and audio tapes will be destroyed at the end of the project; all transcriptions will be coded and free of names;
- All parents participating in the focus group will sign a confidentiality agreement which asks that identities and matters associated with the focus group be kept private. This agreement is included in the Consent Form;
- The group facilitator and support professional are bound by ethical guidelines to maintain the privacy of all identities and matters associated with the focus group.

## **10. How were you selected as a possible participant?**

This project aims to include the experiences, needs, knowledge and opinions of a range of parents and families representing differing choices, situations, and backgrounds.

You have been suggested by your service organisation as a parent who may be interested to participate in this project.

## **11. Your participation is voluntary at all times**

- You do not need to answer every question within the focus group unless you wish to do so;
- You can remain silent at any time during the focus group if you do not wish to discuss particular matters that may arise;
- You are free to withdraw from the project at any time;
- You are free to leave the focus group at any time;
- Your decision to withdraw in no way impacts on your relationship with your service organisation

## **12. Will participation cost you anything?**

This consultation project can provide:

- A contribution of \$25.00 towards transport costs to and from the venue; and, if needed, a further \$25.00 to assist with child-care costs while you attend the focus group;
- Refreshments will be provided for your comfort and enjoyment.

Loss of income cannot be reimbursed in any way.

## **13. Will there be feedback to you about the consultation?**

You will receive a copy of the report which will document the findings of this consultation project. This will be sent to you via your service organisation.

## **14. How is it ensured that this consultation is conducted ethically?**

This consultation project is:

- Conducted in line with the *National Statement on Ethical Conduct in Research Involving Humans*;
- Managed and funded by Queensland Health, and endorsed by the Healthy Hearing Expert Advisory Committee;
- Conducted with the support and cooperation of key service organisations, units, and groups.

If you have concerns, questions or complaints about the ethical conduct of this project you can contact:

Helen Little

Acting Director, Statewide Health Services  
Statewide Health & Community Services Branch  
Queensland Health  
Ph: 07-3131 6979  
Em: helen\_little@health.qld.gov.au

**15. Do you have any questions or need further information?**

You can contact the following people at any time:

Shirley Glennon

Statewide Coordinator  
Queensland Healthy Hearing Program  
Statewide Health Services  
Statewide Health & Community Services Branch  
Queensland Health  
Ph: 07 3131 6814  
Em: shirley\_glennon@health.qld.gov.au

Helen Spork

Consultant  
  
Ph: 07 3397 0728  
Em: h.spork@epok.com.au

## (a) CONSULTATION BY PERSONAL PHONE INTERVIEW

### RESOURCE DEVELOPMENT CONSULTATION

#### FOR INFORMING THE QUEENSLAND HEALTHY HEARING PROGRAM QUEENSLAND HEALTH

#### Personal Experiences & Information and Service Needs of Parents who have a Child with a Hearing Loss

### INFORMATION SHEET

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Queensland Healthy Hearing Program  
Statewide Health Services  
Statewide Health & Community Services Branch  
Queensland Health  
Ph: 07 3131 6814  
Em: shirley\_glennon@health.qld.gov.au

#### 2. Why is this consultation being done?

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For most families, receiving the news that their baby has a hearing loss can be a very challenging time. The Queensland Healthy Hearing Program wants to provide a range of supports to parents and families as they make many important decisions for their child's future.

One way to support parents and families is to provide them with information and resources, such as brochures, booklets, videos etc. The Queensland Healthy Hearing Program is in the process of developing such resources.

The Queensland Healthy Hearing Program wants to make these resources as appropriate and responsive to the needs of parents and families as possible. Talking directly with parents who have already experienced this time of finding out that their child has a hearing loss, can be a very effective way to find out what resources and information parents most need at this time. Therefore, the Queensland Healthy Hearing Program would

like to invite a number of parents to discuss their ideas and views on this, as well as the types of support services that parents most need.

In the near future, the Queensland Healthy Hearing Program will run a number of focus groups in Brisbane so that parents who have a child with hearing loss can come together for a shared discussion about their experiences, including their information, resource, and service needs. For parents such as yourself, who live in more regional or remote areas of Queensland, a number of personal phone interviews will be run so that the needs of more “distant” parents can be considered in the development of resources.

This information sheet gives you the specific details about these personal phone interviews, so that you can decide if you would like to participate.

### **3. What is a personal interview?**

A personal interview is a specific technique for exploring a topic or issue by discussing it with one other person, the interviewer. Therefore, an interview usually involves only 2 people – the participant and the interviewer. Typically, the participant in a personal interview discusses a set of preset questions, but other associated issues and questions which arise naturally will also be encouraged and included. Interviews can be done either face to face, or over the phone.

### **4. If you decide to participate, what will you be asked to do?**

- Read this information sheet carefully and make sure you fully understand all the aspects of participating in this consultation project;
- Sign a consent form to show if you agree with the terms of your participation;
- Participate in one phone interview session, 45 minutes in duration;
- Discuss your experiences, needs, knowledge, opinions during a personal phone interview – by responding personally to a set of interview questions (please find a guide to these questions in section 5 of this information sheet);
- Allow your dialogue to be audio-taped during the phone interview. Your ideas will be documented into a report, and some of your actual quotations (word for word) may be printed in the resource. Your name will not be identified with any of your ideas or words, unless you give your permission for this (all data is kept confidential).

### **5. What types of questions will I be asked during the focus group?**

During the interview, the consultant will ask you a range of questions and invite you to discuss them. These questions will be about (a) your experiences of being a parent to a child with hearing loss; (b) your information requirements; (c) the decision making process you go through; and (d) your service and support needs.

Listed below are some examples of the types of questions you will be asked. These examples are only a guide, because other associated issues and questions which arise naturally from the conversation will be followed too.

#### (a) Your Experiences

“How did you find out that your child has a hearing loss?”

“What were your first reactions to the diagnosis?”

“What other reactions have you had since?”

“What are the key times that you have felt the greatest stress or anxiety?”

(b) Your Information Requirements

“How did you develop your understanding of your child’s hearing loss?”

“What has been the most crucial piece of information that has helped you?”

“At what points have you needed specific pieces of information?”

“What information resources have you liked and found useful? What would you have ideally liked?”

(c) Your Decision Making

“What have been the key decisions you have made?”

“How did you make these decisions?”

“What has helped and hindered you in making these decisions?”

“Have you modified any of your key decisions along the way? How? Why?”

(d) Your Service and Support Needs

“During the first 12 months after diagnosis, what information would you have liked about the various service organisations?”

“What has been the most helpful aspect of service support? Why?”

“Have you needed to rethink your decisions about service choice?”

“In an ideal world, what supports would be provided to parents?”

**6. What are the expected benefits of the consultation?**

It is intended that this consultation with parents, such as yourself, will inform the Queensland Healthy Hearing Program about the information, resource and service needs of parents and families, in order to:

- develop resources which are responsive to the real and daily needs of parents and families, and which are in the most useable form and mode;
- develop early intervention services which directly meet the needs of parents and families.

**7. What are the risks to you of participating in the consultation?**

There are 2 main areas of potential risk which you should be aware of.

1. STRESS

If you decide to participate, this consultation project will ask you to share and discuss your past and present needs, your experiences, your feelings, and your problems concerning having your child diagnosed as having a hearing loss. Therefore, it is possible that you may experience some levels of personal emotional stress as a result of your participation.

This project will provide the following supports to you so that personal emotional impacts be minimised:

- (a) The phone interview will be conducted in a friendly, relaxed, supportive and open way. If you are feeling emotional stress at any time during the interview, then you can ask the interviewer to stop discussions. The interviewer will then support you to decide what steps you would like to follow from that point;*
- (b) A qualified professional, who is familiar to you from your service organisation, will make phone contact with you on the day following interview for any follow-up support that you may require.*

## 2. PRIVACY

If you decide to participate, you will be discussing your needs, experiences, feelings and problems with an interviewer. This interviewer will be privy to the things that you say.

This project will provide the following mechanisms to you so that your privacy is maximised:

- (a) The interviewer and the follow-up support professional are bound by ethical guidelines to keep all your information private at all times;*
- (b) your name will not be identified with any of your ideas or words (unless your permission is given to do so);*
- (c) you have control over what you choose to say or not say in the interview – there is no pressure to answer every question or to participate in all aspects of discussions.*

## **8. What will happen to the information you give?**

The information which you, and other participating parents, give during the project will be:

- collected and documented in a written report. This report will be made available to:
  - a) various management and advisory groups associated with the Queensland Healthy Hearing Program, to assist in their decision making and planning roles;
  - b) other associated organisations;
  - c) parents who have participated in the project.
- used to advise the development of various educational and supporting resources for parents and families who have a child with a hearing loss.

Some of your direct speech (in word-for-word quotation) may be used in the resource. This would provide parents who are reading the resource, with “real and personal” experiences of others who have shared similar experiences. Often personal statements of others can be very supportive, comforting, empowering and therapeutic.

## **9. What about confidentiality?**

This project makes sure that all the information you offer in the consultation will remain anonymous. This means that your name will not be connected in any way to the information that you give (unless your permission is given to do so).

The following things will be done to protect your rights to confidentiality:

- Names will not be identified with ideas and words – complete anonymity is ensured;
- If, in a special case, it is thought useful that your name accompany your specific information and words, then this would be done only with your formal permission;
- While in the process of transcription (writing down word-for-word what is recorded on the tape), audio-tapes will be stored in a locked secure place – names of participants will not be kept in the same location as the tapes;
- Audio-tapes will be destroyed at the end of the project; all transcriptions will be coded and free of names;
- The interviewer and support professional are bound by ethical guidelines to maintain the privacy of all identities and matters associated with the interview.

## 10. How were you selected as a possible participant?

This project aims to include the experiences, needs, knowledge and opinions of a range of parents and families representing differing choices, situations, and backgrounds.

You have been suggested by your service organisation as a parent who may be interested to participate in this project.

## 11. Your participation is voluntary at all times

- You do not need to answer every question within the interview unless you wish to do so;
- You are free to withdraw from the project at any time;
- You are free to stop the interview at any time;
- Your decision to withdraw in no way impacts on your relationship with your service organisation.

## 12. Will participation cost you anything?

This consultation project will organise the phone connection to you for the interview. The phone interview will occur at your convenience, and at no cost you.

Loss of income cannot be reimbursed in any way.

## 13. Will there be feedback to you about the consultation?

You will receive a copy of the report which will document the findings of this consultation project. This will be sent to you via your service organisation.

## 14. How is it ensured that this consultation is conducted ethically?

This consultation project is:

- Conducted in line with the *National Statement on Ethical Conduct in Research Involving Humans*;
- Managed and funded by Queensland Health, and endorsed by the Healthy Hearing Expert Advisory Committee;
- Conducted with the support and cooperation of key service organisations, units, and groups.

If you have concerns, questions or complaints about the ethical conduct of this project you can contact:

Helen Little  
Acting Director, Statewide Health Services  
Statewide Health & Community Services Branch  
Queensland Health  
Ph: 07-3131 6979  
Em: helen\_little@health.qld.gov.au

## 15. Do you have any questions or need further information?

You can contact the following people at any time:

Shirley Glennon  
Statewide Coordinator  
Queensland Healthy Hearing Program  
Statewide Health Services  
Statewide Health & Community Services Branch  
Queensland Health  
Ph: 07 3131 6814  
Em: shirley\_glennon@health.qld.gov.au

Helen Spork  
Consultant  
  
Ph: 07 3397 0728  
Em: h.spork@epok.com.au

## APPENDIX 2 Question schedule for guiding the consultation discussions

### YOUR PERSONAL EXPERIENCES

- a. How did you find out that your child is Deaf or has a hearing loss? What were your first reactions, emotions, feelings?
- b. What other reactions have you had since? Have there been specific times when you've had stronger reactions than others? Why do you think your reactions change over time?
- c. What are the realities of having a child who is Deaf or has a hearing loss (*highlights & difficulties*)?
- d. What do you think are your child's experiences of life as a Deaf child or as a child with a hearing loss?
- e. How do other people in your family participate in the journey of your Deaf child, or your child who has a hearing loss? Do you feel it is a family issue?
- f. What impacts does having a child who is Deaf or has a hearing loss, have on other relationships and friendships?
- g. What is it like to tell your family, friends, about your child's Deafness or hearing loss?

### YOUR INFORMATION & RESOURCE NEEDS

#### (a) CONTENT

- a. Do you feel you know enough now about your child's Deafness or hearing loss? What else would you like to know, and how would this help you? Do you know where to get this information?
- b. What has been the most crucial piece of information that has helped you?
- c. Finish this sentence: If only I knew -----, then I would have done ----- differently.
- d. How important is technical information to you? What other types of information have you found useful / would you have found useful?

#### (b) STYLE

- How do you like information to be presented to you?
- What information resources (booklets, pamphlets, websites, people, AV) have you liked and found useful?

LOOK AT VARIOUS RESOURCES AND DISCUSS: e.g.

- Conventional standard information such as "Choices" – on audiology, devices, communication options, services available
  - Little Introductory Booklets
  - Video/DVD
  - A Family File e.g. "Early Support"
  - Emotions & Personal Stories
- a. What do you need in addition to "Choices"?
  - b. In your experience, what isn't available?
  - c. What resources would you ideally have liked?
  - d. What mediums do you like, and for which types of information?
  - e. What kinds of professional support would you like around the resources you are given?

#### (c) TIMING

- a. What were your first questions which you wanted answers to?
- b. At what points have you needed specific pieces of information?

#### (d) ACCESS

- a. What has helped and hindered you from getting the information you needed?

### **YOUR DECISION MAKING & SERVICE NEEDS**

- a. How have you made your key decisions about which communication mode and service organisation to use?
- b. Apart from your standard decisions (e.g. communication mode, devices), what other decisions have you had to make?
- c. What has helped and hindered you in these decisions?
- d. Have you had to modify key decisions and choices you have made about communication mode and service organisation?
- e. What has been the most helpful aspect of service support – why?
- f. In an ideal world, what supports would be provided to parents upon diagnosis of their child having a hearing loss?

### **CLOSING QUESTIONS:**

- a. Is there anything else that you would like contribute to this consultation?
- b. How do you feel now about participating in this focus group consultation?