



## Children with cochlear implants: parental perspectives

### Guidelines for use

A questionnaire devised by Sue Archbold and Mark Lutman

Development supported by RNID

### Guidelines

#### Introduction

This questionnaire was designed to be used with parents following their child's cochlear implant and aims to tap a range of significant issues, such as socio-emotional behaviour, real-life communication and family relations. Unlike many other assessments, its content is derived from parental reports of significant areas, rather than professional concerns (Archbold et al, 2002).

The questionnaire is used by a number of cochlear implant centres world-wide and is included in the Bawtry Computer Services system for cochlear implant centres.

#### Description

The questionnaire consists of 74 statements. Parents are asked to tick their response to each statement using the following choices:

- Strongly Agree
- Agree
- Neither Agree or Disagree
- Disagree
- Strongly Disagree

There is a different form for parents of boys and parents of girls; these are both downloadable from The Ear Foundation website. The questionnaire is clearly and attractively presented to encourage completion.

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#### Development

The development of the questionnaire is described fully in Archbold et al (2002). The parents of 30 deaf children were asked to complete an open-format questionnaire three years after implantation. Seventeen prompts were given to elicit their free text responses. Rigorous content analysis of the scripts using illuminative research methods led to the development of a closed-questionnaire covering the following areas: child's functioning, parental implications, family implications, educational liaison, influences on progress, the process of implantation, future needs and advice given by parents to others. The paper by Archbold et al reports fully on the scripts, including quotations, to give full value to the parents' views. Thus the ensuing closed-set questionnaire, necessary to collect and analyse larger quantities of data,

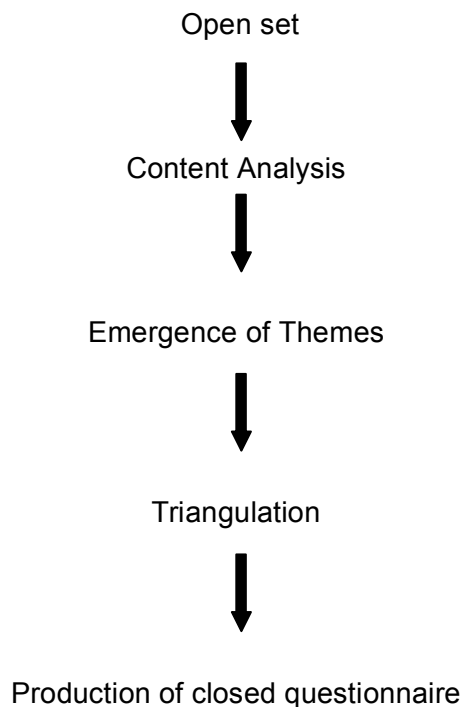
Marjorie Sherman House 83 Sherwin Road Lenton Nottingham NG7 2FB

Tel: +44 (0) 115 942 1985 (voice & text) Fax: +44 (0) 115 924 9054 Email: [ear@foundation.org.uk](mailto:ear@foundation.org.uk)

Web: <http://www.earfoundation.org.uk>

is based on the issues considered of importance to parents themselves. The statements in the questionnaire are taken from the comments given by the parents in their scripts.

The process undergone in order to develop the closed-set questionnaire was as follows:



Care was taken to ensure a balance of positive and negative statements in the questionnaire and to present them in no logical order, to promote accurate responses. The questionnaire has been shown to be robust and repeatable (O'Neill et al, 2004). Two researchers from Oxford Brookes University, Nunes and Pretzlik, carried out an independent validation, funded by The Royal National Institute for Deaf People. They administered the questionnaire, as well as a new parallel questionnaire and also interviewed the parents of 81 deaf children; 60 with cochlear implants and 20 with hearing aids. Their study (Nunes and Pretzlik, submitted) showed that the questionnaire has high content validity, in that parents views are well represented, a high level of criterion validity in that it strongly correlates with the parallel questionnaire, and a high level of construct validity. They found the final closed questionnaire to be a suitable instrument to inform policy makers and implant teams.

Thus, this questionnaire has been found to be repeatable and valid. It enables these important issues to be explored systematically across larger groups of parents and implant centres.

### **Use and administration**

It is recommended that this instrument is not used until at least one year after implantation. In addition, it would be inappropriate to use it on an annual basis, but useful information may be gained by its administration several years later, for

Marjorie Sherman House 83 Sherwin Road Lenton Nottingham NG7 2FB  
Tel: +44 (0) 115 942 1985 (voice & text) Fax: +44 (0) 115 924 9054 Email: [ear@foundation.org.uk](mailto:ear@foundation.org.uk)  
Web: <http://www.earfoundation.org.uk>

example ten years after implantation. It should be completed independently by parents, without assistance from a member of the implant team in order to ensure independent views, and local ethical and confidentiality protocols followed. Care must be taken with its administration with families of ethnic minority groups. Parents should be asked to give their initial responses to each statement, rather than giving each one a great deal of thought. There is a space for additional comments. It has been found useful with parents of children with a wide range of additional disabilities.

### **Scoring and Results**

Responses to large numbers of questionnaires will give topics for consideration by the implant team. Areas of satisfaction and concern may be highlighted by the use of the questionnaire. The responses of individual parents may well provide a basis for discussion with them; ultimately norms for the data collected will be published and provide additional information for comparison.

In scoring, it is useful to look at questions in the following groups:

<i>Issues related to the child</i>	<i>Questions</i>
Communication	1, 18, 27, 66, 71, 72,
General Functioning	4, 6, 7, 35, 51, 53
Self Reliance	12, 32, 33, 47,
Well being and Happiness	16, 59, 61, 64, 70,
Social Relations	5, 30, 39, 41, 45, 65, 74
Education	9, 23, 31, 37, 48, 50, 69
<i>Issues related to the family</i>	
Process of Implantation	10, 13, 21, 22, 24, 25, 29, 34, 36, 38, 40, 42, 43, 44, 49, 52, 54, 55, 63,
Effects of Implantation	2, 8, 11, 14, 17, 26, 73
Decision to Implant	28, 46, 56, 57, 58, 60, 68
Supporting the child	3, 15, 19, 20, 62, 67

A software package is available on The Ear Foundation website.

### **Who will find the questionnaire useful?**

Cochlear implant teams wishing to monitor the more general effect of cochlear implantation. Parents wishing to reflect on the effect of cochlear implantation on family and local teachers of the deaf working with families. It will provide a systematic way in which the issues arising from cochlear implantation can be explored in individual cases.

### **For which children is it considered useful?**

The questionnaire is considered useful with families of children who have had their implants for at least one year. It is designed for parents of children under ten years of age, although some aspects may be useful for families of children who may be older than this at time of implantation.

### **References**

Archbold SM, Lutman ME, Gregory S, O'Neill C, Nikolopoulos TP (2002) Parents and their deaf child: their perceptions three years after cochlear implantation. *Deafness and Education International*. 4 (1) 12- 40

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