

Bylae A



Universiteit van Pretoria

Pretoria 0002 Republiek van Suid-Afrika Tel 012-420-2357
/ 012-420-2816 Faks 012-420-3517 <http://www.up.ac.za>

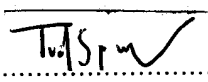
Departement Kommunikasiepatologie
Spraak- Stem- en Gehoorkliniek

November 2004

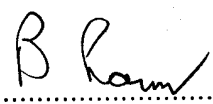
INGELIGTE TOESTEMMING: OUERS

1. **Titel van die studie:** Gehoorgestremdheid by jong kinders: Ouers se inisiële behoeftes vir inligting en ondersteuning.
2. **Doel van die studie:** Die doel van hierdie studie is om ouers van gehoorgestremde kinders se behoeftes vir inligting en ondersteuning by tye van diagnose en tydens vroeë intervensie te bepaal.
3. **Prosedure:** Daar sal van my verwag word om 'n vraelys in te vul en om die voltooide vraelys saam met hierdie brief van ingeligte toestemming dadelik aan die navorser terug te besorg.
4. **Risiko's en ongerief:** Daar bestaan geen risiko's verbonde aan hierdie studie nie en dit sal nie lank neem om die vraelys te voltooi nie.
5. **Waarde van studie:** Die resultate van hierdie studie sal pediatriese oudioloë rig in hoe die diagnose van gehoorgestremdheid oorgedra moet word. Verder sal resultate ook aangewend word om die huidige dienslewering aan jong gehoorgestremde kinders en hulle ouers te verbeter in terme van inligting-verskaffing en volgehoue ondersteuning. Ouers se spesifieke behoeftes vir inligting en ondersteuning by tye van diagnose, asook tydens vroeë intervensie sal bepaal word.
6. **Regte van die deelnemer:** Ek aanvaar om vrywillig aan hierdie studie deel te neem en het die volste reg om enige tyd te onttrek.
7. **Vertroulikheid:** Ek verstaan dat die inligting wat ek gaan verskaf vertroulik hanteer sal word en dat ek anoniem sal bly. Die resultate van hierdie studie mag in professionele tydskrifte gepubliseer word of voorgedra word by professionele konferensies, maar my naam en persoonlike besonderhede sal nie bekend gemaak word nie.

Indien ek enige verdere vrae of onsekerhede het kan ek te alle tye vir **Talita van der Spuy** skakel by 082 839 8343.


.....
Talita van der Spuy
Navorser


.....
Lidia Pottas
Studieleier


.....
Prof. Brenda Louw
Hoof: Dept. Kommunikasiepatologie

Naam van Deelnemer: Datum:

SKRIFTELIKE TOESTEMMING TOT DEELNAME AAN STUDIE

**Gehoorgestremdheid by jong kinders:
Ouers se inisiële behoeftes vir inligting en ondersteuning**

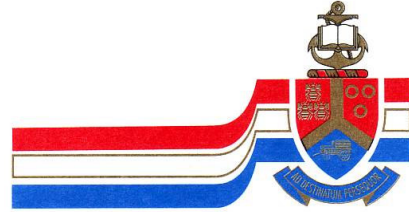
Ek verstaan my regte as deelnemer aan hierdie navorsing en verstaan ook die waarde van die studie en waarom dit uitgevoer word.

Ek verbind myself vrywillig om deel te neem aan hierdie studie.

.....
Handtekening van Deelnemer

.....
Datum

.....
Handtekening van Navorser



University of Pretoria

Pretoria 0002 Republic of South Africa Tel 012-420-2357
/ 012-420-2816 Fax 012-420-3517 <http://www.up.ac.za>

Department of Communication Pathology
Speech, Voice and Hearing Clinic

November 2004

INFORMED CONSENT – PARENTS

1. **Title of Study:** Hearing impairment in young children: Parent's initial needs for information and support.
2. **Purpose of this study:** The purpose of this study is to determine parents of hearing impaired children's specific needs for information and support at diagnosis and during early intervention.
3. **Procedure:** I will be requested to complete a questionnaire together with this letter of consent, and I will hand it back to the researcher directly after it has been completed.
4. **Risk and discomforts:** There are no risks or discomforts associated with this study and it will not take long to complete the questionnaire.
5. **Benefits:** The results of this study will guide pediatric audiologist on how to carry over the diagnosis of a hearing impairment and will shape current service delivery to parents and their young hearing impaired children in terms of the giving of appropriate information and ongoing support. Parent's specific needs for information and support at the time of diagnosis and during early intervention will be determined.
6. **Participant's rights:** I agree to voluntary participate in this study and may withdraw from it at any time.
7. **Confidentiality:** I understand that the information that I will provide will be treated as confidential and I will remain anonymous. The results of this study may be published in professional journals or presented at professional conferences, but my name or personal details will not be revealed.

Should I have any questions or concerns, I may contact **Talita van der Spuy** at 082 839 8343 at any time.

.....
Talita van der Spuy
Researcher

.....
Lidia Pottas
Research Leader

Prof. Brenda Louw
Head: Dept. of Communication Pathology

Name of Participant : Date:

WRITTEN CONSENT TO PARTICIPATION OF STUDY

**Hearing impairment in children:
Parent's initial needs for information and support**

I understand my rights as a research participant and I voluntarily consent to the participation of this study.

I understand what the study is about and how and why it is being done.

.....
Signature of Participant

.....
Date

.....
Signature of Principle Investigator

Bylae B

AANPASSING VAN VRAE IN VRAELYS GEBASSEER OP RESULTATE VAN DIE VOORSTUDIE

(Die Engelse vraelys is ook diensooreenkomstig gewysig en aangepas)

AFDELING A

VRAE INGESLUIT IN DIE VOORSTUDIE	VRAE INGESLUIT IN DIE HOOFSTUDIE
A1. Wat is die geslag van u kind?	A1. Wat is die geslag van jou kind met 'n gehoorverlies?
A2. Wat is u verhouding tot u kind met 'n gehoorgestremdheid?	A2. Wat is jou verhouding tot jou kind met 'n gehoorverlies?
A3. Wat is die ouderdom van u kind?	A3. Wat is die geboortedatum van jou kind met 'n gehoorverlies?
A4. Waar is u woonagtig?	A4. Waar is jy woonagtig?
A5. Wat is u huistaal?	A6. Wat is oorwegend jou huistaal?
A6. Wat is u hoogste kwalifikasie?	A6. Wat is jou hoogste kwalifikasie?
A7. Beskryf u etniese agtergrond.	A7. Hoe sal jy jou etniese agtergrond beskryf?
A8. Wat is die oorsaak van u kind se gehoorverlies?	A8. Wat dink jy is die oorsaak van jou kind se gehoorverlies?
<ul style="list-style-type: none"> • Onbekend • Oorerflik • Prematuriteit • Meningitis • Rubella • Ander (spesifiseer) 	<ul style="list-style-type: none"> • Onbekend • Oorerflik • Prematuriteit (te vroeg gebore) • Meningitis/ breinvliesontsteking • Rubella (Duitse Masels) • CMV (Cytomegalovirus) • Trauma/ besering met geboorte • Onseker • Ander (spesifiseer)
A9. Is u kind gepas met 'n kogleêre implanting?	A9. Het jou kind 'n kogleêre implanting?
A10. Hoeveel kinders het u buiten u kind met 'n gehoorverlies?	A10. Hoeveel kinders het jy (totale aantal)?
	A11. Hoeveel ander kinders het jy wat ook 'n gehoorverlies het?

AFDELING B

VRAE INGESLUIT IN VOORSTUDIE	VRAE INGESLUIT IN HOOFSTUDIE
B1. Hoe oud was u kind toe die diagnose van gehoorgestremdheid bevestig is?	B1. Hoe oud was jou kind toe hy/sy gediagnoseer is met 'n gehoorverlies?
B2. Was u kind opgeneem in die Neonatale Intensiewe Sorg Eenheid (NISE)?	Vraag is uitgelaat
B3. Indien ja, waarom en vir hoe lank?	Vraag is uitgelaat
B4. Is u kind se gehoorgetoets net na geboorte?	B3. Is jou kind se gehoorgetoets met geboorte?
B5. Indien ja, wat was die rede daarvoor? <ul style="list-style-type: none"> • Hospitaal beleid • Opname in Neonatale Intensiewe Sorg Eenheid 	Vraag is uitgelaat
B6. Indien nee, wie het u verwys vir 'n gehoortoets?	B3. Indien nee, wie het jou verwys vir 'n gehoortoets?
B7. Wie het die diagnose aan u oorgedra?	B4. Wie het die diagnose van jou kind se gehoorverlies oorgedra?
B8. Wie sou u verkies om die diagnose oor te dra?	B5. By wie sou jy die graagste sulke nuus wou verneem?
B9. Het die persoon wat die diagnose oorgedra het omgegee oor u gevoelens?	B6. Het die persoon wat die slegte nuus/ diagnose oorgedra het omgegee oor jou gevoelens?
B10. Was hierdie persoon in beheer van die situasie?	B7. Was hierdie persoon in beheer van die situasie?
B11. Het hierdie persoon u voorsien van voldoende inligting?	B8. Het hierdie persoon vir jou voldoende inligting verskaf?
B12. Het hierdie persoon u gerig in die volgende stap wat geneem moet word?	B9. Het hierdie persoon jou gerig in die volgende stap wat geneem moet word?
B13. Het hierdie persoon u genoegsaam tyd gegun om vrae te vra?	B10. Was daar vir jou genoeg tyd gegun om vrae te vra?
B14. . Wanneer die diagnose van gehoorgestremdheid deur 'n oudioloog aan ouers oorgedra word, hoe sou u die belang van die volgende riglyne beskryf ?	B11. Wanneer die diagnose/ nuus van 'n gehoorverlies aan ouers oorgedra word, dink jy dit is belangrik dat die oudioloog wat die toets uitgevoer het die nuus moet oordra ?
noodsaaklik = 1 verkieslik = 2 onseker = 3 nie belangrik nie = 4, moet glad nie gedoen word nie =5	(Noodsaaklik/ Verkieslik/ dit maak nie saak nie/ nie belangrik nie/ Moet glad nie gedoen word nie/ Onseker)

<ul style="list-style-type: none"> • Die diagnose moet oorgedra word deur die oudioloog wat die toetsuitgevoer het • Die oudioloog moet privaatheid en genoegsame tyd (sonder enige onderbrekings) verseker wanneer die diagnose oorgedra word • Die oudioloog moet seker maak dat ouers insig in die situasie het • Ouers moet aangemoedig word om uiting aan hulle gevoelens te gee • Die oudioloog moet met warmte en empatie optree • Die oudioloog moet aan ouers 'n breedvoerige raamwerk gee vir toekomstige besluite en aksies • Daar moet konkrete aktiwiteite aan ouers gegee word wat uitgevoer kan word tot en met die volgend opvolg-besoek • 'n Opvolg besoek moet dadelik geskeduleer word <p>B15. Hoe oud was u kind toe julle begin inskakeel het in 'n vroeë intervensie program?</p> <p>B16. Hoe oud was u kind met sy/haar eerste gehoorapparaatpassing?</p> <p>B17. Is daar enige ander riglyne wat u as belangrik sou beskou vir oudioloë wanneer slegte nuus aan ouers oorgedra moet word?</p> <p>B18. Wat sou u beskou as die grootste behoefte vir oudiologie en vroeë intervensie dienste wat aan families gebied word in die eerste jaar na die diagnose van gehoorgestremdheid?</p> <p>B19. Toe my kind gepas is met gehoorapparate, wasek bekommerd:</p> <ul style="list-style-type: none"> • Oor hoe die gehoorapparate gaan lyk • Dat my kind sosiaal aanvaarbaar sou wees • Oor wat my vriende/ familie sou sê oor die gehoorapparate • Oor of my kind sou baatvind by die gehoorapparate • Oor die hantering en versorging van gehoorapparate 	<p>B12. Hoe belangrik sou jy sê is dit dat die oudioloog moet sorg vir privaatheid en genoegsame tyd (sonder onderbrekings) wanneer die nuus/ diagnose oorgedra word?</p> <p>(Noodsaaklik/Verkieslik/dit maak nie saak nie/nie belangrik nie/Moet gladnie gedoen word nie/Onseker)</p> <p>B13. Hoe belangrik sou jy sê is dit dat die oudioloog met warmte en empatie moet optree?</p> <p>(Noodsaaklik/Verkieslik/dit maak nie saak nie/nie belangrik nie/Moet gladnie gedoen word nie/Onseker)</p> <p>B14. Dink jy dit is nodig dat die oudioloog aan ouers 'n breedvoerige raamwerk moet gee vir toekomstige besluite en aksies?</p> <p>(Noodsaaklik/Verkieslik/dit maak nie saak nie/nie belangrik nie/Moet gladnie gedoen word nie/Onseker)</p> <p>B15. Hoe oud was jou kind toe hy/sy/julle begin inskakeel het in 'n vroeë intervensie program (bv. Carel du Toit Sentrum)?</p> <p>B16. Hoe oud was jou kind toe hy/sy vir die eerste keer gepas is met gehoorapparate?</p> <p>Vraag is uitgelaat</p> <p>Vraag is uitgelaat</p> <p>B17. Toe jou kind gepas is met gehoorapparate, was jy bekommerd oor hoe die gehoorapparate gaan lyk? (Ja/Onseker/Nee)</p> <p>B18. Was jy bekommerd oor of jou kind sosiaal aanvaarbaar sou wees? (Ja/Onseker/Nee)</p> <p>B19. Was jy bekommerd oor wat jou familie/vriende sou sê oor die gehoorapparate? (Ja/Onseker/Nee)</p> <p>B20. Was jy bekommerd oor die versorging en hantering van die gehoorapparate? (Ja/Onseker/Nee)</p>
---	---

<p>B20. Nadat u kind gepas is met gehoorapparate, wat was oorwegend die respons van u familie en vriende?</p> <ul style="list-style-type: none">• Gereageer met aanvaarding en 'n positiewe houding teenoor die gehoorapparate• Gereageer met verbasing en skok• Gereageer met simpatie omdat hulle geweet het dat my kind die gehoorapparate benodig• Gedink dat die gehoorapparate nie my kind sal kan help nie• Gedink my kind beskik oor minder vaardighede aangesien hy/sy gehoorapparate dra	<p>B21. Nadat jou kind gepas is met gehoorapparate, wat was oorwegend die reaksie van jou familie en vriende (merk slegs een)?</p> <ul style="list-style-type: none">• Gereageer met aanvaarding en 'n positiewe houding teenoor die gehoorapparate• Gereageer met verbasing en skok• Gereageer met simpatie omdat hulle geweet het dat my kind die gehoorapparate benodig• Gedink dat die gehoorapparate nie my kind sal kan help nie• Gedink my kind beskik oor minder vaardighede aangesien hy/sy gehoorapparate dra
--	---

AFDELING C

<p>C1. Behoeftes vir Berading</p> <p>(Ja/Onseker/Nee)</p> <ul style="list-style-type: none"> • Ek het hulp nodig om die emosionele aspekte van om 'n kind met 'n gehoorgestremdheid te hê, te hanteer • Ek het iemand in my gesin/familie nodig met wie ek kan praat oor my kind • Ek het iemand buite my familie nodig met wie ek kan gesels oor my kind • Ek het 'n behoefte om ander ouers met gehoorgestremde kinders te ontmoet • Ek het 'n behoefte om ander ouer kinders/ volwassenes met 'n gehoorgestremdheid te ontmoet • Ek sou graag wil deel word van 'n ondersteuningsgroep vir ouers van gehoorgestremde kinders • Ek het 'n behoefte om met 'n berader te praat oor my agressie/ frustrasie met my kind • Ek het meer tyd nodig vir myself • Ek benodig hulp om my kind se toestand aan ander te verduidelik • Ek benodig hulp/ riglyne oor hoe om ander se response oor my kind te hanteer 	<p>C1. Behoeftes vir Berading</p> <p>(Ja/Onseker/Nee)</p> <ul style="list-style-type: none"> • Ek het hulp nodig om die emosionele aspekte van om 'n kind met 'n gehoorgestremdheid te hê, te hanteer • Ek het iemand in my gesin/familie nodig met wie ek kan praat oor my kind • Ek het iemand buite my familie nodig met wie ek kan gesels oor my kind • Ek het 'n behoefte om ander ouers met gehoorgestremde kinders te ontmoet • Ek het 'n behoefte om ander ouer kinders/ volwassenes met 'n gehoorgestremdheid te ontmoet • Ek sou graag wil deel word van 'n ondersteuningsgroep vir ouers van gehoorgestremde kinders • Ek het 'n behoefte om met 'n berader te praat oor my agressie/ frustrasie met my kind • Ek het meer tyd nodig vir myself • Ek benodig hulp om my kind se toestand aan ander te verduidelik • Ek benodig hulp/ riglyne oor hoe om ander se response oor my kind te hanteer
<p>C2. Behoeftes vir Familie Ondersteuning</p> <p>(Ja/Onseker/Nee)</p> <ul style="list-style-type: none"> • My huweliksmaat benodig hulp om ons kind te verstaan / te aanvaar • Onsgesin/familie benodig iemand om op 'n gereelde basis mee te praat oor hoe om ons kind te hanteer • Onsgesin/ familie benodig geleenthede waar ons ander gesinne met gehoorgestremde kinders kan ontmoet • Onsgesin/ familie benodig hulp oor hoe om mekaar te ondersteun en by te staan • Ons benodig hulp oor hoe om ons kind te disiplineer 	<p>C2. Behoeftes vir Familie Ondersteuning</p> <p>(Ja/Onseker/Nee)</p> <ul style="list-style-type: none"> • My huweliksmaat benodig hulp om ons kind te verstaan / te aanvaar • Onsgesin/familie benodig iemand om op 'n gereelde basis mee te praat oor hoe om ons kind te hanteer • Onsgesin/ familie benodig geleenthede waar ons ander gesinne met gehoorgestremde kinders kan ontmoet • Onsgesin/ familie benodig hulp oor hoe om mekaar te ondersteun en by te staan • Ons benodig hulp oor hoe om ons kind te disiplineer
<p>C3. Finansiële Behoeftes</p> <p>(Ja/Onseker/Nee)</p> <ul style="list-style-type: none"> • Ek benodig finansiële ondersteuning vir die betaling van gehoorapparate / kogleêre inplanting 	<p>C3. Finansiële Behoeftes</p> <p>(Ja/Onseker/Nee)</p> <ul style="list-style-type: none"> • Ek benodig finansiële ondersteuning vir die betaling van gehoorapparate / kogleêre inplanting

<ul style="list-style-type: none"> • Ek benodig hulp in die betaling van spesiale dienste wat my kind benodig (spraakterapie, konsultasie van dokters ens.) • Ek benodig hulp in die betaling en organisering van vervoer vir my kind • Ek benodig finansiële ondersteuning vir addisionele uitgawes/ spesiale toerusting wat my kind benodig (FM sisteem, batterye ens.). <p>C4. Hoeveel ondersteuning kry u huidiglik van die volgende persone?</p> <p>(Geen/Baie min/Gemiddeld/Baie)</p> <ul style="list-style-type: none"> • Huweliksmaat • Familie • Vriende • Oudioloog • Ouerleidingsterapeut 	<ul style="list-style-type: none"> • Ek benodig hulp in die betaling van spesiale dienste wat my kind benodig (spraakterapie, konsultasie van dokters ens.) • Ek benodig hulp in die betaling en organisering van vervoer vir my kind • Ek benodig finansiële ondersteuning vir addisionele uitgawes/ spesiale toerusting wat my kind benodig (FM sisteem, batterye ens.). <p>C4. Hoeveel ondersteuning kry jy op die oomblik van die volgende persone?</p> <p>(Geen/Baie min/Gemiddeld/Baie)</p> <ul style="list-style-type: none"> • Huweliksmaat • Familie • Vriende • Oudioloog • Ouerleidingsterapeut
--	--

AFDELING D

VRAE INGESLUIT IN DIE VOORSTUDIE	VRAE INGESLUIT IN DIE HOOFSTUDIE
<p>D1. Behoeftes vir inligting oor gehoor en gehoorverlies</p> <p>(Ja/ Nee/ Onseker)</p> <ol style="list-style-type: none"> 1. inligting oor normale gehoor 2. hoe my kind hoor 3. oorsake van gehoorverlies 4. oudiogram 5. hoe gehoorapparate werk 6. verwagtinge van gehoorapparate 7. versorging van gehoorapparate 8. FM sisteme 9. kogleêre inplantings 10. hoe om gehoorapparate in my kind se ore te hou <p>D2. Behoeftes vir inligting oor taal en kommunikasie</p> <p>(Ja/ Nee/ Onseker)</p>	<p>D1. Behoeftes vir inligting oor gehoor en gehoorverlies</p> <p>(Ja/ Nee/ Onseker)</p> <ol style="list-style-type: none"> 1. nligting oor normale gehoor (hoe gehoor werk) 2. hoe my kind met 'n gehoorverlies hoor 3. oorsake van gehoorverlies 4. verstaan hoe oudiogram werk 5. hoe gehoorapparate werk 6. wat om te verwag van gehoorapparate 7. versorging en instandhouding van gehoorapparate 8. FM sisteme en ander tipe gehoorapperate 9. kogleêre inplantings 10. hoe om gehoorapparate in my kind se ore te hou <p>D2. Behoeftes vir inligting oor taal en kommunikasie</p> <p>(Ja/ Nee/ Onseker)</p>

<p>11. hoe 'n gehoorverlies my kind se vermoë om te leer praat beïnvloed</p> <p>12. hoe om my kind te leer luister en praat</p> <p>13. hoe taal ontwikkel</p> <p>14. hoe my kind wil kommunikeer</p> <p>15. hoe ek met my kind kan kommunikeer</p> <p>D3. Behoeftes vir inligting oor intervensie en opvoedings-opsies</p> <p>(Ja/Nee/Onseker)</p> <p>16. inligting oor kommunikasie-opsies</p> <p>17. inligting oor vroeë intervensie dienste</p> <p>18. inligting oor opvoedings-opsies vir my kind</p> <p>19. inligting oor oudiologiese dienste</p> <p>20. inligting oor spraak en taal terapie dienste</p> <p>D4. Vanuit bogenoemde genummerde lys (1 – 20), dui die 3 onderwerpe aan wat vir u die belangrikste was met tye van die diagnose van u kind se gehoorgestremdheid.</p> <p>D5. Vanuit bogenoemde genummerde lys (1 - 20), dui die 3 onderwerpe aan wat vir u die belangrikste was 'n paar maande na die diagnose van gehoorgestremdheid (gedurende vroeë intervensie):</p> <p>D6. Lys asb. ander onderwerpe vir inligting wat volgens u belangrik sou wees om te ontvang/ te bespreek:</p>	<p>11. hoe 'n gehoorverlies my kind se vermoë om te leer praat beïnvloed</p> <p>12. hoe om my kind te leer luister en praat</p> <p>13. hoe taal ontwikkel</p> <p>14. hoe my kind wil kommunikeer</p> <p>15. hoe ek met my kind kan kommunikeer</p> <p>D3. Behoeftes vir inligting oor intervensie en opvoedings-opsies</p> <p>(Ja/Nee/Onseker)</p> <p>16. inligting oor kommunikasie-opsies/ benaderings (gebaretaal, natuurlik ouditief-oraal ens.)</p> <p>17. inligting oor vroeë intervensie dienste/ programme beskikbaar vir my kind</p> <p>18. inligting oor opvoedings-opsies vir my kind</p> <p>19. inligting oor oudiologiese dienste</p> <p>20. inligting oor spraak en taal terapie dienste</p> <p>D4. Vanuit bogenoemde genummerde lys (1-20), dui die 5 onderwerpe aan wat vir jou die belangrikste was net toe jou kind met 'n gehoorverlies gediagnoseer is (met ander woorde, wat wou jy die graagste weet net toe jy gehoor het jou kind het 'n gehoorverlies)</p> <p>D5. Vanuit bogenoemde genummerde lys (1-20), dui die 5 onderwerpe aan wat vir jou die belangrikste was 'n paar maande nadat jy gehoor het jou kind het 'n gehoorverlies.</p> <p>Vraag uitgelaat</p> <p>D6. Graad van gehoorverlies (slegs vir kantoorgebruik)</p> <ul style="list-style-type: none"> • gering • gemiddeld • gemiddeld-ernstig • ernstig • uitermatig
--	---

Bylae C
GEHOORGESTREMDHEID BY JONG KINDERS:
OUERS SE INISIËLE BEHOEFTE VIR INLIGTING EN ONDERSTEUNING

Merk telkens slegs **EEN** toepaslike antwoord by elk van die volgende vrae deur 'n kruisie in die ooreenstemmende blokkie te trek:

Afdeling A: Biografiese Inligting

A1. Wat is die geslag van jou kind met 'n gehoorverlies?

Manlik	<input type="checkbox"/>
Vroulik	<input type="checkbox"/>

A2. Wat is jou verhouding tot jou kind met 'n gehoorverlies?

Ouer	<input type="checkbox"/>
Pleegouer	<input type="checkbox"/>
Stiefouer	<input type="checkbox"/>
Versorger	<input type="checkbox"/>

A3. Wat is die geboortedatum van jou kind met 'n gehoorverlies?

JJJJ	MM	DD
<input type="text"/>	<input type="text"/>	<input type="text"/>

A4. Waar is jy woonagtig?

Stad	<input type="checkbox"/>
Dorp	<input type="checkbox"/>
Plaasen/of Platteland	<input type="checkbox"/>

A5. Wat is oorwegend jou huistaal?

Engels	<input type="checkbox"/>
Afrikaans	<input type="checkbox"/>
Xhosa	<input type="checkbox"/>
Ander (spesifiseer)	<input type="checkbox"/>
.....	

A6. Wat is jou hoogste kwalifikasie?

Geen	<input type="checkbox"/>
Primêre/ laerskool (Graad 1-7)	<input type="checkbox"/>
Hoërskool (Graad 8-11)	<input type="checkbox"/>
Matriek voltooi	<input type="checkbox"/>
Tersiere (na-skool) kwalifikasie	<input type="checkbox"/>

A7. Hoe sal jy jou etniese agtergrond beskryf?

Blank	<input type="checkbox"/>
Swart	<input type="checkbox"/>
Kleurling	<input type="checkbox"/>
Asiaties	<input type="checkbox"/>

A8. Wat dink jy is die oorsaak van jou kind se gehoorverlies?

Onbekend	
Oorerflik	
Prematuriteit (te vroeg gebore)	
Meningitis/ Breinvliesontsteking	
Rubella (Duitse Masels)	
CMV (Cytomegalovirus)	
Trauma / besering met geboorte	
Onseker	
Ander (spesifiseer)	
.....	
.....	

A9. Het jou kind 'n kogleêre inplanting?

Ja	
Nee	

A10. Hoeveel kinders het jy (totale aantal)?

A11. Hoeveel **ander** kinders het jy wat ook 'n gehoorverlies het?

Afdeling B: Ervaring van Diagnose en Vroeë Intervensie

B1. Hoe oud was jou kind toe hy/sy gediagnoseer is met 'n gehoorverlies?

Jaar	Maande
.....

B2. Is jou kind se gehoor getoets met geboorte?

Ja	
Nee	
Onseker	

B3. Indien nee, wie het jou verwys vir 'n gehoortoets?

Self	
Pediater	
Familielid / vriend/ vriendin	
Ander (beskryf)	
.....	
.....	

B4. Wie het die diagnose van jou kind se gehoorverlies oorgedra?

Oudioloog	
Pediater	
Oor-, Neus- en Keelspesialis	
Verpleegster	
Weet nie	
Iemand anders (Spesifiseer)	
.....	
.....	

B5. By wie sou jy die graagste sulke nuuswou vemeem?

Oudioloog	
Pediater	
Oor-, neus- en Keelspesialis	
Ander (Spesifiseer)	
.....	
.....	

B6. Het die persoon wat die slegte nuus/diagnose oorgedra het omgee oor jou gevoelens?

Totaal en al	
Gedeeltelik	
Glad nie	

B7. Was hierdie persoon in beheer van die situasie?

Totaal en al	
Gedeeltelik	
Glad nie	

B8. Het hierdie persoon vir jou voldoende inligting verskaf?

Totaal en al	
Gedeeltelik	
Glad nie	

B9. Het hierdie persoon jou gerig in die volgende stap wat geneem moet word?

Totaal en al	
Gedeeltelik	
Glad nie	

B10. Was daar vir jou tyd gegun om vrae te vra?

Totaal en al	
Gedeeltelik	
Glad nie	

B11. Wanneer die diagnose/ nuus van 'n gehoorverlies aan ouers oorgedra word, dink jy dit is belangrik dat die oudioloog wat die toets uitgevoer het die nuus moet oordra?

Noodsaaklik	
Verskieslik	
Dit maak nie saak nie	
Nie belangrik nie	
Moet glad nie gedoen word nie	
Onseker	

B12. Hoe belangrik sou jy sê is dit dat die oudioloog moet sorg vir privaatheid en genoegsame tyd (sonder onderbrekings) wanneer die nuus/diagnose oorgedra word?

Noodsaaklik	
Verskieslik	
Dit maak nie saak nie	
Nie belangrik nie	
Moet glad nie gedoen word nie	
Onseker	

B13. Hoe belangrik sou jy sê is dit dat die oudioloog met warmte en empatie moet optree?

Noodsaaklik	
Verskieslik	
Dit maak nie saak nie	
Nie belangrik nie	
Moet glad nie gedoen word nie	
Onseker	

B14. Dink jy dit is nodig dat die oudioloog aan ouers 'n breedvoerige raamwerk moet gee vir toekomstige besluite en aksies?

Noodsaaklik	
Verskieslik	
Dit maak nie saak nie	
Nie belangrik nie	
Moet glad nie gedoen word nie	
Onseker	

B15. Hoe oud was jou kind toe hy/sy/julle begin inskakel het in 'n vroeë intervensie program (bv Carel du Toit Sentrum)?

Jaar	Maande
---------------	-----------------

B16. Hoe oud was jou kind toe hy/sy vir die eerste keer gepas is met gehoorapparate?

Jaar	Maande
---------------	-----------------

B17. Toe jou kind gepas is met gehoorapparate, was jy bekommerd oor hoe die gehoorapparate gaan lyk?

Ja	
Onseker	
Nee	

B18. Was jy bekommerd oor of jou kind sosiaal aanvaarbaar sou wees?

Ja	
Onseker	
Nee	

B19. Was jy bekommerd oor wat jou familie/ vriende sou sê oor die gehoorapparaat?

Ja	
Onseker	
Nee	

B20. Was jy bekommerd oor die versorging en hantering van die gehoorapparaat?

Ja	
Onseker	
Nee	

B21. Nadat jou kind gepas is met gehoorapparaat, wat was oorwegend die reaksie van jou familie en vriende (merk segseen):

Gereageer met aanvaarding en 'n positiewe houding teenoor die gehoorapparaat	
Gereageer met verbasing en skok	
Gereageer met simpatie omdat hulle geweet het dat my kind die gehoorapparaat benodig	
Gedink dat die gehoorapparaat nie my kind sal kan help nie	
Gedink my kind beskik oor minder vaardighede aangesien hy/sy gehoorapparaat dra	

Afdeling C: Behoeftes vir Berading en Ondersteuning

C1. Behoeftes vir Berading

	Ja	Onseker	Nee
Ek het hulp nodig om die emosionele aspekte van om 'n kind met 'n gehoorverlies te hanteer			
Ek het iemand buite my familie nodig met wie ek kan gesels oor my kind			
Ek het 'n behoefte om ander ouers met gehoorgestremde kinders te ontmoet			
Ek het 'n behoefte om ander ouer kinders/ volwassenes met 'n gehoorverlies te ontmoet			
Ek sou graag wil deel word van 'n ondersteuningsgroep vir ouers van gehoorgestremde kinders			
Ek het 'n behoefte om met 'n berader te praat oor my aggresie/ frustrasie met my kind			
Ek het meer tyd nodig vir myself			
Ek benodig hulp om my kind se toestand aan ander te verduidelik			
Ek benodig hulp/ riglyne oor hoe om ander se reaksie oor my kind te hanteer			

C2. Behoeftes vir Familie Ondersteuning

	Ja	Onseker	Nee
My huweliksmaat benodig hulp om onskind te verstaan / te aanvaar			
Onsgesin/familie benodig iemand om op 'n gereelde basis mee te praat oor hoe om onskind te hanteer			
Onsgesin/ familie benodig geleenthede waar onsander gesinne met gehoorgestremde kinders kan ontmoet			
Onsgesin/ familie benodig hulp oor hoe om mekaar te ondersteun en by te staan			
Ons benodig hulp oor hoe om onskind te disiplineer			

C3. Finansiële Behoeftes

	Ja	Onseker	Nee
Ek benodig finansiële ondersteuning vir die betaling van gehoorapparate / kogleêre inplanting			
Ek benodig hulp in die betaling van spesiale dienste wat my kind benodig (spraakterapie, konsultasie van doktersens.)			
Ek benodig hulp in die betaling en organisering van vervoer vir my kind			
Ek benodig finansiële ondersteuning vir addisionele uitgawes/ spesiale toerusting wat my kind benodig (FM sisteem, batterye ens.).			

C4. Hoeveel ondersteuning kry jy op die oomblik van die volgende persone?

	Geen	Baie min	Gemiddeld	Baie
Huweliksmaat				
Familie				
Vriende				
Oudioloog				
Ouerleidings terapeut				

Afdeling D: Behoeftes vir Inligting

Meeste ouers van kinders met 'n gehoorverlies het 'n behoefte vir voldoende inligting en hiervolg 'n lys van die mees algemene onderwerpe. Het jy 'n behoefte om inligting oor elk van hierdie onderwerpe te ontvang?

D1. Behoeftes vir inligting oor gehoor en gehoorverlies

	Ja	Nee	Onseker
1. inligting oor normale gehoor (hoe gehoor werk)			
2. hoe my kind met 'n gehoorverlies hoor			
3. oorsaak van gehoorverlies			
4. verstaan hoe die oudiogram werk			
5. hoe gehoorapparate werk			
6. wat om te verwag van gehoorapparate			
7. versorging en instandhouding van gehoorapparate			
8. FM sisteme en ander tipe gehoorapparate			
9. kogleêre inplantings			
10. hoe om gehoorapparate in my kind se ore te hou			

D2. Behoeftes vir inligting oor taal en kommunikasie

	Ja	Nee	Onseker
11. hoe 'n gehoorverlies my kind se vermoë om te leer praat beïnvloed			
12. hoe om my kind te leer luister en praat			
13. hoe taal ontwikkel			
14. hoe my kind wil kommunikeer			
15. hoe ek met my kind kan kommunikeer			

D3. Behoeftes vir inligting oor intervensie en opvoedings-opsies

	Ja	Nee	Onseker
16. inligting oor kommunikasie opsies/ benaderings (gebaretaal, natuurlik ouditief-oraal ens.)			
17. inligting oor vroeë intervensie dienste / programme beskikbaar vir my kind			
18. inligting oor opvoedings-opsies vir my kind			
19. inligting oor oudiologiese dienste			
20. inligting oor spraak en taal terapie dienste			

(Gedeeltelik saamgestel vanuit: *The Family Needs Survey*, Baily & Smeonsson, 1990)

D4. Vanuit bogenoemde genommerde lys (1-20), dui die **5** onderwerpe aan wat vir jou die belangrikste was **net toe jou kind met 'n gehoorverlies gediagnoseer is** (met ander woorde, wat wou jy die graagste weet net toe jy gehoor het jou kind het 'n gehoorverlies?)

D5. Vanuit bogenoemde genommerde lys (1-20), dui die **5** onderwerpe aan wat vir jou die belangrikste was 'n **paar maande nadat jy gehoor het jou kind het 'n gehoorverlies?**

Baie dankie vir jou deelname! Dit word opreg waardeer.

Segs vir kantoorgebruik:	
Respondent nommer:	
Graad van gehoorverlies:	
Gering (15-40 dBHL)	
Gemiddeld (40-55 dBHL)	
Gemiddeld-ernstig (55-70 dBHL)	
Ernstig (70-90 dBHL)	
Uitermatig (>90 dBHL)	

**YOUNG HEARING IMPAIRED CHILDREN:
PARENTS' INITIAL NEEDS FOR INFORMATION AND SUPPORT**

Please complete the following by selecting **ONE** appropriate answer at each question:

Section A: Biographic Information

A1. What is the sex of your child with a hearing loss?

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>

A2. What is your relationship with your child with a hearing impairment?

Parent	<input type="checkbox"/>
Foster parent	<input type="checkbox"/>
Stepparent	<input type="checkbox"/>
Provider/ Supporter	<input type="checkbox"/>

A3. What is the date of birth of your child with a hearing loss?

YYYY	MM	DD
<input type="text"/>	<input type="text"/>	<input type="text"/>

A4. Where do you live?

City	<input type="checkbox"/>
Town	<input type="checkbox"/>
Farm/ country-side	<input type="checkbox"/>

A5. What is for the most part your home language?

English	<input type="checkbox"/>
Afrikaans	<input type="checkbox"/>
Xhosa	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>
.....	

A6. What is your highest qualification?

None	<input type="checkbox"/>
Primary School (Grade 1-7)	<input type="checkbox"/>
High School (Grade 8-11)	<input type="checkbox"/>
Matric completed	<input type="checkbox"/>
Tertiary qualification	<input type="checkbox"/>

A7. How would you describe your ethnic background?

White	<input type="checkbox"/>
Black	<input type="checkbox"/>
Colored	<input type="checkbox"/>
Asian	<input type="checkbox"/>

A8. What do you think caused your child's hearing loss?

Unknown	
Heredity	
Prematurity (born too early)	
Meningitis	
Maternal rubella (German Measles)	
CMV (Cytomegalovirus)	
Trauma/ injury at birth	
Other (please specify)	
.....	
.....	

A8. Does your child have a cochlear implant?

Yes	
No	

A9. How many children do you have in total?

A10. How many **other** children do you have which also has a hearing loss?

Section B: Experience of Diagnosis and Early Intervention

B1. How old was your child when his/her hearing loss was diagnosed/confirmed?

Years	Months
.....

B2. Was your child's hearing tested at birth?

Yes	
No	
Unsure	

B3. If No, who referred you for a hearing test?

Self	
Pediatrician	
Family member/ friend	
Other (please explain)	
.....	
.....	

B4. Who made the diagnosis of your child's hearing loss?

Audiologist	
Pediatrician	
Ear, Nose and Throat Specialist	
Nurse	
Someone else (please specify)	
.....	
.....	

B5. From whom should you like to receive such bad news/ the diagnosis?

Audiologist	
Pediatrician	
Ear, Nose and Throat Specialist	
Someone else (please specify)	
.....	
.....	

B6. Did the person conveying the diagnosis of your child's hearing loss care about your feelings?

Totally	
Partially	
Not at all	

B7. Was this person in control of the situation?

Totally	
Partially	
Not at all	

B8. Did you receive sufficient information from this person?

Totally	
Partially	
Not at all	

B9. Did this person guide you in what the next step is to be taken?

Totally	
Partially	
Not at all	

B10. Were you given time to ask questions?

Totally	
Partially	
Not at all	

B11. Do you think it is important that when the diagnosis of a hearing loss is conveyed to parents, that the same audiologist who administered the test should break the news?

Essential	
Desirable	
Doesn't matter	
Not necessary	
Should not be done	
Unsure	

B12. How important do you think it is for the audiologist to ensure privacy and adequate time (with no interruptions) when the diagnosis is conveyed to parents?

Essential	
Desirable	
Doesn't matter	
Not necessary	
Should not be done	
Unsure	

B13. How important is it that the audiologist should respond with warmth and empathy?

Essential	
Desirable	
Doesn't matter	
Not necessary	
Should not be done	
Unsure	

B14. Do you think it is important that the audiologist should give parents a broad frame for future decisions and actions?

Essential	
Desirable	
Doesn't matter	
Not necessary	
Should not be done	
Unsure	

B15. How old was your child when he/she started in an Early Intervention program (Carel du Toit Centre)?

Years	Months
----------------	-----------------

B16. How old was your child when he/she was fitted with hearing aids?

Years	Months
----------------	-----------------

B17. When your child initially was fitted with hearing aids, were you concerned about what the hearing aids would look like?

Yes	
Unsure	
No	

B18. Were you concerned that your child would not be socially accepted?

Yes	
Unsure	
No	

B19. Were you concerned about what friends and family would say about the hearing aids?

Yes	
Unsure	
No	

B20. Were you concerned about the care and maintenance of the hearing aids?

Yes	
Unsure	
No	

B21. After the initial hearing aid fitting, what was for the most part your family members and friends' response (mark only one):

Reacted to my child's hearing aids with acceptance and a positive attitude	
Reacted to my child's hearing aids surprise or shock	
Were sympathetic because my child needed hearing aids	
Thought the hearing aids would not help	
Thought my child was less capable because he/she wore hearing aids	

Section C: Needs for Counseling and Support

C1. Counseling Needs

	Yes	Unsure	No
I need help in coping with the emotional aspects of having a child with a hearing impairment			
I need someone outside my family to talk to about my child			
I need opportunities to meet with other parents of hearing impaired children			
I need opportunities to meet older children/ adults with a hearing impairment			
I would like to be part of a support-group for parents of children with a hearing impairment.			
I need to talk to a counselor about my aggressions/ frustrations about my child			
I need more time for myself			
I need help in how to explain my child's condition to others			
I need help/ guidelines on how to handle other people's responses to my child			

C2. Family Support Needs

	Yes	Unsure	No
My spouse needs help on how to understand and accept our child			
Our family need someone to talk to on a regular basis on how to handle and cope with our hearing impaired child			
Our family need opportunities to meet with other families of hearing impaired children			
Our family need help on how to support each other			
Our family need help on how to discipline our child			

C3. Financial Needs

	Yes	Unsure	No
I need financial support for paying for hearing aids/ cochlear implant			
I need help in paying for special services for my child (speech therapy, doctor's consultation etc.)			
I need help in paying and arranging transport for my child			
I need help in paying for additional expenses/ special equipment my child need (FM system, batteries etc.)			

C4. How much support do you currently receive from the following persons?

	Very much	Average	A little bit	Non
Spouse				
Family members				
Friends				
Audiologist				
Parent guidance therapist				

Section D: Information Needs

Many parents of children with a hearing loss have needs for information. To follow is a list of the topics frequently identified. Do you have the need to receive information on each one of these topics?

D1. Needs for information on hearing and hearing loss:

	Yes	No	Unsure
21. how normal ears hear and how the ear works			
22. how my child with a hearing loss hears			
23. causes of hearing loss			
24. understanding the audiogram			
25. how hearing aids work			
26. what to expect from hearing aids			
27. care and maintenance of hearing aids			
28. FM systems and other types of hearing aids			
29. cochlear implants			
30. how to keep hearing aids in my child's ears			

D2. Needs for information on language and communication:

	Yes	No	Unsure
31. how will a hearing loss affect my child's ability to learn to talk			
32. how to teach my child to listen and talk			
33. how language develops			
34. how my child will communicate			
35. how can I communicate with my child			

D3. Needs for information on intervention and educational options:

	Yes	No	Unsure
36. information about communication options/ approaches (sign language, natural auditory oral etc.)			
37. information about early intervention services/ programs available for my child			
38. information about educational options for my child			
39. information about audiological services			
40. information about speech language pathology services			

(Compiled in part from: *The Family Needs Survey*, Baily & Smeonsson, 1990).

D4. From the numbered list above (1-20), indicate the **5** most important topics that applied to you **at the time your child's hearing loss was identified** (in other words, what were the most important things you wanted to know at the time of the diagnosis):

D5. From the above numbered list (1-20), indicate the **5** most important topics that applied to you **a few months after the hearing loss was identified**:

Thank you so much for your participation!

For office use only

Respondent number:

Degree of hearing loss:

Sight (15-40 dBHL)	
Mild (40-55 dBHL)	
Mild-severe (55-70 dBHL)	
Severe (70-90 dBHL)	
Profound (>90 dBHL)	

Bylae D



Universiteit van Pretoria

Pretoria 0002 Republiek van Suid-Afrika Tel 012-420-2357
/ 012-420-2816 Faks 012-420-3517 <http://www.up.ac.za>


Departement Kommunikasiepatologie
Spraak- Stem- en Gehoorkliniek


Mei 2005


INGELIGTE TOESTEMMING TOT DEELNAME AAN FOKUS GROEPE

1. **Titel van die studie:** Gehoorgestremdheid by jong kinders: Ouers se inisiële behoeftes vir inligting en ondersteuning.
2. **Doel van studie:** Die doel van hierdie studie is om ouers van gehoorgestremde kinders se behoeftes vir inligting en ondersteuning by tye van diagnose en tydens vroeë intervensie te bepaal.
3. **Prosedure:** Daar sal van my verwag word om deel te neem aan 'n fokus groep bespreking deur my persoonlike ervarings en opinies met ander groepslede te deel.
4. **Risiko's en ongerief:** Die fokus groep bespreking sal ongeveer 'n uur en 'n half van my tyd in beslag neem. Daar is geen verdere risiko's verbonde aan hierdie studie nie.
5. **Waarde van studie:** Die resultate van hierdie studie sal pediatriese oudioloë rig in hoe die diagnose van gehoorgestremdheid oorgedra moet word. Verder sal resultate ook aangewend word om die huidige dienslewering aan jong gehoorgestremde kinders en hulle ouers te verbeter in terme van inligtingverskaffing en volgehoue ondersteuning. Ouers se spesifieke behoeftes vir inligting en ondersteuning by tye van diagnose, asook tydens vroeë intervensie sal bepaal word.
6. **Regte van die deelnemer:** Ek aanvaar om vrywillig aan fokus groep besprekings deel te neem en het die volste reg om enige tyd te onttrek.
7. **Vertroulikheid:** Ek verstaan dat die inligting wat ek gaan verskaf vertroulik hanteer sal word en dat ek anonim sal bly. Die resultate van hierdie studie mag in professionele tydskrifte gepubliseer word of voorgedra word, maar my en my kind(ers) se name en persoonlike besonderhede sal nie bekend gemaak word nie.

Indien ek enige verdere vrae of onsekerhede het kan ek te alle tye vir **Talita van der Spuy** skakel by 082 839 8343.


.....
Talita van der Spuy
Navorser


.....
Lidia Pottas
Studieleier


.....
Prof Brenda Louw
Hoof: Dept. Kommunikasiepatologie

Naam van Deelnemer: Datum:

SKRIFTELIKE TOESTEMMING TOT DEELNAME AAN FOKUSGROEP BESPREKINGS

**Gehoorgestremdheid by jong kinders:
Ouers se inisiële behoeftes vir inligting en ondersteuning**

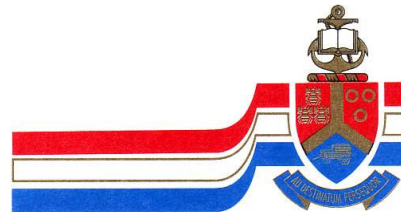
Ek verstaan my regte as deelnemer aan hierdie fokusgroep bespreking en verstaan ook die waarde van die studie en waarom dit uitgevoer word.

Ek verbind myself vrywillig om deel te neem aan hierdie studie.

.....
Handtekening van Deelnemer

.....
Datum

.....
Handtekening van Navorser



University of Pretoria

Pretoria 0002 Republic of South Africa Tel 012-420-2357
/ 012-420-2816 Fax 012-420-3517 <http://www.up.ac.za>

Department of Communication Pathology
Speech, Voice and Hearing Clinic

May 2005

INFORMED CONSENT TO PARTICIPATE IN FOCUS GROUP DISCUSSIONS

1. **Title of Study:** Hearing impairment in young children: Parent's initial needs for information and support.
2. **Purpose of this study:** The purpose of this study is to determine parents of hearing impaired children's specific needs for information and support at diagnosis and during early intervention.
3. **Procedure:** I will be requested to participate in a focus group discussion, by sharing my personal experiences and opinions with other group members.
4. **Risks and discomforts:** The focus group discussion will take approximately one and a half hours. There are no further risks or discomforts associated with this study.
5. **Benefits of study:** The results of this study will guide pediatric audiologists in how to carry over the diagnosis of hearing impairment and will shape current service delivery to parents and their young hearing impaired children in terms of the giving of appropriate information and ongoing support. Parents' specific needs for information and support at time of diagnosis and during early intervention will be determined.
6. **Participant's rights:** I agree to voluntary participate in focus group discussions and may withdraw from it at any time.
7. **Confidentiality:** I understand that the information that I will provide will be treated as confidential and I will remain anonymous. The results of this study may be published in professional journals and presented at conferences, but my name and my child(ren)'s names and/or personal details will not be revealed.

Should I have any questions or concerns, I may contact Talita van der Spuy at 082 839 8343 at any time.

.....
Talita van der Spuy
Researcher

.....
Lidia Pottas
Research Leader

.....
Prof Brenda Louw
Head: Dept. of Communication Pathology

Name of Participant :

Date:

WRITTEN CONSENT TO PARTICIPATION IN FOCUS GROUPS

**Hearing impairment in children:
Parent's initial needs for information and support**

I understand my rights as a research participant and I voluntarily consent to the participation in focus groups.

I understand what the study is about and how and why it is being done.

.....
Signature of Participant

.....
Date

.....
Signature of Principle Investigator

Bylae E
FOKUSGROEPGIDS

1. Openings vraag:

“Wat is jou naam en vertel vir onseen ding van jou kind wat jou laat glimlag”

2. Inleidende vraag:

“Hoe het julle uitgevind julle kind het 'n gehoorverlies? Vertel ons van jou persoonlike ervaring daarvan”

3. Oorgangsvraag:

“Noudat jou kind reeds gediagnoseer is, gepas is met gehoorapparate/ kogleêre inplanting en inskaker by (intervensie sentrum), hoe gaan dit nou met jou?”

4. Seutel vrae:

- “Wat is ouers se behoeftes wanneer die diagnose van 'n gehoorverlies oorgedra word (wat word beskou as leemtes)?”
- “Wat sal jy sê is ouers se spesifieke behoeftes vir inligting wanneer hulle hoor hulle kind het 'n gehoorverlies?”
- “Wat is ouers se behoeftes vir ondersteuning en berading wanneer hulle hoor hulle kind het 'n gehoorverlies?”
- “Hoe moet ouers deurlopend by (intervensie sentrum) ondersteun word?”

5. Afsluitings vrae:

- **Refleksie vraag:**
“Van alles wat ons nou bespreek het, wat sou jy sê is die grootste behoefte van ouers van kinders met 'n gehoorverlies?”
- **Opsommende vraag:**
“Het ek alles waaroor ons gepraat het korrek opgesom?”
- **Finale vraag:**
“Is daar enige iets wat belangrik is waaroor ons nie gepraat het nie?”

FOCUS GROUP GUIDE

1. Opening question:

“What is your name and share with us one thing about your child that makes you smile”

2. Introductory question:

“How did you first discovered that your child has a hearing loss. Share with us your personal experience.”

3. Transitional question:

“Now that your child is diagnosed, fitted with hearing aids/ cochlear implant and you are part of the (intervention center), how is it going with you now?”

4. Key Questions:

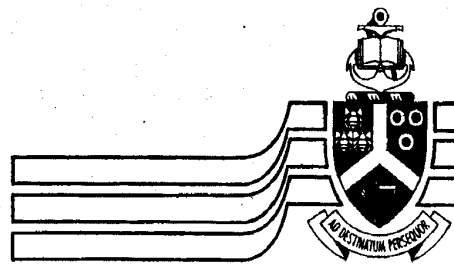
- “What is parents’ needs when the diagnosis of a hearing loss is carried over (what is considered as the pitfalls)?”
- “What would you say are parents’ specific needs for information when they hear their child has a hearing loss?”
- “What is parents needs for support and counseling when they’ve heard their child has a hearing loss?”
- “How should parents continually be supported at (intervention center)?”

5. Closing Questions:

- **Reflection question:**
“From everything we’ve discussed up to now, what would you consider to be the greatest need of parents with children with a hearing loss?”
- **Summary question:**
“Did I sum up everything that we’ve discussed correctly?”
- **Final question:**
“Is there anything important that we haven’t talked about?”

Bylae F

Lede: Navorsingsvoorstel- en Etiekkomitee
Dr P Chiroro; Dr L Davis; Prof C Delport;
Dr JEH Grobler; Prof KL Harris; Prof E Krüger;
Prof B Louw (Voorsitter); Prof D Prinsloo;
Prof G Prinsloo; Dr E Taljard; Prof H van der Mescht;
Prof J van Eeden; Prof A Wessels; Mnr FG Wolmarans



Universiteit van Pretoria
Navorsingsvoorstel- en Etiekkomitee
Fakulteit Geesteswetenskappe

22 Junie 2005

Beste Doktor Pottas

Projek: *Gehoorgestremdheid by jong kinders: Ouers se inisiële behoeftes vir inligting en ondersteuning*
Navorser: T van der Spuy
Leier: L Pottas
Departement: Kommunikasiepatologie
Verwysingsnommer: 9805629

Baie dankie vir u respons op die komitee se skrywe van 8 November 2004.

Die aansoek is op 'n *ad hoc* basis deur die komitee goedgekeur op 20 Junie 2005.

Die goedkeuring word verleen onderhewig aan die voorwaarde dat die kandidaat wel die navorsing volgens die beginsels en binne die parameters soos in die aansoek en navorsingsvoorstel deur haar uiteengesit, sal uitvoer.

Die komitee wil u graag versoek om bogenoemde goedkeuring aan me van der Spuy oor te dra.

Ons wens u sukses met die projek toe.

Vriendelike groete

Prof Brenda Louw
Voorsitter: Navorsingsvoorstel- en Etiekkomitee
Fakulteit Geesteswetenskappe
UNIVERSITEIT VAN PRETORIA

Bylae G

FOKUS GROEP BESPREKING

AFRIKAANSE FOKUS GROEP

F: As julle nou terugdink, hoe het julle uitgevind jou kind het 'n gehoorverlies? Vertel bietjie vir ons wat was jou persoonlike ervaring daarvan.

2: 2001, het taal opgetel, niks het vir my laat agterkom ek sit met 'n dowe kind nie. Sy taal was dan daar. Ek het eendag van die werk af gekom, ek het geroep, maar hy het doodstil gestaan. Ek het iets laat val, maar hy het steeds doodstil gestaan. Ek het hom TV toe gevat, dit kliphard aangesit en enige kind se reaksie istog om na hulle ore te gryp..... het net gestaan. Toe sê ek vir my ma ek dink hier is 'n probleem. Die volgende dag het ek hom na die huisdokter toe gevat en hy verwys my toe na 'n oudioloog en daar het sy fisies vir my gesê het 'n gehoorprobleem. Toe is ek verwys na hospitaal toe en daarvandaan na die (intervensie sentrum). En die oorsaak van sy gehoorverlies is vir ons almal steeds onbekend. Hy was amper 3 jaar oud en dit was 'n helse skok. My kind het taal en nou het hy eweskielik alsverloor en hy was nie siek nie en niemand kon iets sê nie. Hy is deur toets en toets...

1: Was julle by genetika?

2: Daar is nie doofheid in ons familie nie, niks nie.

1: My seuntjie is geneties. Sy doofheid is geneties.

4: Onsgaan ons maar laat toets.

1: Is julle enetjie ook geneties van aard?

4: Onsweet nie.

F: Vertel bietjie vir ons van julle ervaring met klein

5: Vir ons was dit 'n baie hartseer storie. Om 'n lang storie kort te maak is dat almal vir ons gesê het daar is nie fout met nie.

F: Julle was bekommerd....?

5: Ja, omdat hy elke dag by my ma bly. My ma kyk na sy nefie ook, die tweetjies speel elke dag saam. Toe bel my ma my eendag en sê maar hiersdan fout met Toe vat ons vir na 'n gehoorsentrum toe, toe sê hulle vir my nee, hulle kan sien daar is nie fout met hom nie. Ons probleem was het toe nog nie gepraat nie, hy het nie eers een woordjie, hy het niks gesê nie. Hy was so jaar en sy nefie kon toe al babbel. Maar is verskriklik intelligent. Toe vat onshom gehoorsentrum toe en hulle sê daar is nie fout met ons kind nie, ons moet hom nie druk nie, seuntjiespraat later en ons aanvaar dit dan so. Ons moet so na 3 jaar oud terugkom en as daar nog fout is, dan weet ons nou daar is fout. En toe soos die liewe Heer dit wil hê, gaan haal ek hom een middag daar in die Paarl en ek sit hom in sy kamer en hy speel en ek vat die lego blokkies en ek gooi dit agter hom. Ek sien hy sit net daar in die hoekie en toe dadelik die middag maak ek 'n afspraak by 'n spesialis en hy verwys my toe na, die oudioloog. Ag, toe hulle die eerste toets doen, toe sê ek vir my vrou die kind is doof. En daarna toe doen hulle die breinstam, toe maak hulle hom aan die slaap. Hulle kon ongelukkig net die regter oortjie doen want toe word hy wakker. Toe sê hy (die oudioloog) vir ons maar dit wat hy nou sien bevestig die breinstam. En ek is eerlik, daai middag, (dit was 'n Vrydagmiddag), daai middag het ek ge-"crack". Totaal en al ge-"crack". Oppad van die oudioloog tot in die Paarl het ek die heelyd gehuil. Baie dae vat dit nog aan 'n man, ek glo nie met 'n dowe kind jy sal sommer eweskielik regkom nie. Dit is amper soos iemand wat jy aan die dood afgestaan het. Eendag is jy hier bo en die ander dag is jy weer heel onder. Toe het ons die apparaatjies gekoop en toe kom ons weer sodat hulle hom kan meet. Toe sê hulle vir ons hy sal nooit die spraak kan hoor wat ons praat nie. Want die apparaat het hom baie mooi gebring van 70 na omtrent so 55. Hy sal nou wys daar is iemand by die deur wat klop of wanneer die hond blaf. En toe het ons nou die implanting laat doen en van toe af kon jy sien is 'n ander kind. Dis "amazing". Hy is totaal en al 'n ander kind. Hy was voor die aparate hiper-aktief, jy kon nie met hom huis gehou het nie. Ek sê vir my vrou hy het my party dae so kwaad gehad en dan het ek hom geslaan en gevra hoekom luister jy nie vir Pappa nie? Na ek nou gehoor het hy's doof, jy benader hom heeltemal op 'n ander manier. Maar hy het ook maar soos enige ander

kind "tantrims" en goed. Dis maar moeilik om te hanteer. Wanneer slaan jy en wanneer nie? So dit is nou in 'n neutedop ons situasie. Maar dit is 'n skok, skok, skok, skok, skok. Van die begin tot aan die einde. En ek dink my vrou vat dit erger asek.

4: (huil)

1: Maar dit is goed dat sy huil. Jy mag huil. Jy moet huil. Snaaksgenoeg, laasjaar met die kleintjies se modeparade het ek 'n "depro" geslaan toe ek hoor hoe die groter kinders praat. Om te dink my kind sal ook so kan praat....

F: Nou dat jy aan die gesels is, vertel ons van jou ervaring.

1: Myne was sommer net 3 dae oud toe weet ek al. Met daai gehoortoets, die OAE in die hospitaal.

3: Toe 'n baba was het hulle dit nog nie gedoen nie.

1: Toe het hulle vir my gesê daar is fout. Toe sê hulle maar hy kan vog in sy oortjies hê en ons moet oor 6 weke weer laat toets. Toe weet ons daar is fout en ek is toe verwys na (die oudioloog). Hulle het die breinstam gedoen en op 4 maande het hy appaarte gekry. Hy het gelukkig nie 'n kogleêre implanting nodig nie.

5: Maar asek nou maar kan vra, die dag toe hy gebore is, het hulle hom dadelik getoets?

1: Hy was 3 dae oud, net voor ek ontslaan is.

5: Ek is tot 'n mate, ek sal nou nie verwydte gooi nie, maar kyk soos in ons geval, hy is gebore in die hospitaal in My redenasie is net dit help nie die pediater kyk net die kind so, sien voetjies is daar, 10 tone, woeps waps en als is reg nie. Maak nie saak waar nie, as enige kind gebore word, moet daar toetsê gedoen word. En daai tyd, maar ek glo ook dis hoe die Here se wil is en hy stap 'n pad met 'n man en ek glo ek moes nou seker nie daai tyd dit geweet het nie. As mens dit daai tyd al geweet het, dit kon soveel anderster geweeshet. Maar nou moet jy die hele proses deur maak, die hele skok na 2 jaar en 'n maand.

F: vertel ons van jou kind,

3: is 'n 2000 gebore en ons was 'n klomp vriendinne wat saam babas gehad het en toe het ek hom nou later bietjie begin vergelyk met die ander en ek was bietjie bekommerd oor sy gehoor. My hele familie weet ek het dit die heelyd gesê. Ons het ook glad nie doofheid aan albei van ons se kante nie. Maar ek was bekommerd Ek dink dit is daai moederlike instink. Almal het natuurlik gedink ek is heel mal. Die pediater in Stellenbosch het gesê daar is geen fout met my kind nie. Sy response was toevallig en ek het gewag tot sy 6 maande ondersoek. En ek onthou nog die pediater het die rateltoets gedoen en sy sê toe maar se gehoor is swak want hy het nie gereageer nie! Sy sê toe sy dink nie hy is doof nie, want hy het goeie balans en sit toe ook al. Dalk het hy vog in sy ore. Toe bel ek vir (wat ook 2 dowe kinders het) en ek vra toe waar het sy haar kinders laat toets. Ek vat hom toe na (die oudioloog) toe. Sy toets toe en sê daar is 'n blokkasie in sy ore, daar is vog in sy middelore en ek vat hom toe na Dr. toe ('n Oor-, Neus- en Keelspesialis). En so begin dit toe. Ek was seker 20 keer by die ONK en die oudioloog en mens raak so vies. My man was ook vies dat mens elke keer moet teruggaan. Op die ou einde was 'n jaar en 1 maand toe hy sy gehoorapparaat gekry het. Daardie dag met die breinstam, ek het op Worcester grootgeword, so ek sien toe net Del a Bat Sy verduidelik toe vir my die hele storie en ek is toe in tranes. Maar hy hoor goed met sy appaarte. Ek was ook hartseer, maar asek vandag terugdink, dis 'n fase waardeur mens moet werk.

1: Ek sê nou nie ek raak nie meer hartseer nie, maar my dogtertjie het ook breinskade opgedoen en is 'n spasiese dipleg, mens sou dit nooit kon sê nie. Toe vat ek haar fisio toe en toe besef ek wat is gestremd. Ons kinders gaan 'n normale lewe kan lei, sal na 'n normale skool toe kan gaan. So troos jou net daaraan, ek weet dit is hartseer, jy moet daardeur gaan, dis deel van die helings-proses. Maar daar is soveel erger.

3: En het ook nie dowe intonasie nie, waaroor ek dankbaar is. Aanvanklik weet mens mos nie wat vir jou kind wag nie en dit maak jou hartseer. Jy weet nie hoe hy gaan praat nie.

5: Maar snaaks, wat ek nou in hierdie tydjie by (intervensie sentrum) geleer het. Ek ondervind dit by alle dowe kindertjies, hulle is nie skaam nie. Maar soos julle ook nou sal weet, met 1 normale kind en 1 dowe, wat ek ondervind, lyk my die liewe Heer het nou

vir hom doofheid gegee, maar in ander situasies is hy baie sterk. Hy “perform” net beter in iets anderste.

F: Dit bring ons somer by ons volgende vraag waaroor ons bietjie gaan gesels. Wat sou julle sê is ouers se spesifieke behoeftes as dit kom by hoe die diagnose van 'n gehoorverlies oorgedra word. Met ander woorde, hoe sou julle graag die diagnose wou verneem en wat is die bestaande leemtes?

2: My oudioloog het so die nuus aan my oorgedra: “Man, ek dink jou babatjie sit met 'n probleem, ek gaan jou verwys na mense wat jou verder kan help”. Dit is nou kalmerend.... Ek wil hoor wat is die diagnose. Ek verwag ook natuurlik die ergste. het toe 'n ergere hoor probleem. Dit is nou November en Desember (skoolvakansie) lê om die draai en sy kon nie vir 'n afspraak kry by die spesialisnie. Ek sê toe maar dan maak jy nou by iemand vir my 'n afspraak, want elke dag wat ek nou my kind kan help is 'n stukkie goud.

1: het ook 'n magdom breinstamme gehad want hy het elke keer wakker geword. Ek het die heelyd geweet daar is 'n probleem. Maar daai dag, 9 Januarie toe sy (die oudioloog) vir my sê hy is doof of het 'n erge gehoorverlies, het ek my byna dood gehuil. Ek het by die huis gekom, hom in sy kot gaan sit, na my kamer toe gegaan en ek het gaan huil. Maar maak nie saak hoe dit oorgedra word aan jou nie, dit is skokkend.

5: Wat ek nou wel kan sê toe ons nou by (die oudioloog) was, hy het dit vir my op 'n baie mooi manier gesê. Wat ek baie admireer van hom is dat, wat vir my 'n groot skok was, hy't vir ons gesê: “..... en (ma en pa), ek wil nou vir julle iets reguit sê en ek wil nou nie doekies omdraai nie, maar het 'n baie baie hoë grens van doofheid”. Soos in die ou taal sou mens sê hy is stokdoof. Toe sê hy vir ons op 'n baie mooi manier: “Daar is hoop. Daar is baie hoop en hulle vorder baie met sulke kindertjies. In die eerste plek is daar gehoorapparate en as dit nie werk nie, 'n kogleêre implanting”. Maar wat ek nou baie van hom geadmireer het, elke dag nadat ons nou daar was, het hy my gebel. Eerste ding wat hy gesê het, apparaatjies, dit kos R30 000. Waar krap jy nou somer vinnig R30 000 uit? Ek sê vir hom, man, maar ek huil..... Vrydag het jy die R30 000, jy kan die apparaatjies solank bestel. Maar wat ek nou baie admireer, elke dag het hy gebel, “Hoe gaan dit? Jy moet vir my sê as daar fout is, ek help jou”. So dit was vir my 'n groot skok, maar aan die ander kant was dit vir my 'n vertroosting, daai ou dink elke dag aan ons. So daar haal ek nou eintlik my hoed vir hom af, ek het nou al baie dingetjies by hom geleer. Dit sal ek nou “like” as iemand dit só doen. Die probleem is mense sê nou die ding en dan is dit op die tafel en nou's jy op jou eie. Ek dink hulle wat dit oordra aan jou moet saam met jou daai paadjie stap. Mens wonder nou wat is die pad vorentoe? So ek dink daar is dalk 'n groot leemte by hoe hulle dit oordra.

F: Is daar enige iemand wat nog hieroor iets wou bylas? Kom ons gesels dan oor die volgende aspek wat julle al klaar aangeraak het. Wat sou julle sê is ouers se spesifieke behoeftes vir inligting wanneer hulle hoor hulle kind het 'n gehoorverlies? Met ander woorde, wat presies wou julle op daardie stadium weet? Watter inligting wou julle by die oudioloog kry?

3: Hoe lyk my kind se toekoms was my eerste ding.

1: Vir my was dit die oorsaak. Ek wou dadelik weet hoekom is my kind doof.

4: Ek dink in die geval van die gehoorsentrum, ek gooi nie verwydte en klippe nie. Hulle het vir ons gesê hy makeer niks. As hulle getwyfel het, hoekom het hulle nie gesê wat is die volgende stap nie?

5: Hulle het gesê ons moet die kind ryp druk, ek sê die dag vir die vrou: “Dame ek hoor wat jy sê, dis waar seuntjiespraat later”. Maar toe sê sy nog kom op 3 jaar terug dan sal ons presies vir jou kan sê wat fout is. Nou moet ek weer terugkom en dit is mense wat geleerd is in die goed en ek dink tog as jy geleer word leer jy darem die basiese goed, hoe hanteer jy die mense. Wat vir my net baie kwaad gemaak het is as sy getwyfel het oor, dan moes sy gesê het, ek is nie 'n oudioloog nie. Want dit help nie jy gooi goed in die lug en jy dink goed is maar so en so...

4: Of kry dan nog 'n opinie, ek verwys jou na 'n gehoorsentrum dan hoor jy wat hulle sê. Toe ons die derde keer terug gaan, toe dring my man aan dat ons 'n spesialis sien.

5: Daar is 'n groot leemte vir my, ek weet nie of dit orals so is nie, maar daar is tog 'n groot leemte.

4: Hulle het nie vir ons vertel hier is 'n sentrum in die Kaap waar jy kan gaan vir breinstamtoetse nie. As iemand twyfel, gaan verder, hoe vroeër, hoe beter....

- 5: Vir my die volgende "major" behoefte vir inligting is finansies. Julle almal weet self hoeveel kosgoed. Dank die liewe Vader ons mediese fondse het alles betaal. Maar ek sê baie aande vir my vrou as ons godsdiens hou, wat van die ander pa's en ma's wie se kindertjies appaarte of inplantings moet kry - dit kos alles geld en al die mediese fondse betaal dit nie. Dan wil ek hê die ou wat dit vir my oordra moet vir jou bietjie raad en wysheid gee en ook darem begrip. Want R30 000 of R140 000 is nie 'n grap nie. Dit is so groot skok, dit is skok op skok. Hulle sê jou kind is doof, die volgende skok die finansiële komplikasies- wat is die volgende prosedure en die prosedure daarna? Ten opsigte van kennis en ten opsigte van mediese uitgawes moet hulle vir jou baie meer inligting gee.

F: Dit wil vir my voorkom asof leiding met die finansies regtig vir julle 'n behoefte is. Wil iemand nog iets byvoeg met betrekking tot behoeftes vir inligting? Volgende wil ek vir julle vra, wat sou julle sê is ouers se behoeftes vir berading en ondersteuning wanneer hulle hoor van hulle kind se gehoorverlies? Hoe wil ouers ondersteun word? Wat is of was julle spesifieke behoeftes?

- 2: Ek het fisies vir my familie gesê, dit is my kind en ek gaan "deal" met die probleem. Hoe julle gaan "deal" met hierdie probleem is nie my saak nie. Al wat ek van julle vra, moet nie my of my kind bejammer nie, want ek bejammer nie myself nie. Want asek vir myself gaan bejammer, gaan ek my kind elke keer jammer kry en waarop gaan dit afstuur? Ek behandel vir soos enige ander normale kind. Ek het vrede gemaak met die probleem wat hy het. Hy gaan met die probleem sit vir die res van sy lewe en ek gaan hom ondersteun soveel as wat ek kan. En asek die dag nie meer daar is nie, moet hy op sy eie 2 bene kan staan.
- 3: Ek moet sê ek het nogal voldoende ondersteuning gekry by (Ouerleidings-terapeut) hier by Ouerleiding.
- 5: Van my en my vrou se kant af moet ek sê oor die ondersteuning- ons 2 moet albei fisies werk. Wat ons probleem is en waaraan ek so baie dink, as jou kind by 'n sentrum soos die (intervensie sentrum) is en die man en vrou moet albei werk, dan verwag ek dat iemand van hier af na die werks-mense of besighede toe moet gaan en die situasie gaan verduidelik dat 'n dowe kind Ouerleiding en terapie moet kry. Jy moet by jou werkgever 'n vlak van ondersteuning kweek, want ek vind by ons hulle is tog ondersteunend, maar sal party dae vra of hierdie goed werklik nodig is? Mense verstaan nie, en met jou kind ook- hulle verwag wonderwerke. As hulle vra: "Praat jou kind al?", dan wil ek deur die dak klim! Daar moet 'n verteenwoordiger na werke toe gaan, want mense sien die dinge nie in nie....
- 3: Aan die begin in ons situasie, het almal in die familie gesê onsmoenie "worry" nie, hulle sal help. Maar later gaan almal net aan met hulle eie dingetjies. Jy moet leer om op jou eie te "cope"- dis maar net hoe dit werk...
- 2: Oe, en ek haat die woord: "Ag, Shame..."! Ek verpes dit!
- 3: Ek was aan die begin ook baie liggeraak daarvoor. Mense is net oningelig. Maar oordie ondersteuning, ek sou sê ek is nou op daardie punt dat ek regtig sal vra as ek hulp of ondersteuning nodig het. Ek dink ook hierdie behoeftes verander maar oor die tyd heen?

F: En, wat sou jy sê is ouers se behoeftes spesifiek vir berading en ondersteuning?

- 4: Ek onthou, ons was seker so half uur by die huis na se toets, toe het 'n goeie vriendin van my..... (huil.....). Die ondersteuning wat almal aan die begin gegee het is nou nie meer daar nie (huil).
- 5: Iemand wat nie self in die situasie is nie, vergeet en verstaan nie waaroor dit gaan nie. Dit sal 'n baie goeie ding wees om met ander ouers te kan praat, soos nou. Want ons almal weet mos waardeur ons gaan. Byvoorbeeld julle wat nou al bietjie ouer kinders het, julle kan vir ons sê, toemaar jy gaan eendag 'n stadium bereik dat jy só of só gaan voel.
- 3: Ja, mense wat al 'n langer pad gestap het en wat positief is. Mense wie se kinders praat...
- 2: Ai, as jou kind darem die dag by die huis kom en hy sê 'n nuwe woord, dit is wonderlik!
- 5: Ja nee, onsmag nog daarna!

F:, en wat van jou?

- 1: Ek dink ook ek is op daardie stadium dat as ek iets wil weet of bietjie ondersteuning nodig het, dat ek daarvoor sal vra, maar 4 het definitief nog ondersteuning op hierdie stadium nodig. Ek dink dit is so belangrik om te kan praat met ander ouers. Maar 4, daar gaan nog 'n stadium kom dat jy gaan rustig raag oor al hierdie dinge.
- 5: Ek dink die pa's ervaar 'n dowe kind 'n bietjie anders as die ma's. Want dit is maar vir enige ma 'n groot skok. Enige defek by 'n kind..... Die ma moet eintlik 'n bietjie meer terapie kry sou ek sê?
- 3: Ek onthou my man, ek weet nie of hy 'n ander manier het- of hy op sy eie gaan en gaan trane stort het, maar voor my het hy nog nooit gehuil nie. Toe ek so vreeslik gehuil het, het hy net gesê: "Ons gaan hierdie ding wen". Ek dink dis maar 'n manne- ding en dis vir hulle moeiliker om hulle emosies te wys. My man het my net getroos en dan weer aangegaan.
- 5: Ek dink die een dra die ander een. Die terapie op die vrou moet meer wees as vir die man, want ek dink dis maar vir enige vrou 'n groot skok...
- 2: Ek is nog 'n enkel ouer wat maak dat ek nog swaarder dra.
- 3: Dan juis het mens jou familie nodig? Mens sê familie staan agter jou, maar eintlik kan hulle jou nie die tipe raad en bystand gee wat ander mense in dieselfde bootjie vir jou kan gee nie.
- 1: As ek dit kan opsom sou ek sê daar is 3: professionele mense, tweedens ander ouers en derdens jou familie. Mens het al daardie fasette van ondersteuning nodig.

F: Om op te som, wat sou julle sê is ouers se enkele grootste behoefte as dit by ondersteuning kom?

- 3: My grootste behoefte was om te kon praat met iemand oor al hierdie dinge. En dan oor klein, definitief sy spraak, want vir my is die groot ding dat my kind in 'n hoofstroom skool sal kan ingaan en dan moet kan "cope". Daarvoor is ek bang want ek weet nie hoe hy gaan doen as hy daar kom nie. En dan ook hoe gaan die druk op ons as ouers wees? Wat gaan van my verwag word? Gaan jy ure saam met jou kind moet spandeer? Ek is maar skrikkerig....
- 1: Dis dalk nou heeltemal van die punt af, maar aan die begin was ek skaam vir my kind en ek wou nie hê mense moes sy appaarte sien nie. As ek winkel toe gaan, het ek dit uitgehaal, want dan kan die mense mos sien my kind is doof en ek wil nie hê hulle moet weet nie. Maar dit mag mos nie meer 'n "issue" wees nie?
- 5: My grootste ding, en ek sukkel nog 'n bietjie daarmee, is as volg. Wat so saam met die skok gekom het- jy het so baie trappe gemaak toe gebore is. Jy wil hê hy moet goed vaar op skool, hy moet darem sy ma en pa sê goed bereik wat ons bereik het. Maar vandag is my "main" ding net dat moet kan praat en goed kan kommunikeer. En dan ten minste om skool goed te kan klaarmaak. Dit is nou my grootste hoop en verwagting. Verder "worry" ek nie, hy hoef nou nie uit te blink in enige iets anders nie, net daai basiese ding om te kan praat en om soos 'n gewone kind deur die lewe te kan gaan – dit is my grootste behoefte.
- 3: Ek was so bang my kind gaan snaaks praat en dan is hy half 'n bespotting vir ander kinders...
- 5: Dit is mos maar jou wese, jy is eendag hier bo en eendag weer heel onder. Dit sal nooit somer net so klaps en als is reg wees nie. Dit gaan in die skool ook gebeur en ek weet gaan eendag by die huiskom en sê dié kind het vir hom sò gesê ten opsigte van sy gehoorprobleem. Dit is maar 'n moeilike storie.....

F: Ons tyd is verby en ons sluit af. In 'n neutedop, as julle terugkyk: julle persoonlike raad aan ander ouers?

- 1: Hou moed, dit raak makliker
- 3: Dit raak definitief beter, daar is hoop.
- 5: My raad aan ouers wat moet besluit om kinders te hê, as die kindjie gebore word, doen maar daai dag die moeite, laat toetshom. Moet nooit met die eerste antwoord tevrede wees nie, gaan soek liewer nog. Met enige probleem, leerprobleme of iets, gaan kry 'n ander opinie en 'n groter geheelbeeld. Dit het ek nou geleer.

F: (Samevatting en bedanking)

FOCUS GROUP DISCUSSION

ENGLISH FOCUS GROUP

- F: How did you first discover that your child has a hearing loss? Share with us in short your personal experience.
- 1: was premature, born at 6 months and 1 week. Death and life situation. With God's help we both made it. was in hospital for about 10 weeks, 3 or 4 serious bacterial infections. So that is why he is my miracle baby, I can't talk enough about that. I was prepared for anything worse.... Blindness, paralysis, anything..... I think God was preparing me beforehand for what was lying ahead. We don't know what was the cause, I think in his case it was the medication as well as being a premature baby. I've accepted the fact that this was the cause, well, the medication saved his life. I did a test at home for his hearing, I asked the doctor what is the side effects of premature babies and I came home the day after visiting the pediatrician. I stood behind and clapped my hands. So the funny thing about these children, they interact and you don't know whether they can hear or not. I told my husband there was something wrong. I phoned my friend (who also has a child with a hearing loss) for a number of an audiologist and got an appointment for 2 weeks later. I went to (the Audiologist), a very sweet man, very sensitive, asking me how did I feel about this issue. I said to him there's nothing wrong, but what can we do about this? What is the next step? My husband would say that I am so hard. What can I do to help my son to hear? I was already in the next step, my trauma was 10 weeks before this happened. To me this was a small blessing. So he's got a disability, not a liability. That to me was standing out. That's how I look at with that.
- 2: My child was only one month premature. She was in hospital for a month and at the end of that month they did the hearing test in the hospital, which at that point in time had no response. The explanation was that just like many other prems she has fluid in her ears and let's follow that up later on. There was no second thought about that. The pediatricians reacted as if deafness never existed. And then, being a second-time mom, I realized that her responses were completely different, although it was confusing, because she had one better ear- she would hear loud claps close to her, but she wouldn't respond at all to other sounds.... And then at 4 months old, because she was in and out of hospital, I just didn't have the courage to deal with the deafness, because there were so many other things. And finally in January I tackled this because it's a new year and then the audiologist confirmed the deafness, which I think still come as a big shock to me- you know it, but denial is an amazing tool, it's not that bad. But life goes on and the fact that the audiologist told me about (intervention center), you realize it is not the end of the world. You get hearing aids. You can do something about it, in comparison to someone who is paralyzed and you can't do anything about it. The moment I've heard they don't have to go into sign-language and that they can speak, it was fine and not such a big deal. Let's move on with life. So right now, what the deafness is concerned, it's the only thing that makes me feel really good about I know from my side I am doing every single thing I can. I'm at the right place and we do as much as we can. So it's a tough blow, but it's something you can overcome.
- 3: was born on 40 weeks on the dot, but an emergency caesarian. They had to transfer her to Panorama's NICU for 2 weeks. The pediatrician keep on telling me she was not going to make it, but then she proved everybody wrong. The day she was due to be discharged from NICU they did the hearing test and she didn't pass. They said come back because there is a chance that there could be fluid in the ears, so in 6 week time I went back. I didn't tell anyone, just keeping it to myself, but I was watching her and she wasn't responding that much. She is my first child, I didn't know, but in my mind I knew.... At 6 weeks we went back and they did the same screening test, which she didn't pass. And then they did the sleep test, so it was confirmed when she was 6 weeks and 2 days old. I was quite devastated, worrying also about what else could be wrong. When I came to (intervention center) and saw the kids running around and talking with hearing aids on – that was good. Because what you see is the deafness and sign language. And at 8 weeks we were at (intervention center) and now thinking about everything else that could have gone wrong, technically she wasn't suppose to make it, so dealing with deafness in that sense was easier.

- 4: My baby,, was born like the size of a pencil, he was just more than 500g. When after 6 months he came home, he was like a little chocolate, he just sat there.... You look at him and a mother's intuition.... you just know that there was something.... I went to a neurologist first and he confirmed the deafness. My initial response was: is he going to hear me speak? Your mind wanders.... As soon as I came in contact with the (intervention center), that's when there was a radical shift. I had a very good experience and I carry on. One needs honesty.
- 2: Initially you think worst case scenario, you think your child is going to be a social outcast. This poor child will never be able to do athletics, she won't hear the gun.... I lived life and this is how important hearing was. And now she wouldn't be able to do anything. That was my first sort of first panic attack....
- 4: Before you gather information and before you do anything, your mind wanders like when he is running into the sea, will he hear when someone calls him to stop? You do think about these things, but you very quickly get over that and you relax. You carry on so that your child can reach his actual potential.
- 3: (intervention center) turned me around when I was feeling it was the end of the world. Now you do things differently and things are a little bit more work....

F: And, last but not the least, tell us about

- 5: was born and was in NICU for 2 months. They didn't know what was wrong with him. But he was really ill. He had 2 major operations at only 2 months old. Every time we saw a doctor, I thought everything is going to be all right, and then it was actually not. The past 3 years I am riding high because he hasn't had any operations! He is turning 6 now. He was starting at (intervention center) almost simultaneous when we found out that he was deaf. The reason I found out was that he never really said "Mommy". We were just so grateful that he was alive – he was so responsive. But with a lot of close time I've spend with him, I realized he wasn't picking up everything, because he is severely hearing impaired, not profoundly. We then went for the sleep test and the hearing loss was confirmed. At that time there was so much else happening that the deafness wasn't the most important thing. He got his hearing aids at (the audiologist) and she (the audiologist) was lovely, she was gentle and at the same time very professional. The interaction at (intervention center) and the fact that he has an amazing godmother and –father helped a lot. And then his language is phenomenal.... And all of you who still have young children, it's still a long way to go. Part of my journey is accepting that I cannot always be there for him and I have to let him go.... I also have to acknowledge that every time I think I've dealt with everything, I realized I haven't. It is a long process. And it is about learning and being honest with ourselves and our children. Now and I talk about what is hearing and I tell him that when you take your aids out, you cannot hear, but I (Mommy) can hear. You have to teach them a love for hearing and a love for their hearing aids. It has been an incredible learning process. But at the moment just to give you all hope, is just taking off with learning to read and write. It's been a heck of a process, but you just take one small step at a time. There is times when I feel completely confused wondering what to do – and then I sit down and realize, it will come.... Sometimes other professionals is getting more anxious than I am, but then again, we take things at his pace. Let's encourage and motivate, but not push. He still gets a lot of ear infections, having one aid in and one aid out, but we have been taught how to deal with that....
- 3: Something you said that strikes home is that you can never say that you've dealt with it, we can still see that it is still emotional for you.... And here I am with my eyes full of tears. Sometimes I struggle to classify my tears, there will always be the emotion.....

F: Moving to our next question linking onto all that's been said so far. What would you say are parents' needs when the diagnosis of a hearing loss is conveyed? What would you consider to be the pitfalls, looking back at your own experience?

- 4: I felt my needs were met, I really do. I think here at (intervention center) they took control of the whole situation and they gave me a feeling of stability.
- 5: My audiologist wasn't very emotional, so much so that I couldn't even remember her surname and it was not her offering me anything. She just diagnosed and didn't contain me at all.
- 2: I think that moment in that room when you hear it, different audiologists will deal differently in terms of their own personalities. But to me the most important thing was heard but could definitely be bettered. That was my extreme need for information. I didn't care if it was 10 files of reading work, I would have gone through it that night – that is

what you need. I mean, even if it is a list of every single deaf school in South Africa, then that be it. Actually thinking about it, I would like to have it. I don't have that. Because so much go through your mind. I mean even with (intervention center), the first thing, where do I live? Do I have to move? We are lucky that we live in Cape Town. Deaf Schools, different approaches, auditory approach.... Never heard about it. I think if you've been given that information right there and then, just go and read. And I know we all do things differently, but to me, just give me information..... let me find out more. The more you know about it, the more you can find a way of dealing with it. So I think information..... so very important. I was lucky being sent into the direction of the (intervention center) and that is good and bad, because then you never know, was there maybe something else? It is natural for parents to want to know am I at the best place for my child. What is all available out there? Where do you start? If my audiologist haven't told me about it....? Would one go to the Yellow Pages? You are so hopelessly lost when you get that news.... Where is what and what do you do?

- 3: When I was in hospital and they did the test in NICU, well for a start the nurses came to me saying, well your child failed the hearing test.... Well at that stage I didn't think it was dealt with correctly. With the screening in the hospitals it is very important how it is conveyed. The audiologist didn't take the time to come and speak to me herself. She was there and that to me was poor taste. At 6 weeks we went back, I didn't really like the approach, because it was a case of taking the baby and make it asleep. She was only 6 weeks old and didn't want to sleep. I just didn't connect to the audiologist at all. I found that she was not really sympathetic towards the fact that it was really a young baby. Her approach was we now have to wait for a month and I don't want to wait for a month..... She was really like abrupt. To parents—you cannot let them wait for a month to get it confirmed. And then it was just your child is deaf with no information, and I will see you again in a month It was a case of just deal with it. There could have been a little bit more compassion. Speak to someone about that grief and that it doesn't just go away. The pediatrician then referred us to someone else. He (the other audiologist) was phenomenal. Everything that frustrated me, was now totally opposite. "How are you doing Mommy?" I found that to be very good. He phoned (intervention center) while we were there, saying he's got a new mom and dad, the sooner they can see you the better. So we were here very quickly. We had 1 or 2 sessions before even had her hearing aids. So for audiologists, they are not actually dealing with the child, but dealing with the parents. They don't need to be counselors. They just need to recognize that you are in a very bad place.
2. Even if they for example get permission from other parents who has gone through the same, just giving you a telephone number of a parent who has just recently been through it. Something as simple as that would have made the world's difference for someone who has got the need, but just don't know which direction.
4. The neurologist gave us the diagnosis. I just wanted honesty - someone saying this is it. I want to know. The Audiologist went to write down all the important information. And I have to say, relatively speaking, listening to all of you, I think my experience was a very guided one.... A lot of people helped me and there was a lot of support. My family as well as the audiologist was phenomenal. They gave the info that I needed and they were honest with me.
3. One thing I found with the medical profession in a whole, they always take the more negative approach than the more positive approach. I also found the first audiologist we were dealing with very negative in her outlook. Maybe because she knew 's history and all the other things that were wrong, where as the second audiologist didn't know much about her history, but were much more optimistic about what her future would be like. I do not say she should be perfect, but he was much more optimistic and I appreciated his optimism.
5. To me it's about honesty and empathy and the information. Where from here? Is there going to be support? It actually seems that (intervention center) has done that, more than the audiologist.
1. In my case, I am a very inquisitive person. I had another parent as a friend who knows about everything. She gave me the number of (intervention center) and also prepared me. The audiologist was very sympathetic, but to me it was not about sympathy, but honesty. Something I had to deal with was saying to my husband: is deaf. We come from different backgrounds. He always says I am very hard. I will deal with it but there is no time to wait. I had to get my husband through his denial to get him quick, quick, quick where I am. The audiologist was very sympathetic, he explained to me the whole thing. I didn't understand a thing about decibel and I am still confused... But eventually I now can explain to a normal person what it is all about. My concern was about hearing aids, because at that stage we had these huge hospital

bills. To me the diagnosis was nothing, maybe I didn't have the feeling at that stage. I think it is all about information being ready and available and having parents available that you can speak to. It is comforting to know there's another parent you can speak to who are in the same boat.

F: What would you say are parent's specific needs for information when they hear that their child has a hearing loss? In other words, what exactly did you want to know at that stage?

- 2: I think the first thing is that somebody really makes you sit down, because I mean you've been knocked with a bomb or actually stepped on a landmine. Someone explaining to you exactly what is hearing. We all take it for granted and it takes a long time figuring out what it really means.
- 1: Explaining that whole charting with the decibels, making sure that I understand, that is where is hearing now. Then I can explain it to the layman in street, I tell you that is my main frustration. I make it my duty now to explain and educate anyone who asks about deafness, but I explain the proper thing.....
- 2: That is what is so important is that we sound knowledgeable. And how on earth do I explain these things to my husband?
- 3: And how to understand the whole frequency thing. I just understood that when you are deaf you are deaf at one level. You don't know how you hear. And then further information – I am always a “what is next” person. I'm always busy planning the future. I only understood about the future when I first came to (intervention center), because the audiologist didn't give me that information. I wanted to know that almost all of these children go to a mainstream school. And you can't sit and have too much information at one time, you can't remember everything. To conclude our needs for info is the whole audiogram thing with all the frequencies, pinpointing the deafness. I know my greatest fear was that’s hearing is going to deteriorate and then she will need a cochlear implant. I think what would probably do most good is 5's story. To hear the story from people who has been through it and their children are fine. And even older kids, hearing that this one is studying this and this one is being an accountant and that this is not the end of the world. About our children reaching their own potential. Testimonials from moms, actually I would like to read them. You know a professional will always tell you one thing, and then you talk to a mom, and then I understand.
- 1: I still can't cry. I still can't cry. I don't know why? I just can't cry. I think maybe it's the time that Luke's been in hospital, the trauma I've been through. I don't know why? Maybe it is a weakness as well. My eyes will just slightly fill with tears. Maybe I should learn from 5. To me it's a weakness in yourself if you cry. Because if I'm going to cry, who is going to comfort me? There's nobody who's going to comfort me. Because my husband and I, we are in the same boat. What we must realize is that we are woman, but we don't know how our husbands are also feeling. They can comfort, but they don't talk. So to me it's difficult to cry.
- 5: When it comes to the audiologist giving support to us crying – If you had for example an audiologist who starts off with you and be the center and same person, it makes it much easier than having different ones. But I also think a lot of it is based on the personality of that specific person.
- 3: If you connect you connect, and if you don't, you recognize it straight away.
- 5: They could have all these steps written out, but as a person not be able to provide parents with what they need. There are matches and then that relationship grows over time (everyone agrees).
- 3: But I think audiologists need to recognize how important that relationship is. I don't need to have a relationship with my dentist, as long as he does well with my teeth. But with my audiologist I want a relationship and it is such an important relationship. My other need is also the costs of everything, because you don't know what the costs of everything are. The moulds, the tests (everyone agrees).
- 2: Yes, if you could have that as well, I mean the types of hearing aids....
- 3: Like I didn't know which of the hearing tests are for free and which ones you should pay for. And everything about the moulds. We are replacing the moulds all of the time. What are the costs? What is the service I can expect from (intervention center)?
- 2: I think to have all that information up-front. That would really help.

- 5: We virtually run through moulds. During that first month I use to phone the audiologist' room ten times a day! Because I didn't know about the physical reality of those moulds and we had a problem with them flopping forward all of the time!
- 2: I am a black and white person when it comes to information. In a booklet: I would for example on my first page have a picture of the audiogram. Pictures do very well. On the second page I would like a list of all the schools, but on top of that explain what is audition and hearing and also the different approaches that you get. And then finances A list of all the options in hearing aids, the costs and the practical thing, like if it is a small baby, we are looking at changing the moulds often.
- 1: I like sessions when one of the speech therapists or audiologists came back from a conference explaining and reporting back about cochlear implants. It's a continuous thing these needs—it changes over time. I would really like to attend conferences.
- 2: What is going to make it easier, country-wide for audiologists, is that if there is a big website with all of this on. All you have to do then is get access to it. A website that parents can log on to and write their own story down. And if you have a question you can ask it or give an answer if you know it. We actually need a big web-site for all parents in South Africa Or either give us a list of all available web-sites, please just give me all the web-sites. I just need this wave of information right there and then.
- 4: I think my information needs were met very well. My audiologist explained everything to me in layman's terms and I was comfortable with that. I can see I love information, I'm a person who needs just the right amount of information. I don't like "information-overdose". At the stage when they told me that my child was deaf I wanted to go home and then go and think in which direction I have to go. I didn't have this desire to go to the internet and find out – at that stage. But you know, things change as my child changes. But I just need to know the fundamentals. To me also talking to people, there's nothing better than talking to people. Like listening to 5 whose child is 6 years old and speaking. For me it is very difficult to believe
- 2: But that was actually my biggest desire, I just wanted to hear from other parents.
- 5: When we initially came to visit (intervention center), we walked into the garden, and there was this one little boy called and he was speaking. And that was when I realized we were in the talking-process. And (the little boy), he doesn't know, but that was meaning more than any other adult, because I saw that could talk and could hear me when I speak to him.
- 3: The whole cochlear thing - at first I didn't understand why my child wasn't deaf enough to have a cochlear implant. My question also has been that cochlear kids had a step up from those kids having hearing aids, but after a while it evened out a bit.
- 4: At first I was very scared about cochlear implants, and I'm still scared. But when I did come to the school and I heard the Implant children speak, I was like wow! We need more information about the implants.
- 5: At the end of the day, is the quality of those children's speech better? If it gives my child who has hearing aids a better quality of speech, I would do it.
- F: (explaining and giving information about cochlear-implant criteria)**
- F: Listening to you all and moving on to the next question, what would parents' needs then be for support and counseling after the diagnosis of a hearing loss? What are your specific needs for counseling and support?**
- 4: Over here at (intervention center) I've got the perfect combination of support and counseling. I had a team consisting of the social worker, my Parent Guidance Therapist... you have this little team looking after my son's needs. And then obviously I have the support of my parents. I get financial support from my parents in a big way, it helps me a lot. I think (intervention center) is doing very well and they are really going the extra mile. The social worker, I mean she is really a nice person.
- 3: The sooner and the closer you can get to (intervention center), the better. Then you start forming a long-term relationship with them. I find my Parent Guidance Therapist to be absolutely wonderful, she helps me sorting things out so that I can get on the right track. The only thing if I look back now that I would have done differently, I was given a name of a parent to phone. But it is very difficult to make that call. You're in a very bad place, how do you actually make that call?
- 2: I was desperate to phone someone.

- 5: I'm just thinking about it now, I'm really concerned about counseling and I'm dealing with a private therapist on and off. But when it comes to (son)'s thing, it's kind of I didn't always want to be involved with the other moms to talk to them initially. But now I'm far more ready to share and talk to other moms, only now for the last year I would say. Initially I had a lot of resistance to get involved. But I think there comes a readiness for one to get involved in counseling.
- 3: Probably different people need it at different times. To me it would have been nice to meet parents with young children, but also older children as well. Even if my child is not there yet, I want to know the kids. But just to see how other kids are doing. To get opportunities to speak to parents who's got kids in school or even got kids who have moved on.... Just to see the whole experience, not only the parents.
- 5: I also think Parent Guidance is a learning process, because sometimes it could be quite intimidating working with your child in this room alone. All of us have taken responsibility for our children – everything is always our own fault. And it is not all our fault and our children are separate from us. They are not part of us. Not everything happening to your child is about you. And things doesn't get better immediately – it is a process. Initially you feel you are the only person who can make things work, and it is not like that.
- 4: Wow, listening to all you other people's experiences... You know with (son) it's Gavin, my husband, he's got only one arm, and you just carry on and I think that is how we go on. And then things like using the hearing aids drives me crazy.... To pull it out and get it back into his ears... He is naughty, but life goes on.
- 1: It's that word "disability", not liability.
- 5: You know I felt for a long time that my son is not disabled at all, because he is doing so phenomenally well. And to me everything felt very simple and easy. But I think for them it's not. And if we give them a false sense of what it's like, and if we tell them that they are the same as everybody else, we are doing them wrong. Things are different for them than for us. I realized that needs to know that he is different because what happens sometimes, and I'm saying this over and over to people: We all have our stuff, but there are things that is more difficult for children who can't hear than for normal children. There just are.... It's harder.... They have to concentrate more. I started to realize that I needed to start to live in the reality. Because people and the world are not accepting deafness. I've come to a point now where I've realized that I have to tell him that he is different and that things can become difficult. To talk about these things when they happen is extremely important. I had to grow to accept it....
- 3: I felt very similar to that.
- 4: It is so good to hear that from all of you.
- 5: When parents come to (intervention center) and when parents have accepted the disability, they can more easily get integrated into mainstream schools and into society. But parents who are still at a point where they don't want other people to see their child's hearing aids makes the child feel like that also and that is where emotional problems start and stuff like that. And that really hit home to me....
- 3: I think it is an important thing to think about. And it is hard teaching your child to not limit herself because of this, but let's deal with the fact that it's more different and more of a challenge.
- 5: The more we know ourselves, the more we would open ourselves up.
- 4: With, he is very small, and I think his smallness is drawing more attention than his ears.
- 2: You raised a very important issue now: hearing impairment versus deaf. Theoretically all our children, because none of them got a cochlear implant, we should all be speaking about our hearing impaired children. Are we doing them harm by classifying them as deaf? Do we actually say deaf because the rest of the world understands it better? Or do we speak about deaf because you actually get a little bit more sympathy. Or then hearing impaired and people say, oh well, it can't be that bad? Should we actually make an effort to not use the word deaf? Or if you are talking about hearing impairment are you trying to be a little bit more fancy, because let's face it, deaf is deaf?
- 4: Don't you think sometimes we manipulate it. Like when I want extension for an exam I use the word deaf?

2: I think within myself if I use the word deaf, I've accepted it. I'm not trying to make excuses for it to be better than what it might be.

F: Looking at the road ahead, what about future support? How should parents continually be supported at this intervention center?

4: We need the financial support. The finances are the start. We also need the technology to keep on improving because I'm hoping that one day there would be something that they could just put into the ear.... When it comes to ears, yes for technology. And then I would say support groups like this, to support each other, to share....

3: It's a good guide. I mean we are here for research, so I must do my part.... But at the end of the day, I gain more for myself than I think you (the researcher) gained from me! You know what I'm saying?

4: Yes, something like this hour. It will teach me a lot!

3: Listening to you all when it comes to support, I think I am a balance between 2 and 4, in terms of the amount of information. Don't overload, I won't take in all of it! But I would just like to be updated in terms of what is happening in the world – changes in hearing aids, new technology. Whatever I would be told from (intervention center) in terms of technology, I would believe it more than an audiologist just trying to make a sale. You know, acting on my best interest. Just information. And I also think it is a lot about asking as well. When you ask, you get. I find that whenever I'm battling with something, I speak to (Parent guidance Therapist) and we tackle it together.

F: And what about support family wise?

2: I think there's definitely a need for husbands to be somehow drawn into it. And I don't exactly know how? It would need to be a forced braai, maybe on a Saturday or something. Because that's where I've learned that denial could keep you going. My husband showed me that. It's actually a way of living life. The other thing that I don't know who should be the person, it could be a private psychologist..... The school could help you or should we just turn to a mother's group..... For instance, my first daughter is 3 now and when and where do I explain to her that she's got a sister that's not normal? That to me is a big issue. Luckily I haven't crossed that bridge yet, but I'm going to have to do it, and I want to know the when and how....

3: 's brother is 3 and likes to put hearing aids in and take it out. So he feels part of it and the end of it is that he also hearing aids now because his brother got aids! I think it's about inclusion. It can come in a practical way rather than in an emotional way.

F: If I understand you correctly in terms of support, you need somebody outside the family, an outsider?

2: I think everyone is just focusing on the mom, because the mom takes all upon herself. Even if it is told at (intervention center) or just a website or information on who is the best counselor available to see. I think somehow one needs to look at the family as a whole. Maybe just to talk right here every now and again a psychologist to come and address that these are the right things you need to look out for and these are the things you need to focus on.

3: I think the integration with the siblings is important and then the issue of where the deaf child is placed. With me now it's different because my older child is hearing impaired and my younger child not. How should we deal with that? How will she react when she gets older and her older sister gets more attention and have these things on her ears and positively accepting all of this. Maybe put me in contact with parents with a similar age gap, having a couple of sessions together. Sometimes you're not aware of the fact that you've got a need until somebody else brings it up.... And then also to be very up-front about all the services that (intervention center) can provide.

5: It will take time to understand how this whole school system is running...

3: They should keep Parent Guidance's parents just as informed as they do school children's parents. I want to know about everything that is happening at this center. I'm happy to support, either financially or just to be there.

2: I sometimes think that what they sometimes forget is that new parents have all the energy and the drive and would love to raise a million rand for the school, because that is the future of their child. I was like that, but I've got disillusioned along the way, and right now to be honest, I've got no interest in raising money. I think the school needs to

realize that a new parent needs to stay motivated till the time that they really actually hit the school, because apart from me, I've got a wide circle of friends. If I stay motivated about the school, that could bring in an incredible amount of money from the outside world towards the school.

1: To me it is basically on the basis of my work that is a problem. I always have to go through drastic measures to be here. In a work situation they don't always understand that I have to be here. I just think there is a gap where your work-situation is involved. That is my main concern. Juggling everything and knowing that they always expect me back at the office. This I'm making use of every possible way of support that (intervention center) is offering.

5: I realize that as we grow our needs are changing. It doesn't stay the same...

1: That's why we are continuously asking ourselves: Are we doing things right? Are we on the right track? I think it will go on and on, we change and our needs change.

F: Is there anything that needs to be added to all of this? (Summary and reflection, thanking everyone for their participation)