

## Introduction

### SURVEY INSTRUCTIONS: PLEASE READ CAREFULLY

This survey is intended only for parents and caregivers of children who have a hearing loss -anywhere in the world. The survey will take approximately 10 minutes to complete. Your participation in this survey is completely voluntary. Your survey responses will be anonymous and if you feel uncomfortable answering any questions, you can withdraw from the survey at any point.

The term "professional" is used throughout the survey. For the purposes of this survey, "professional" can refer to a variety of different people including an audiologist, paediatrician, teacher of deaf students or any other professional that you have consulted about your child's hearing loss.

### PURPOSE OF SURVEY

The results will be used to produce formal recommendations for Best Practice in Family Support and will be presented at NHS 2010 in Como, Italy – the final international conference on newborn hearing screening.

### WHO IS COLLECTING THIS INFORMATION?

The survey is being undertaken by GPOD – a Global Coalition of Parents of children who are deaf or hard of hearing - which was formed at NHS 2008 with the goal of "promoting improved systemic protocols and practices which encourage informed choice and the empowerment of families with a deaf child throughout the world."

### CONTACT INFORMATION

If you have any questions about the survey or would like to know the results of the survey, please contact:

Janet Des Georges – [janet@handsandvoices.org](mailto:janet@handsandvoices.org)

Ann Porter – [info@aussiedeafkids.org.au](mailto:info@aussiedeafkids.org.au)

Thank you very much for taking the time to participate in this survey!

### MESSAGE TO ORGANISATIONS AND SERVICE PROVIDERS

We are mindful that many families will not have access to the Internet. We would appreciate it if organisations and service providers could print this survey and distribute it to families and carers in their region, if required.

Please mail completed hard copies to:

Ann Porter

Aussie Deaf Kids

35 Wharf 8

56A Pirrama Road

Pymont NSW 2009

Australia

## About your Family

These questions will help us to understand basic information about your family and child.

If you have more than one child with a hearing loss – please base your answers on your experiences with your older child with a hearing loss.

### 1. My relationship to the child

- mother
- father
- grandmother
- grandfather
- other

### 2. Please tell us about where you live

City/Town:

State/Province:

ZIP/Postal Code:

Country:

### 3. What is the highest level of education that you have completed?

- No formal schooling completed
- Formal schooling but did not complete high school
- High School graduate
- Post - school vocational training
- University degree

### 4. At what age was your child diagnosed with a hearing loss?

- at birth
- under 6 months
- 6 months - 1 year
- 1 year - 2 years
- 3 or older

### 5. How old is that child now?

- under 6 months
- 6 months - 1 year
- 1 year - 2 years
- 3 or older

6. What is your child's level of hearing loss?

Mild

Moderate

Severe

Profound

don't know

7. Is your child's hearing loss

in one ear (unilateral)

in both ears (bilateral)

## Family - to - Family Support

This section asks about your opportunities to be connected with other families.

Think of Family-to-Family support as the different ways in which families with deaf and hard of hearing children interact so that they can share their knowledge, concerns, and experiences with each other.

8. Did professionals suggest that you talk with other parents to learn more about raising a child who is deaf or hard of hearing?

Yes

No

9. Were you given information about how to contact or be contacted by parent to parent support organizations or individuals?

Yes

No

10. Please indicate which family - to - family support services are available to you (select all that apply)

A local or county/state/province support group made up of parents of children who are deaf or hard of hearing

A local or county/state/province support group made up of parents of children with disabilities but not exclusively deaf or hard of hearing

A national support group made up of parents of children who are deaf or hard of hearing

A national support group made up of parents of children with disabilities but not exclusively deaf or hard of hearing

A support group made up of families who share a specific communication modality

A support group organized or sponsored by a service provider

11. Have you used any of the family to family support services offered by any of the groups & organizations?

Yes

No

12. If so, Do you know if any of the parents that you received support from were trained to provide that support?

Yes, they were

No, they weren't

I don't know

13. Overall, how do you rate the quality of family support you have received?

Excellent

Good

Adequate

Poor

Very Poor

have not received any support

14. How could the family support services provided to you be improved? Please enter your suggestions below.

## Types of Information

This section asks about the information you needed and where you got that information.

15. When you first began looking for information about your child's hearing loss, did you feel you received complete and balanced information about all communication options and educational programs from the professionals who served you? Please explain

	Yes	No	I don't Know
Communication Options	jn	jn	jn
Educational Programs	jn	jn	jn

Tell us your experience

16. Where did you get information about your child's hearing loss and related information? Check all that apply

	Received	Desired, but did not receive	Did not need
Written materials	jn	jn	jn
Videos or movies	jn	jn	jn
Websites	jn	jn	jn
Online Parent support groups	jn	jn	jn
Blogs	jn	jn	jn
Youtube	jn	jn	jn
Face to face interaction with professional	jn	jn	jn
Visiting various educational programs in person	jn	jn	jn
Discussion with other parents (face to face, by phone, email etc)	jn	jn	jn

17. From the list above, please rank in order of importance (one being the most important, seven being the least; N/A for not available)

written materials	<input type="text"/>
videos or movies	<input type="text"/>
websites	<input type="text"/>
online parent groups, blogs, youtube	<input type="text"/>
face to face interaction with professionals	<input type="text"/>
visiting various education programs in person	<input type="text"/>
discussion with other parents (face to face, by phone, email etc.)	<input type="text"/>

18. Social/Emotional Support: We are interested in identifying types of social-emotional support that are important to families. How important is it that programs....

	Very important	Somewhat important	unimportant
Help all family members understand hearing loss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understand your family's experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Connect you with families of children who are deaf or hard of hearing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Connect you with parents who are trained to provide support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide unbiased emotional support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide access to adults who are deaf or hard of hearing for mentoring	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
comments	<input type="text"/>		

19. Please check the topics for which you have received information from the professionals who serve your family (physicians, ENT's, Audiology, Teachers, Therapists etc.)

	Yes, have received	Not needed	Desired, but not received
Sign language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Age Appropriate play and toys	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Assistive technology (FM, alerting devices)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Listening skill development and auditory training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication choices (sign language, cued speech, auditory etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deaf Community/Culture	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parent rights under the law	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Funding sources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing aids and/or cochlear implants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How to promote language development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Preschool programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How to promote speech development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How hearing works	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Degrees of hearing loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Causes of hearing Loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stages of grief/acceptance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other parents to contact	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Impact on family	jn	jn	jn
Sibling issues	jn	jn	jn

20. What are your issues/concerns regarding the education of your deaf child(ren)?

	Primary	Secondary
Academic progress	jn	jn
Social/emotional needs	jn	jn
Choice of school	jn	jn
Access to full curriculum	jn	jn
Access to Communication	jn	jn
Location/transport	jn	jn
Post-school options	jn	jn

Other (please specify)

21. Do you feel you are in control when decisions are made about communication and education choices for your child?

- Never
- Some of the time
- Most of the time
- Always

22. Do you feel comfortable letting professionals know when/if you disagree with the advice and recommendations for your child?

- Never
- Some of the time
- Most of the time
- Always

23. Please check which activities you have participated in

	Yes	No
Attend social gatherings or support groups with parents of children who are deaf or hard of hearing.	jn	jn
Contact a parent or caregiver who has a child who is deaf or hard of hearing (phone, email, or TTY).	jn	jn
Meet with a parent or caregiver who has a child who is deaf or hard of hearing.	jn	jn
Contact an adult who is deaf or hard of hearing.	jn	jn



## Parent Involvement

This section asks you to describe your experience or knowledge about parents who work with service providers, decision makers and governments on behalf of other families to bring about change and improve practices and services for families of children with a hearing loss.

24. Are you involved as a parent consultant/representative/volunteer/staff member to give family perspective in any program in screening, diagnosis, intervention, and/or education for children who are deaf/hard of hearing?

Yes

No

List committees or agencies you work/volunteer with

25. Are you aware of opportunities in your country to be involved at a systemic level?

Yes

No

26. Are you ever contacted by any other parents who function in the role above to get your input about the agencies/programs that serve you?

Yes

No

27. If you would like to be added to an email list for further surveys and/or communication add your email address here

28. Want to share anything else? Tell us your Story!