

Cochlear Implant Questionnaire for Parents

In the first two sections, we would like to learn more about you, the parent/primary caregiver as well as your child with a cochlear implant(s)

Section A: Information about you as a parent/primary caregiver of a child with a cochlear implant(s)

1. What is your relationship to the child with a cochlear implant(s)?

Mother	1
Father	2
Primary caregiver (grandparent, foster parent, stepparent)	3
Other (please specify)	4

2. Your highest qualification level obtained can best be described as:

Primary/ high school (< Grade 12)	1
Secondary education (Grade 12/matric) completed	2
Tertiary qualification (University)	3
Tertiary qualification (other)	4

3. Marital status:

Married	1
Partner (not married)	2
Divorced/ separated	3
Previously divorced, now remarried	4
Single	5
Widowed	6

Section B: Information about your child with a cochlear implant(s)

4. Child's name: _____

(Please note that your child's name is needed for data tracking purposes and will be omitted during data analysis)

5. Date of birth of your child: _____

(dd/mm/yyyy)

6. Gender of your child:

Male	1
Female	2

7. Did your child receive Newborn Hearing Screening (was his/her hearing screened shortly after birth/within the first 4-6 weeks after birth)?

Yes	1
No	2
Unsure	3

8. Current health care sector of your child:

Private health care	1
Public health care	2

9. At which Cochlear Implant Centre/ Program does your child currently receive cochlear implant services from?

Bloemfontein Cochlear Implant Program	1
Chris Hani Baragwanath Academic Hospital Cochlear Implant Program	2
Durban Cochlear Implant Program	3
Johannesburg Cochlear Implant Centre	4
Port Elizabeth Cochlear Implant Program	5
Pretoria Cochlear Implant Unit	6
Tygerberg Hospital-Stellenbosch University Cochlear Implant Unit	7

10. How was your child's (first) cochlear implant funded?

Private funding (no medical aid)	1
Medical aid complete	2
Medical aid and private funding	3
Donations only	4
Sponsor(s)	5
Donations and medical aid	6
Donations and private funding	7
Donations, medical aid and private funding	8
Public: government funding	9
Other (please specify)	10

11. If your child uses two cochlear implants, how was the second cochlear implant funded?

Private funding (no medical aid)	1
Medical aid complete	2
Medical aid and private funding	3
Donations only	4
Sponsor(s)	5
Donations and medical aid	6
Donations and private funding	7
Donations, medical aid and private funding	8
Public: government funding	9
Other (please specify)	10

12. Your child currently uses:

Two cochlear implants	1
One cochlear implant and a hearing aid in the non-implanted ear	2
One cochlear implant without a hearing aid in the non-implanted ear	3

13. How does your child currently communicate?

Spoken language only	1
Sign Language only	2
Spoken language and Sign Language (mixed/total communication)	3
Manual communication (informal gestures)	4
Alternative Augmentative Communication (AAC) device	5
Other (please specify)	6

14. Your child's current educational setting can best be described as:

Not yet in school (too young)	1
Full mainstream nursery school or pre-school	2
Special nursery school or pre-school for children with hearing loss: oral approach (spoken language)	3
Special nursery school or pre-school for children with hearing loss: Sign Language or Total Communication approach	4
Mainstream school	5
School for the Deaf: Sign Language or Total Communication approach	6
School for children who are hard-of-hearing: oral (spoken language) approach	7
Special needs school: mainstream syllabus	8
Special needs school: special syllabus	9
Home school	10
Doesn't go to school (even though at a school-age)	11
Other (please specify)	12

15. If your child is enrolled in a formal educational setting, is this setting a public or private institution?

Public	1
Private	2
N/A	3

16. Has your child repeated a grade/multiple grades in school?

Yes	1
No	2
N/A	3

17. Did you choose to hold your child back during a grade(s) or enroll him/her in school at a later age?

Child was electively (non-compulsory) held back during a grade	1
Child started school at a later age	2
Child started school at a later age and was electively (non-compulsory) held back during a grade(s)	3
N/A	4

18. Has your child been diagnosed with a genetic syndrome? (e.g. Down Syndrome, Ushers Syndrome, Waardenberg Syndrome etc.)

Yes	No
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19. If yes, please specify

20. Does your child present with one or more of the following additional developmental condition(s)/needs?

Attention Deficit Hyperactivity Disorder (ADHD)/Attention Deficit Disorder (ADD)	1
Apraxia	2
Autism/ Autism Spectrum Disorder (ASD)	3
Cleft lip and/or palate	4
Cerebral Palsy	5
Developmental cognitive delay	6
Developmental behavioural delay	7
Developmental motor delay	8
Diagnosed learning disability (e.g. dyslexia)	9
Epilepsy	10
Feeding and/or swallowing disabilities	11
Mobility impaired	12
Visual impairment	13
Other (Please specify)	14
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Section C: Information about the process to obtain a cochlear implant(s)

21. Please rate the following statements as best you can:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
	1	2	3	4	5
<ul style="list-style-type: none"> * It was a difficult time waiting for the results of the cochlear implant assessment before implantation 					
<ul style="list-style-type: none"> * It was a problem getting someone to look after the family when we had to go to the Cochlear Implant Centre 					
<ul style="list-style-type: none"> * The costs of travel to the Cochlear Implant Centre were a problem 					
<ul style="list-style-type: none"> * It was hard to take time off work for the appointments at the Cochlear Implant Centre 					
<ul style="list-style-type: none"> As a family, we were financially prepared to meet the financial demands of the cochlear implantation process 					
<ul style="list-style-type: none"> We are currently financially able to meet the long-term and continuous financial demands following cochlear implantation (costs relating to habilitation, device maintenance etc.)? 					

22. In your opinion, do you think that the timing between the diagnosis of your child's hearing loss and eventual cochlear implantation was delayed?

Yes	No
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23. If yes, what do you think possible reason(s) for this delay could be? Please select possible reasons (more than one reason can be selected)

	Yes	No
• Progressive hearing loss (my child did not meet the audiologic criteria for cochlear implant candidacy and later showed a deterioration in his/her hearing levels)	1	2
• Clinical issues: Medical or presence of additional developmental conditions	1	2
• Difficulty in taking off from work to attend appointments at the Cochlear Implant Centre	1	2
• Difficulty in finding someone to look after the family when we go to the Cochlear Implant Centre	1	2
• Family indecision/uncertainty	1	2
• Family's geographical location/ travelling distance to the Cochlear Implant Centre	1	2
• Family's geographical location/ travelling costs to the Cochlear Implant Centre	1	2
• Financial costs and obtaining the required funding for the implant procedure	1	2
• Lack of information/support from the Cochlear Implant Centre	1	2
• Stress of surgery to my child (stress of having my child undergo anesthesia, drilling into the skull etc.)	1	2
• Lack of prompt referral to specialized Cochlear Implant services	1	2
• Opted for a second opinion	1	2
• Cultural/religious beliefs: seeking alternative/traditional treatment	1	2
• Other (please specify)	1	2

24. If your child currently has one cochlear implant, would you like him/her to receive a second implant?

Yes	No	N/A
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25. If yes, what do you think are the barriers preventing your child from obtaining the second implant? Please select possible reasons (more than one reason can be selected)

	Yes	No
• Family indecision/uncertainty	1	2
• Financial costs and funding of the second implant procedure	1	2
• Financial costs and funding of the device maintenance	1	2
• Lack of information/support from the Cochlear Implant Centre	1	2
• Stress of having my child undergo a second surgery (surgical anxiety)	1	2
• Uncertainty of the benefits of a second implant for my child	1	2
• Concerned about the disadvantage of destroying any residual hearing	1	2
• Not recommended by the Cochlear Implant Team	1	2
• Other (please specify)	1	2

26. If no, please list possible reasons for this decision

27. What would you consider as the greatest challenge(s) of being a PARENT/PRIMARY CAREGIVER of a child with a cochlear implant(s)?

28. In your opinion, what would you consider as the greatest challenge(s) that your CHILD experiences as a result of his/ her cochlear implant(s)?

Section D: Information about the education of your child with a cochlear implant(s)

29. Please rate the following statements as best you can

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	N/A
• Finding an adequate educational setting for my child has been a challenge	1	2	3	4	5	6
• * I am happy about my child's progress at school currently	1	2	3	4	5	6
• * My child is keeping up well with other children (normal hearing) his/her age in school	1	2	3	4	5	6
• My child is able to follow/keep up with the pace at which the teacher presents information	1	2	3	4	5	6
• * My child is able to cope academically in a mainstream school setting	1	2	3	4	5	6
• * The local school and its support services adequately meet all our needs concerning the use of my child's implant at school	1	2	3	4	5	6
• My child's current school placement is appropriate for his/her specific needs	1	2	3	4	5	6
• There is a shortage of appropriately trained teachers to deliver intervention services, specifically for children with cochlear implants	1	2	3	4	5	6

30. Which professional(s) assisted you in obtaining a school for your child? (indicate all applicable options)

Audiologist	1
Speech-Language Therapist	2
Educational Psychologist	3
Parent-Guidance Therapist	4
Auditory-Verbal Therapist	5
Did not receive assistance from any professional	6
N/A	7

31. Does your child encounter any of the following challenges in his/her current educational setting (more than one option may be selected)?

	Yes	No	N/A
• The number of children in the classroom is too big	1	2	3
• The classroom environment is too noisy	1	2	3
• No/little consideration is given for our child's unique language needs	1	2	3
• No/little support from school for additional services (we must pay for private tutors, remedial therapy etc.)	1	2	3
• Teachers and therapists often unsure of HOW to support our child's individual needs	1	2	3
• Bullying as a result of his/her cochlear implant is an issue	1	2	3
• As parents, we don't always have adequate finances to pay for all the additional academic support services our child needs	1	2	3
• Teachers have unrealistic expectations of parents	1	2	3
• We do not receive accurate feedback from the teachers (for e.g. they'll report that our child is coping and in another instance report that he/she is not coping)	1	2	3
• Teachers have limited patience with our child and don't have the capacity to go the extra mile in assisting him/her	1	2	3

Section E: Information on support services

32. The professional on the cochlear implant team who provided the most continued support from the time of implantation up until now is:

Audiologist	1
Ear, Nose and Throat Surgeon	2
Parent-Guidance Therapist	3
Psychologist	4
Speech-Language Therapist	5
Other (Please specify)	6

33. Please rate the support services your CHILD with a cochlear implant(s) has received since his/her (first) implant:

Support service	Support service not available	Received limited support	Received adequate support	Received exceptional support	Not applicable
Speech and language therapy	1	2	3	4	5
Occupational therapy	1	2	3	4	5
Behavior support	1	2	3	4	5
Counseling	1	2	3	4	5
Tutoring in school system	1	2	3	4	5
Sign Language instruction	1	2	3	4	5
Other (Please specify)	1	2	3	4	5

34. Please rate the support services you as a PARENT/ PRIMARY CAREGIVER has received since your child's (first) implant:

Support service	Support service not available	Received limited support	Received adequate support	Received exceptional support	Not applicable
Parent guidance	1	2	3	4	5
Counseling	1	2	3	4	5
Guidance for educational placement	1	2	3	4	5
Parent support group	1	2	3	4	5
Financial support	1	2	3	4	5
Tele-intervention	1	2	3	4	5
Technical support for device maintenance	1	2	3	4	5
Support and guidance to discipline my child with cochlear implant(s)	1	2	3	4	5
Counseling and support for the siblings of my child with a cochlear implant(s)	1	2	3	4	5
Other (Please specify)	1	2	3	4	5

35. In your opinion, which of the following support services would you consider as critical for A CHILD with a cochlear implant(s) to ensure optimal outcomes?

Please select **THREE** support services (from the table below) that you deem most important.

Support service	Most Important	Second Important	Third Important
Speech and language therapy	1	1	1
Occupational therapy	2	2	2
Behavior support	3	3	3
Counseling	4	4	4
Tutoring in school system	5	5	5
Sign Language instruction	6	6	6
Other (Please specify)	7	7	7

36. In your opinion, which of the following support services would you consider as critical for THE PARENTS/PRIMARY CAREGIVERS of a child with a cochlear implant(s) to ensure optimal outcomes?

Please select THREE support services (from the table below) that you deem most important.

Support service	Most Important	Second Important	Third Important
Parent guidance	1	1	1
Counseling	2	2	2
Guidance for educational placement	3	3	3
Parent support group	4	4	4
Financial support	5	5	5
Tele-intervention	6	6	6
Technical support for device maintenance	7	7	7
Support and guidance to discipline my child with cochlear implant(s)	8	8	8
Counseling and support for the siblings of my child with a cochlear implant(s)	9	9	9
Sign Language instruction	10	10	10
Other (Please specify)	11	11	11

THANK YOU for taking the time to answer these questions

**Questions adapted from the 'Children with cochlear implants: Parental perspectives' questionnaire by (Archbold et al., 2008)*