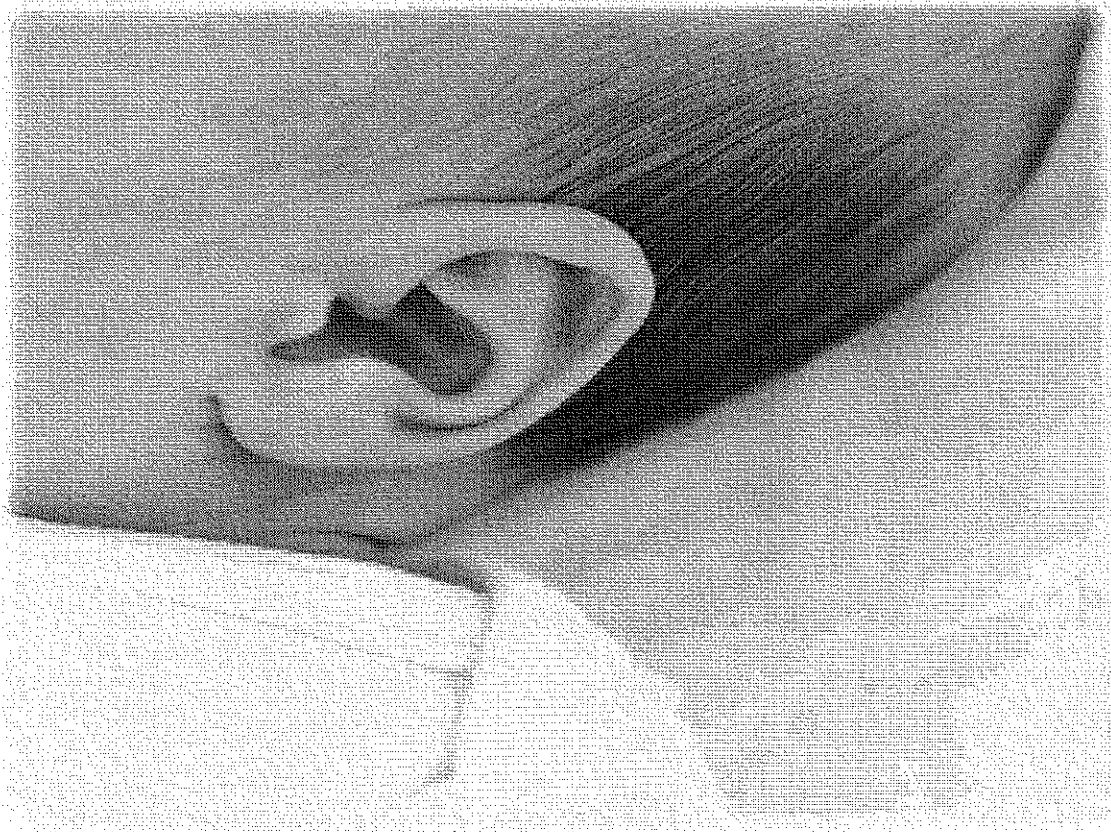


Survey of Infant and Toddler Services



This survey is about **your child who is 3 years of age or younger and has a hearing loss**. If you have more than one child younger than 3 years of age with hearing loss, please answer for your youngest child or request another survey.

Your participation is voluntary and anonymous. For questions about your rights as a participant in this project: Name, Phone Number and/or email of IRB contact.

For questions or requests about the study: Aneesha Pretto at (919) 593-3381 or pretto@med.unc.edu

Sponsored by the University of North Carolina at Chapel Hill

SECTION A: ABOUT YOUR CHILD

This survey is about your child who is 3 years of age or younger and has a hearing loss. If you have more than one child younger than 3 years of age with hearing loss, please answer for your youngest child or request another survey.

1. Your child is

A boy..... ₁

A girl..... ₂

2. What is your child's age today?

Example: If your child is 28 months old, you would then write 2 years and 4 months as:

Your Child's Age Today

0	2
---	---

 Years, and

0	4
---	---

 Months

Your Child's Age Today

--	--

 Years, and

--	--

 Months

3. Does your child have special needs other than hearing loss?

No..... ₁

Yes..... ₂ Please describe _____

4. How would you describe your child's hearing loss over time?

It has stayed the same..... ₁

It has become worse over time.... ₂

I'm not sure..... ₃

5. What is the cause of your child's hearing loss or hearing disorder?

Check all that apply.

Unknown ₁

Genetic/heredity..... ₂

Meningitis..... ₃

Prematurity..... ₄

Low oxygen..... ₅

Hyperbilirubinemia..... ₆

Cytomegalovirus..... ₇

Maternal Rubella (Measles)..... ₈

Had treatment with drugs that caused a hearing loss..... ₉

Other (_____) ₁₀

6. Does your child have hearing loss in both ears or one ear?

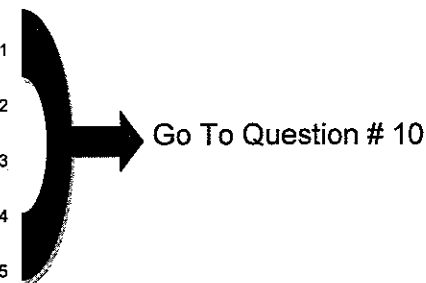
Both ears..... ₁  Go to Question # 9

One ear ₂

7. Your child's hearing loss is in the ...

- Right ear..... ₁
- Left ear ₂
- I'm not sure..... ₃

8. Which category best describes your child's hearing in this ear? Check one.


- Mild to Moderate loss ₁
 - Moderate to Severe loss..... ₂
 - Severe to Profound loss ₃
 - Auditory Neuropathy..... ₄
 - I'm not sure..... ₅
- 
- Go To Question # 10

9. Your child has difficulty hearing in both ears. If your child's hearing is not the same in both ears, describe the hearing in the better ear. Check one.


- Mild to Moderate loss..... ₁
- Moderate to Severe loss..... ₂
- Severe to Profound loss..... ₃
- Auditory Neuropathy..... ₄
- I'm not sure..... ₅

SECTION B: NEWBORN HEARING SCREENING & AUDIOLOGICAL MANAGEMENT

10. Was your child's hearing screened at birth?

- Yes..... ₁
- No ₂  Go to Question # 12
- I'm not sure..... ₃  Go to Question # 12

11. When your child's hearing was screened, did he/she pass?

- No..... ₁  Go to Question # 13
- Yes ₂

12. Why did you become concerned about your child's hearing? Check all apply

- Wasn't developing speech normally..... ₁
- Wasn't responding to sounds..... ₂
- Concerns expressed by friends..... ₃
- Concerns expressed by other family members..... ₄
- Concerns expressed by health care provider (e.g., physician or nurse)..... ₅
- Did not pass a later hearing screening..... ₆
- Had serious illness requiring a hospital stay..... ₇
- Other (_____) ₈


13. How old was your child when the hearing loss was confirmed by an audiologist?

Example: If your child's hearing loss was confirmed at 2.5 months (10 weeks old), write 2 months:

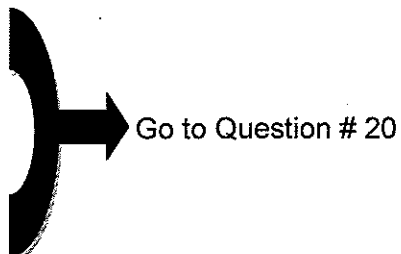
Age Hearing Loss was Confirmed Years, and Months

Age Hearing Loss was Confirmed Years, and Months

14. Has your child ever been fitted with hearing aids?

- Yes..... ₁  Go to Question # 16
- No..... ₂

15. If hearing aids were *never* fitted, why? Check all that apply.

- My child's hearing loss is mild or in only one ear... ₁
 - My child has auditory neuropathy..... ₂
 - I was not ready to get hearing aids for my child.... ₃
 - Cost of hearing aids..... ₄
 - Other (_____) ₅
- 


16. How old was your child when hearing aids were fitted?

Years, and Months

17. How much time passed between identification of the hearing loss and hearing aid fitting?

- 2 weeks or less..... ₁
- 3 to 4 weeks..... ₂
- 5 to 8 weeks ₃
- 9 to 12 weeks..... ₄
- More than 12 weeks ₅
- I'm not sure..... ₆




18. How did you feel about the amount of time your child waited for hearing aid fitting?

- It was reasonable ₁  Go to Question # 20
- It was a little too long..... ₂
- It was much too long ₃

19. What were the reason(s) for the delay? Check all that apply.

- Delay in 3rd party payments like Medicaid or private insurance..... ₁
- Appointments were not available..... ₂
- Ear infections..... ₃
- My child was ill..... ₄
- I was not ready to get hearing aids for my child..... ₅
- Had trouble getting transportation to appointments ₆
- My child's paperwork was not yet complete..... ₇
- Physician said that hearing aids were not needed..... ₈
- Other (_____) ₉

20. Which statement best describes your child with regard to the cochlear implant process?

- My child has a cochlear implant... ₁  Go to Question # 21
- My child is being evaluated for a cochlear implant..... ₂  Go to Question # 23
- My child is not a cochlear implant candidate..... ₃  Go to Question # 23

21. Your child wears...

- One implant on the right or left ear..... ₁
- One implant with a hearing aid on the other ear..... ₂
- Two implants, one on each ear..... ₃

22. How old was your child when the surgery(s) for each implant occurred?

Example: If the first ear was implanted at 12.5 months, you would write 1 Year as:

Age of surgery on first ear

0	1
---	---

 Years, and

0	0
---	---

 Months

Age of surgery on first ear

--	--

 Years, and

--	--

 Months

Age of surgery on second ear

--	--

 Years, and

--	--

 Months

Thank you for sharing about your child and his or her hearing. Now we'd like to find out about your experiences with services to help with your child's development after diagnosis.

SECTION C: EVALUATION FOR INFANT AND TODDLER SERVICES

Before a family receives infant and toddler services, a team of professionals will hold a meeting with the family to discuss your concerns, priorities and resources. The team will also test your child to identify his or her skills and areas for growth. Testing may occur once or twice each year as your child grows. This evaluation process is important in developing an early intervention plan, sometimes called the Individualized Family Service Plan (IFSP) that we ask about in Section D.

23. Which statement best describes your child's experience with testing for services before the age of 3 years?

- My child has been tested at least once.... ₁
- My child is being tested for the first time... ₂
- My child has not been tested..... ₃ Go to Question # 25

24. Now we'd like to ask about the last time your child was tested for services. Thinking about the period before, during or just after testing, did the following occur?

Did the following occur <u>the last time</u> your child was tested?	Yes 1	No 2	I'm not sure 3
I shared my most important concerns with the team of professionals.			
I filled out checklists, wrote down observations or gave other parent report.			
I was invited to be with my child for all testing activities.			
The team made sure I understood the purpose of all activities and tests.			
I was given time to discuss whether my child's behavior during testing was typical for him or her.			

SECTION D : DESIGNING THE INDIVIDUALIZED FAMILY SERVICE PLAN

An Individualized Family Service Plan (IFSP) is a support plan that families and professionals develop together following evaluation. The purpose of the IFSP is to identify the services and people who can help families reach their goals. The IFSP is written and revised at least once each year to show your child and family's changing needs.

25. Was an IFSP developed with your family?

Yes..... ₁

No..... ₂  Go to Question # 31

26. How many IFSPs were written before your child's 3rd birthday?

One..... ₁

Two ₂

Three..... ₃

More than three..... ₄

27. For the next questions, please think about the last time an IFSP was developed for your child. Check one box for each item.

Did the following occur <u>the last time</u> an IFSP was developed?	Yes 1	No 2	I'm not sure 3
I had time to get to know our provider before we wrote the IFSP.			
I helped decide who should participate on the IFSP team.			
I wanted to be more involved than I was.			
I was allowed to make decisions at my own pace.			
I decided my family's priorities for the IFSP.			
I was an equal partner in planning the goals and services for my child and family.			
I had enough time to read the IFSP before signing.			
I didn't sign the IFSP until I was comfortable with it.			

28. If there is disagreement on what is best for your child, your opinion is given more weight.

- Strongly agree..... 1
- Agree..... 2
- Undecided..... 3
- Disagree..... 4
- Strongly Disagree..... 5

29. If there was disagreement between you and another team member while developing the IFSP, what happened?

30. We are interested in what the team did AFTER the last IFSP was developed.
Check one box for each item.

Did the following occur AFTER <u>the last IFSP</u> was developed?	Yes 1	No 2	I'm not sure 3
Each team member carried out the plan we made.			
The therapy provided by each service provider reflected my family's priorities.			
A team member made changes in the plan as my child progressed.			
A team member helped me schedule therapy and assessments for my child.			

SECTION E : YOUR FAMILY'S INFANT AND TODDLER SERVICES

This section asks about your family's experience with infant and toddler services. By infant "infant or toddler services," we mean any professional services (like speech therapy, sign language instruction, occupational therapy, etc.,) received by your family before your child's 3rd birthday. We'd also like to know about the sources of support that have been most helpful to you as a parent.

31. How old was your child when infant and toddler services first began?

Years, and Months

Check here if your child never received services, then Go to Question # 51.


32. How did you feel about the amount of time your child waited to receive services?

- It was reasonable ₁ Go to Question # 34
- It was a little too long..... ₂
- It was much too long ₃

33. What were the reason(s) for the delay? Check all that apply.

- Delay in 3rd party payments like Medicaid or private insurance... ₁
- Difficulty scheduling services..... ₂
- Difficulty finding a qualified provider..... ₃
- My child's paperwork was not yet complete..... ₄
- Our family was not ready to start services..... ₅
- Had trouble getting transportation to services..... ₆
- My child was ill..... ₇
- Other (_____) ₈


34. Does your child currently receive infant and toddler services for his or her hearing loss?

- Yes..... ₁
- No..... ₂  Go to Question # 51

35. How long has your child been enrolled in infant and toddler services?

- Less than 6 months..... ₁
- 6 to 12 months..... ₂
- 13 to 18 months..... ₃
- 19 to 24 months..... ₄
- 24 to 30 months..... ₅
- More than 30 months..... ₆

36. Your child currently receives infant and toddler services at.... Check all that apply.

- Our home..... ₁  Go to Question # 39
- A daycare center..... ₂
- A preschool..... ₃
- A school for the deaf..... ₄
- A clinic or hospital..... ₅
- Other (_____) ₆

37. If your child receives services in a group, how would you describe the other children? Check all that apply.

- Children with hearing loss..... ₁
- Children with normal hearing (typically developing)..... ₂
- Children with other special needs..... ₃
- My child does not receive services in a group..... ₄

38. Is the location where your child receives services appropriate for your family's needs?

- It is convenient and has most of the resources that we need ₁
- It is convenient but has few of the resources that we need..... ₂
- It is not convenient but has most of the resources that we need..... ₃
- It is not convenient and has few of the resources that we need..... ₄

39. Has your family ever moved to another location because of the services available there for your child with hearing loss?

- Yes..... ₁
- No ₂

40. The next questions ask about the choices you were offered the last time you planned infant and toddler services. Mark one box on each row.

Did the following occur the last time you planned services?	Yes 1	No 2	I'm not sure 3
I had a choice about the location where my family received services			
I had a choice about how often my family received services			
I had a choice about how much I participated in the services with my child			

41. Was your family's schedule considered when services were planned?

- Yes..... ₁
- No ₂

42. Given your family's daily routine, the number of total visits scheduled with all service providers was ...

About right..... ₁

Too few..... ₂

Too many..... ₃

Why? _____

Why? _____

43. Place a mark beside the service provider you and your child currently see the most often. For the other service providers, please indicate whether your child does see or does not see these professionals now.

Service Provider	See the most often (check one)	Also see	Does not see
Early childhood special education teacher			
Infant-toddler specialist			
Teacher of the deaf and hard of hearing			
Speech-Language Pathologist			
Audiologist			
Physical Therapist			
Occupational Therapist			
Social Worker			
Other provider (_____)			

44. How often does your child receive services from the Primary Provider?
 The Primary Provider is the person your child sees the most often to help with communication difficulties due to a hearing loss or disorder.

Once a week or more..... ₁

Every other week..... ₂

Once a month..... ₃

Less than once a month..... ₄

How often? _____

45. For the next set of questions, please think about the last 12 months. Then, mark YES or NO to indicate whether your family's Primary Provider provided the following counseling, services or other assistance. Next, check YES or NO to indicate whether your family wanted this type of help. Remember to mark two boxes in each row.

In the <u>last 12 months</u> , did the Primary Provider ...?	Did the Primary Provider ...?		Did your family <u>want</u> this help?	
	Yes ₁	No ₂	Yes ₁	No ₂
Help you fill out forms.				
Help you contact parents of other children with hearing loss.				
Help you find funding for services or equipment like hearing aids or a cochlear implant.				
Demonstrate knowledge of your child's equipment.				
Help you learn to troubleshoot the hearing aids and/or cochlear implant.				
Encourage you to be the major decision-maker about your child.				
Give you time to express your feelings about having a child with hearing loss.				
Give helpful suggestions to manage your child's behavior.				
Use your suggestions about how to work with your child.				
Show you how to use toys, books and play to develop language.				
Show you strategies to develop language during your child's daily activities such as dressing or bathing.				
Help you learn your child's communication approach.				
Help you feel you can positively affect your child's development.				
Help you find community activities and programs for your child that were (could be made) communication accessible.				
Help you find parent support groups.				
Help you meet adults who are deaf or hard of hearing.				


46. What approach best describes how you want to communicate with your child?
Check one.

- Spoken language..... ₁
- A combination of spoken and signed communication..... ₂
- Sign language..... ₃
- A communication board or device ₄
- Cued Speech..... ₅
- Other (_____) ₆

47. How skilled is your Primary Provider in using this approach to communicate with your child? Remember: The Primary Provider is the person your child sees the most often to help with communication difficulties due to a hearing loss or disorder.

- Very skilled..... ₁
- Somewhat skilled..... ₂
- Not at all skilled..... ₃

48. Does the Primary Provider use this approach to communicate with your child?

- Yes..... ₁  Go to Question # 50
- No..... ₂

49. What approach does the Primary Provider use with your child? Check one.

- Spoken language ₁
- A combination of spoken and signed communication..... ₂
- Sign language..... ₃
- A communication board or device ₄
- Cued Speech..... ₅
- Other (_____) ₆

50. Tell us 3 things you would change about your child's infant and toddler services if you could? Please describe your ideas as fully as possible.

1. _____
2. _____
3. _____

51. Instructions: Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This section asks you to indicate how helpful each source is to your family.

Please mark the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, mark NA (Not Available) response.

How helpful has each of the following been to you in terms of raising your child(ren):	Not Available 1	Not at All Helpful 2	Sometimes Helpful 3	Generally Helpful 4	Very Helpful 5	Extremely Helpful 6
My parents						
My spouse or partner's parents						
My relatives/kin						
My spouse or partner's relatives/kin						
Spouse or partner						
My friends						
My spouse or partner's friends						
My own children						
Other parents						
Co-workers						
Parent groups						
Social groups/clubs						
Church members/minister						
My family or child's physician						
Day-care center						
Family advocate program or service						
Audiologist						
Speech-language pathologist						
Teacher of the deaf or hard of hearing						
Other (_____)						

SECTION F: ABOUT YOUR FAMILY

52. How are you related to the child you are responding about?

- | | | | | | |
|--------------------|--------------------------|---|--------------------|--------------------------|---|
| Mother..... | <input type="checkbox"/> | 1 | Foster father..... | <input type="checkbox"/> | 6 |
| Father..... | <input type="checkbox"/> | 2 | Grandmother..... | <input type="checkbox"/> | 7 |
| Stepmother | <input type="checkbox"/> | 3 | Grandfather..... | <input type="checkbox"/> | 8 |
| Stepfather..... | <input type="checkbox"/> | 4 | Other (_____) | <input type="checkbox"/> | 9 |
| Foster mother..... | <input type="checkbox"/> | 5 | | | |

53. What is your marital status?

- Never married..... 1
- Married..... 2
- Widowed..... 3
- Separated..... 4
- Divorced..... 5

54. How would you describe the area where you live?

- City of 100,000 people or more..... 1
- City or town less than 100,000 people... 2
- Suburb..... 3
- Rural area..... 4
- None of these..... 5 Please describe _____

55. What is your racial/ethnic background? (Check all that apply.)

- | | | | | | |
|-----------------------------|--------------------------|---|-----------------------------|--------------------------|---|
| White/Caucasian..... | <input type="checkbox"/> | 1 | Asian/Pacific Islander..... | <input type="checkbox"/> | 4 |
| Black/African-American..... | <input type="checkbox"/> | 2 | Native American..... | <input type="checkbox"/> | 5 |
| Hispanic/Latino..... | <input type="checkbox"/> | 3 | Other (_____) | <input type="checkbox"/> | 6 |

56. What is your age in years?

Your Age years

57. What is the highest level of education you have completed?

- Less than 12th grade..... ₁
- High school graduate or GED... ₂
- Junior college or Technical school..... ₃
- Some college..... ₄
- College graduate..... ₅
- Graduate / Professional school.. ₆

58. If another parent lives in the home, what is the highest level of education he/she has completed?

- Less than 12th grade..... ₁
- High school graduate or GED... ₂
- Junior college or Technical school..... ₃
- Some college..... ₄
- College graduate..... ₅
- Graduate / Professional school.. ₆

59. Thinking about your child with a hearing loss, do his or her biological parents have a hearing loss?

	Yes	No	I'm not sure
Mother			
Father			

The next 2 questions ask about the household of your child who is deaf or hard of hearing. If your child has more than one home, please describe the household where he or she spends the most nights per week.

60. How many adults live in the home with your child? An adult is any person who is 18 years or older.

Total Number of Adults Living in Home: _____

61. Please list the other children living in the home, including their ages, sex, and special needs, if any.

Age	Boy or Girl	Hearing Loss (Yes or No)	Other Special Needs (Describe)
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

62. Is English the only language spoken in your home?

Yes..... **➔** Go to Question # 64

No.....

63. If no, what other languages are spoken in your home?

Other Languages Spoken in Home: _____

64. Is there any other information you would like to share with us about your child, your family, your child's services, or primary provider?

Thank you for completing this survey!