



# Parent to Parent Program and Life Stories Program For Parents of Children with a Hearing Loss

Joint programs funded by Queensland Health and  
administered by Deaf Children Australia



# Parent to Parent and The Life Stories Program



Two recently established family centred programs complement the professional services provided by Qld Health's Healthy Hearing Program:

- **Parent to Parent Program**, linking newly diagnosed families with experienced parents, commenced 2010
- **The Life Stories Program**, linking newly diagnosed families with deaf and hard of hearing adults, commenced in 2012

Both programs follow the Colorado Hands and Voices philosophy of supporting families without bias

# Overview

Opportunities for interaction with other parents of children with hearing loss and individuals who are deaf or hard of hearing:

- were considered by parents of newly diagnosed infants to be important at and following diagnosis

(Face to Face Report, Qld Health, 2006; Newborn Hearing Screening Parent Survey, Deaf Children Australia, 2005)

- should be included in Early Detection and Intervention Programs (Joint Committee on Infant Hearing, Position Statement 2007)

- Help families learn what it means to be deaf or hard of hearing and how to provide a supportive home environment (Marschark, 2007)

# Parent to Parent Program

# Parent to Parent

- Ø Parent to Parent connects families with a child who has been recently diagnosed with a hearing loss (aged 0-6), with a parent who has an older child with a hearing loss.
- Ø Support Parents provide support through sharing experiences, information, listening and empathy.
- Ø State wide free service

# Why parents?



- Ø The impact of a diagnosis of hearing loss in an infant leads to a variety of emotions
- Ø The family's well being and capacity to re-adjust critically influences the development of the child (Bruder, 2000, Dunst 2002, Turnbull and Turnbull, 2001)
- Ø Parents who have been through the same experience of diagnosis are able to provide support and information in a way in which only another parent can do (Santelli, Turnbull, Marquis and Lerner, 1995).

# Rationale

Connecting parents with other parents of children with a hearing loss can:

- Ø Encourage parents and provide parents with role models
- Ø Provide parents with a much better understanding of their situation
- Ø Reduce feelings of isolation, lead to better acceptance of their child, and improved responsiveness during interactions.

(Hintemair, 2000, Nunes, Pretzlik & Ilicak, 2005)

# Who are the Support Parents?

- Ø Support Parents have older children (age range 6 – 21 years) who use a range of communication methods and technological aids
- Ø Carefully selected
- Ø Receive ongoing training and supervision
- Ø Are employed



# Support Parents do:

- Ø Listen, share experiences, refer, encourage early intervention
- Ø Support family choice

# Support Parents don't:

- Ø Sway parents, provide counselling, provide expert information

# How it works

- Ø One to One – home visits, phone, email
- Ø Childhood Hearing Clinics
- Ø Early Intervention Playgroup Visits

To date (Oct 2010 to May 2013):

- Ø Connected with 171 families
- Ø 250.25 contact hours with Support Parents

# What do parents talk about



- Ø Specific questions
- Ø Practical information
- Ø Reflections and reactions
- Ø Concerns

# Feedback

Of survey respondents

Ø100% said that the contact was helpful

Ø100% would recommend the program to others

Improvements reported as a result of contact:

- § Feeling understood
- § Feeling less alone
- § Feeling supported
- § Gaining better understanding of child's needs
- § Being more informed

# What have parents said?

## Some examples...

# Less alone

- *“ She made me feel comfortable and made me feel I’m not alone. ”*
- *“It was nice to know that someone had walked in my shoes”*
- *“Because of G, I didn’t feel alone”*
- *“It was lovely to talk to someone, especially in the early days”*
- *“She was a good listener and I was able to discuss my daughter and not feel out of place. I felt better because I had someone I could talk to that knew how I felt. It has helped me cope having someone to talk to.”*

# Feeling supported/understood



- *“I really enjoyed the connection with someone who has been through the same thing.”*
- *“I could talk about any of the problems I was having.”*
- *“For anyone going into this situation (hearing aid fitting) it is nice to have someone who understands what is about to happen. There was no pressure and no offence taken if you were too busy with appointments”*
- *“I found it really helpful to talk to B. I have lots of friends with babies but none are going through this. They are all very sympathetic but they don’t understand and that’s hard at times.”*

# Feeling more confident/informed



- *“ I understand better the problems hearing impaired children can have.”*
- *“I have more of an understanding of how having a child with a hearing loss has affected her life. I was wondering about putting my daughter into childcare when I go back to work and how that might affect her, so it was great to be able to talk about that”*
- *“It has helped to see what is further down the track”*
- *“I am more informed of my options”*
- *We have many appointments and have a great understanding of what is ahead now. I am happy to continue ahead with what is coming along now. Thank you for everything!”*

# The Life Stories Program

# Life Stories Program

Provides opportunities for families to meet adults who have grown up with a hearing loss and are living fulfilling lives

Aims to:

- Ø Help families feel more confident about what the future might hold for their child with a hearing loss
- Ø Provide encouragement and support
- Ø Help families be aware of some of the possibilities and challenges of living with a hearing loss
- Ø Broaden understanding of deafness

# Rationale



- Ø 95% of deaf babies are born to hearing parents (Mitchell and Karchmer, 2004)
- Ø Majority of parents have never known anyone who has a congenital/early onset hearing loss
- Ø Parents often have gaps in their understanding of deafness
- Ø Exposure to deaf and hard of hearing adults can provide invaluable perspectives that come from personal experience

# Rationale

Studies indicate that Deaf and Hard of Hearing adults can

- Ø Strengthen the family's sense of well being and child's social and emotional development
- Ø Be powerful influences in helping families understand the realities and possibilities for their child
- Ø Help parents feel less anxious about their child's future, have greater acceptance of their child, feel more competent in raising their child

(Beams and Olson, 2007; Hintermair, 2000, 2006; Meadow-Orlans et al., 2003; Meadow-Orlans, Smith-Gray, & Dyssegaard, 1995)

# How does it work?

Families choose from a range of specially trained Deaf and Hard of Hearing ((D/HOH) Adults

D/HOH Adults meet with families via:

- Ø One to One – home visits, phone, Skype, email

- Ø Panels

- Ø Early Intervention Playgroup Visits



To date (Jan 2012 to May 2013):

- Ø Connected with 31 families
- Ø 70 contact hours with Deaf/HOH Adults

# What happens during a visit



- Ø D/HOH adults share their life experiences with the family in a positive and encouraging way. Where challenges have been encountered, solutions and strategies they used for coping are also discussed
- Ø Family members are offered the opportunity to ask questions
- Ø D/HOH adults model good communication strategies
- Ø D/HOH adults may also spend some time playing/talking to siblings and/or child (if older)

# Trends observed in the first year



- Ø Families tend to choose to meet 1:1 with a D/HOH adult with similar degree and cause of hearing loss to their child
- Ø However, families who also meet adults with different degrees of loss or communication method eg through panels, report stories shared were useful, interesting, informative and/or inspiring. Parents don't often see the benefits of meeting a diverse range of D/HOH adults until after they have done so.
- Ø Parents describe positive feelings eg admiration, warmth, empathy and joy, towards the Deaf/HOH adults after hearing their stories and often express a hope that the person(s) will be a role model for their child.
- Ø Newly diagnosed families like several meetings at different stages
- Ø Parents appreciate honesty and openness

# What do parents ask about?



- What does \_\_\_\_\_ sound like to you (eg speech, music)?
  - What helps you/what makes it harder to understand?
  - Did you get teased/bullied?
  - Relationships: with parents, siblings, friends, partners, raising own children
- 
- Education: school experiences, types of support, school grades, post school study, employment prospects and challenges
  - Communication methods
  - Limitations? Sports, workplace, social, hobbies
  - What did your parents do that helped you most?
  - Independence, affordability of aids/CI as an adult

# Survey Feedback

100% of respondents reported:

Ø it was helpful to have met with a D/HOH Adult

Ø they would recommend the program to other families

Reported benefits include:

- Feeling more reassured about the future
- Feeling better informed
- Better understanding of what it is like to have a hearing loss
- Feeling more realistic
- Feeling more confident and/or motivated

# What have parents said?

## Some examples...



# Reassurance

Prior to meeting D/HOH adult:

*“Everyone has been telling me “it will be ok, it will be ok”. My husband, my friends, everyone. But in my head I’m saying “this is not ok, this is **not** going to be ok!!”*

After meeting D/HOH adult:

*“Everyone kept telling me the kids would be ok, it will be ok. For the first time, I feel like it **will** be ok.”*



*“It was so nice to hear what she’s achieved in life. It hasn’t stopped her from doing anything, in fact it’s made her more determined. You fear they won’t have the same opportunities, fear what their life will be like at my age.....how would my daughter look after her baby? It was great to hear that she (D/HOH adult) is doing it. It was really reassuring to hear her story and how normal her life is.”*

# Understanding & Knowledge

- *“Talking to (D/HOH adult) was not a medical opinion of how to wear hearing aids, it was reality, of “this is what life is like”. It was the most beneficial thing I’ve had so far”.*
- *“I understand hearing loss much better. She put in simple terms what she can hear, rather than in clinical terms, like 60 decibels on a chart or level of loss. The way she hears people speaking, or hears the words of a song.....this was really interesting and helpful to know.”*
- *“My husband is really into music. He had been sad to think our daughter would miss out on that. Now we know she might hear it differently, but she will still be able to engage in it and enjoy it. That means a lot.”*

# Understanding and Knowledge



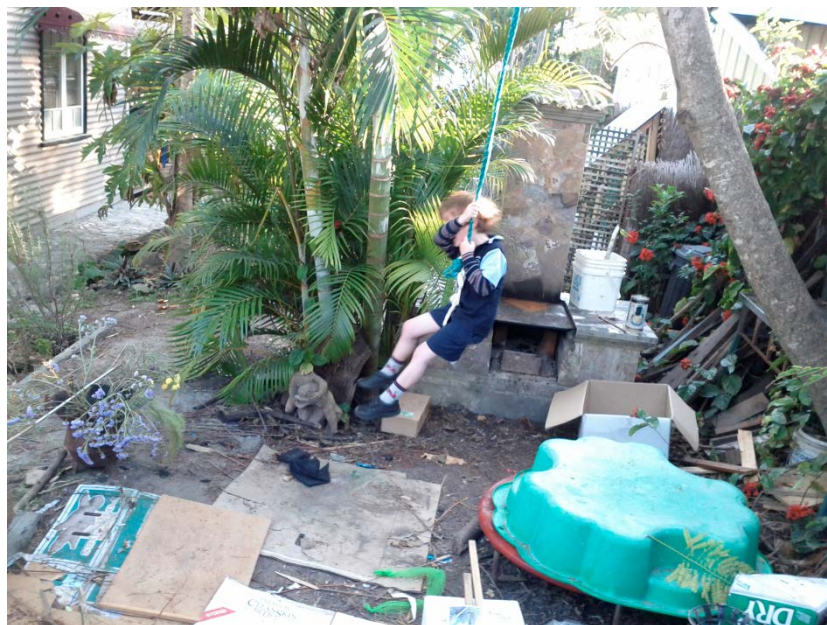
- *“Hearing them talk about how important their mothers were in their lives, and how the support of X’s siblings meant so much to her, helps me to know that I am important, that I make a difference. My older children (aged >8) listened to their stories as well and I think now have a better understanding of why mummy needs to spend so much time with Y, and how important they are in Y’s life. I have talked about this with them too”.*
- *“I asked a lot of questions. They were so patient with me. Everyone wants to be a good mother, and if you know better, you do better.”*
- *“I have a better understanding of how to help. I’m more aware about issues and what helps in school, uni, notetakers, FMs.... it has motivated me to check out the options even though it is years away”.*

# Acceptance

- *“I have been told by ENTs, by Audiologists, by lots of people at the different clinics that my son’s hearing may deteriorate because of CMV. But I have been in denial. I kept thinking “Yeah, his hearing will get better”.*

*Meeting J and hearing his story (with deteriorating loss due to CMV) has helped me accept, has confirmed it for me. I never used to look at the graph results, compare them. Now I do. I am more aware of what is happening for my son. It has helped me a lot, to accept.”*

# Hope



*“I’ve realised it is a big thing, but my children will be able to lead a normal life.”*

*“They made it. They’re working, successful. They can do it, so can my son”.*

*“The way she wore her hair up, and the implant there just like that, (black hair, white processor) **and** she looked beautiful. I would like her to be a role model for my daughter when she is older”.*

# Awareness

- *“While both visitors were similarly deaf and wore cochlear implants, they were different, had different personalities, different experiences of being deaf, different dreams. This is invaluable for us as parents to see deaf people as individuals in their own right, not just “deaf”.*
- *“It was interesting to compare the two signers (during panel trio). I could see that A was a very bubbly, outgoing person and B was quite serious and academic and it wasn’t their deafness that defined who they were or what they did (A working with deaf children, B doing Masters then PhD), but their personalities.”*

# Summary

Parent to Parent and Life Stories Programs are indicating success in:

- Reducing isolation
- Providing support and encouragement
- Providing reassurance and hope for the future
- Increasing confidence and acceptance
- Increasing understanding of child's needs
- Increasing knowledge of what may lie ahead, and strategies to help

All of which aid in the process of adjustment and contribute to the family's sense of well being, which in turn contribute to better child and family outcomes.

# Questions?



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