

Implant Centre Teachers of the Deaf

Guidelines for Good Practice

Working with Children and Young People with Cochlear Implants



Implant Centre Teachers of the Deaf (ICTOD)
Guidelines for Good Practice

CONTENTS

Mission Statement

1. Introduction

- 1.1 Purpose of Guidelines
- 1.2 Outline of Guidelines
- 1.3 Historical Perspective

2. General Service Issues

- 2.1 Remit
- 2.2 Principles of Service Delivery
- 2.3 Models of Working
- 2.4 Recommended ICTOD Input
- 2.5 Quality Standards
- 2.6 Clinical Audit and Outcome Measures

3. Working on the Cochlear Implant Programme

- 3.1 Experience and Skills of the ICTOD
- 3.2 Assessment
- 3.3 Re/habilitation
- 3.4 Report Writing & Record Keeping
- 3.5 Training Role

4. Continuing Professional Development

- 4.1 Ongoing Education Needs of the ICTOD
- 4.2 Research and Development

5. Sources of Information

6. References

Implant Centre Teachers of the Deaf

Guidelines for Good Practice

Working with children and young people with cochlear implants

MISSION STATEMENT

To support consistent and appropriate use of cochlear implant systems by paediatric recipients. To assess and promote the development of the functional listening, speech perception, spoken language and other functional communication skills of deaf children within a multi-disciplinary cochlear implant team. To work in collaboration with families, with local Teachers of the Deaf and other professionals.

1. INTRODUCTION

An implant centre teacher of the deaf (ICTOD) is a core member of a multi-disciplinary cochlear implant team. (National Deaf Children's Society (2005a) *Quality Standards and Good Practice Guidelines: Cochlear Implants for Children and Young People*, London)

1.1 Purpose of Guidelines

These guidelines aim to give an overview of the role of the ICTOD. ICTODs recognise the importance of collaboration between local educational support services and cochlear implant professionals and value multi-agency working.

1.2 Outline of Guidelines

These guidelines cover:

- The roles and responsibilities of ICTODs
- Outreach visits by ICTODs
- ICTOD professional development needs
- The research and development role of the ICTOD
- Sources of information

1.3 Historical Perspective

The first paediatric cochlear implant operation in the UK took place in 1987. Cochlear implantation is now a routine treatment with a strong body of evidence showing benefit for traditional paediatric candidates, especially if they receive their implants under two years of age (Colletti et al, 2005; Verhaert et al, 2008), and if they receive bilateral implants (Tait et al, 2010). The introduction of the Neonatal Hearing Screening Programme across England in 2006 began to drive down the age at first implant and centres are implanting

children under 1 year.

Evidence of benefit is also accumulating for other groups such as the audiologically borderline (Fitzpatrick et al 2006), ANSD (Guidelines for identification and management of infants and young children with Auditory Neuropathy spectrum Disorder: The Children's Hospital, Bill Daniels Centre for Children's Hearing, Guidelines Development Conference at NHS 2008, Como) and those with complex needs (Dettman et al, 2004; Edwards, 2007; McCracken et al, 2012; Speers et al 2010). It is anticipated that the selection criteria will change as research based evidence informs practice.

In January 2009 the National Institute for Clinical Excellence (NICE) recommended bilateral implantation for children with a bilateral severe to profound hearing loss. For children who were existing users of a single cochlear implant, NICE stated that they should have the option of an additional implant in the other ear if this was considered to provide sufficient benefit by the responsible clinician, after an informed discussion with the individual person and their carers. (NICE technology appraisal guidance 166: cochlear implants for children and adults with severe to profound deafness, 2009).

Cochlear implant services around the UK are expanding the type of surgical interventions they offer. The main focus of teams remains cochlear implantation but implant centres are now also offering Bone Anchored Hearing Aids, considering Electrical Acoustic Stimulation Implants (EAS), Middle Ear Implants and Auditory Brainstem Implants (ABI)

2. GENERAL SERVICE ISSUES

2.1 Remit

ICTODs work with children and young people who have severe to profound deafness, their families and local professionals. This involves work in the home, clinic and in a range of educational settings and in their educational settings. The child's hearing loss may be congenital or acquired in origin, or of sudden or progressive onset. Children may be aged birth to eighteen years and may have additional needs.

2.2 Principles of Service Delivery

All paediatric cochlear implant programmes should include qualified and experienced Teachers of the Deaf. ICTODs assesses, monitors, evaluates and provides advice about the child's listening, speech perception, speech and functional communication skills both before and after cochlear implantation within a variety of local settings. ICTODs work particularly closely with the Implant Centre Speech and Language Therapist (ICSLT). ICTODs also contribute to the multiprofessional assessment and decision making process regarding the suitability of cochlear implantation for the child. ICTOD liaise with the child's

family/carer, local professionals, staff in the educational setting and with other members of the cochlear implant team.

ICTODs tailor their approach to each child's individual needs and abilities, providing appropriate support and advice on the use of the cochlear implant and where appropriate any additional assistive listening devices (ALDs) at home and in the local educational setting. ICTODs provide advice and appropriate information and training to local services, families and children as required.

The ICTOD works within the service delivery models and protocols used within their team.

2.3 Models of Working

Implant centres may offer one or more of the following

1. Clinic based monitoring and intervention
2. Outreach monitoring and intervention
3. Outreach consultation, teaching and training.

ICTODs work together with implant centre staff post implantation to provide support and guidance as required on specific habilitation programmes

ICTODs liaise with and advise families and local services regarding expected progress post implant. ICTODs work with colleagues on the Cochlear Implant Programme to identify when children are not making expected progress; to plan joint packages of intervention and to ensure long-term use of the implant (Archbold et al, 2009).

2.3.1 Outreach work

Outreach support from ICTODs provides an invaluable opportunity for collaborative working and for the transfer of information, skills and knowledge between the implant centre, implant users, their families and local professionals. Each individual cochlear implant programme will have its own protocol in place for their visit aims, format, content agreed schedules and subsequent reporting. Children are seen in a range of different settings and at different intervals pre and post implant. The ICTOD is the key link between families, education services and the cochlear implant programme.

2.4 Recommended ICTOD Input

Each implant team will decide how ICTOD time is allocated both pre and post-implant and this will be closely linked to the team's chosen model(s) of service delivery. ICTODs will be involved in an intensive initial re/habilitation phase and in long term post implant monitoring, to support long term use of the cochlear implant (Archbold et al, 2007, 2009). Teams will establish their own protocols for long term monitoring.

Some flexibility is required to ensure that individual needs are met.

Factors that may influence the amount of ICTOD input needed include:

- Setting up and monitoring a hearing aid trial
- Liaising with local services re the choice, use , initial set up, daily management and subsequent monitoring of ALDs, and in particular establishing whether interference is an issue
- Liaising with local services to evaluate and improve listening environments
- Working with children and young people who have a second sequential cochlear implant. This will require additional time to establish consistent use of the second implant and to test separate ears in clinic based or outreach settings
- Working with children with additional or complex needs alongside deafness; this will require a high level of liaison with other professionals across a range of disciplines
- Working with children who make slower than expected progress; this will require additional input and liaison
- Working with multi-lingual children and their families
- Working with children who experience unusual events linked to their device, such as failure and reimplantation, alongside their families and local professionals
- Contributing to the statutory assessment process and SEN annual review meetings and tribunals
- Providing information on requirements of an educational setting to ensure best practice and support for cochlear implant users.

2.5 Quality Standards

At an interdisciplinary level the ICTOD will be asked to contribute to the cochlear implant team's protocols and pathways which are reviewed in the light of developing clinical evidence. ICTOD meetings are arranged twice yearly to share best practice between cochlear implant programmes across the UK.

ICTODs should be aware of Quality Standards for Paediatric Audiology and Cochlear Implantation (NDCS 2005), Local Educational Services and FM systems (NDCS 2008), Quality Standards for Specialist teaching and support services for deaf children and young people (NDCS 2009), Quality Standards – Cochlear Implants for children and young people (NDCS 2010), Quality Standards in the Early Years – guidelines for working with deaf children under 2 years old and their families (NDCS 2003, England/Northern Ireland/Wales versions), Quality Standards – Transition for paediatric to adult audiology services (NDCS 2011) and also Early Monitoring materials used by local Teachers of the Deaf.

2.6 Clinical Audit & Outcome Measures

Clinical audit is an integral part of work both within NHS and non NHS based CI programmes. It provides an opportunity to evaluate, review and improve ICTOD input to the multidisciplinary team. ICTODs routinely record outcome data relating to the child's CI processor use, listening, speech perception, speech and functional communication skills, as well as recording parental views and those of local professionals regarding satisfaction with the child's progress, equipment management and function. This data will enable ICTODs to make an informed holistic review of an individual child's progress and to conduct and contribute to team-based research and audits

3. WORKING ON THE COCHLEAR IMPLANT PROGRAMME

3.1 Experience and Skills of the ICTOD

The ICTOD will be a qualified Teacher of the Deaf. The ICTOD should have a suitable breadth of experience working with deaf babies, children, young people and children with complex needs, and their families. On-going professional development is a requirement for the ICTOD in order to keep up to date with developments in the field.

All newly appointed ICTODs must have access to an experienced ICTOD and have a clearly defined induction, training and supervision programme.

The ICTOD must have the requisite clinical skills to assess and develop

- Functional listening
- Speech perception skills
- Functional use of spoken language in a variety of settings
- Everyday communication and social skills
- Consistent use of the cochlear implant in a variety of settings
- Local maintenance of the device in good working order

The ICTOD must also have:

- An in depth knowledge of cochlear implant technology and an appropriate knowledge of audiology, hearing aids and ALD management
- A full understanding of the impact of deafness on language development, functional communication and educational achievement
- Knowledge of educational policies and practices both locally and nationally
- An understanding of the impact of background noise on listening
- An understanding of Deaf culture and language
- An understanding of the impact of deafness on families in the short and long term
- Skills in Alternative modes of communication such as Sign Language
- Excellent Interpersonal skills
- Counselling skills

- An understanding of the impact of deafness on quality of life

3.2 Assessment

ICTOD assessment begins with a case history and where appropriate, includes information about the impact of the hearing loss on the family and the provision of local educational support. The ICTOD contacts the local Teacher of the Deaf to involve them in the assessment process. The ICTOD provides support to families.

Assessments are administered pre-implant to contribute to decision-making and to establish baseline measures and these are repeated post-implant to monitor progress. The child's listening, speech perception, speech and communication skills may be assessed using a combination of observation, discussion, and formal and informal assessment in the clinic setting and in the local environment. The exact battery of assessments may vary from team to team.

Assessment results will be shared with the child (where appropriate), their family, the implant team and local professionals. They will be used to discuss the likely outcomes post-implant and to contribute to a care plan. Goals may be set collaboratively with local professionals.

3.3 Re/habilitation

The aim of re/habilitation is to ensure optimal benefit of the cochlear implant system for each child; to develop listening, speech perception, speech and functional communication skills. It will be important to ensure that the child's implant system is being managed appropriately at home and in educational settings so that it functions optimally at all times. It will also be necessary to monitor and advise on listening conditions and the provision of ALDs. Re/habilitation will vary depending on the service delivery model employed by the team and on the individual needs of the child.

Individual teams may establish protocols to identify those children who do not make the expected progress post implantation (Red Flags or similar) and to offer further diagnostic assessment and intervention as appropriate.

3.4 Report Writing & Record Keeping

ICTODs keep detailed notes and provide written reports at regular intervals to the child's family/carers and other professionals. The purpose of these reports is to convey information about the child's progress and to provide recommendations about future management. The frequency and format of reports may vary according to team protocol. ICTODs may contribute a written submission if requested by a local authority or similar body.

3.5 Training Role

ICTODs provide training for a broad range of professionals, including cochlear implant team members, local Teachers of the Deaf, teachers and other education and NHS and social care professionals. ICTODs also provide training for families and carers. ICTODs present at formal courses, academic meetings and conferences. More experienced ICTODs act as mentors for newly appointed ICTODs, providing regular contact for discussion and peer support.

4. CONTINUING PROFESSIONAL DEVELOPMENT

4.1 Ongoing Education Needs of the ICTOD

The research and knowledge base in the area of cochlear implantation is expanding rapidly and ICTODs need continuing professional development to remain at the forefront of the field. Access to established post-qualification courses is essential for the ICTOD. Attendance at national and international meetings, conferences, seminars, specific interest groups, BCIG meetings and ICTOD meetings will offer further necessary professional development opportunities.

4.2 Research and Development

The ICTOD has an active role in research and development. Research is used to monitor trends and develop innovative assessment and rehabilitation techniques and procedures. The ICTOD must be given adequate support for research through the allocation of study time and resources.

5. SOURCES OF INFORMATION

Refer to the BCIG website (www.bcig.org.uk) to find the contact details for implant centres throughout the UK.

Additional information regarding Cochlear Implants, management and intervention can be found on the following websites:

Advanced Bionics (Cochlear Implant Manufacturer) www.bionicear.eu

Cochlear Corporation (Cochlear Implant Manufacturer) www.cochlear.com

MEDEL (Cochlear Implant Manufacturer) www.medel.com

Neurelec (Cochlear Implant Manufacturer) www.neurelec.com/en

British Cochlear Implant Group (Professional organisation) www.bcig.org

Cochlear Implanted Children's Support Group (CICS) www.cicsgroup.org.uk

National Cochlear Implant User Association (NCIUA) www.nciua.org.uk

The Ear Foundation www.earfoundation.org.uk

National Deaf Children's Society www.ndcs.org

Sounding Board www.soundingboard.earfoundation.org.uk

2 ears to hear www.2ears2hear.org.uk

UK Council on Deafness - Working with children who experience device failure and reimplantation www.deafcouncil.org.uk

6. REFERENCES

Archbold SM, Nikolopoulos TP, Lloyd-Richmond H. (2009). **Long-term use of cochlear implant systems in paediatric recipients and factors contributing to non-use.** *Cochlear Implants International.* 10 (1) 29-40

Archbold S, O'Donoghue G (2007) **Ensuring the long-term use of cochlear implants in children – the importance of engaging local resources and expertise,** *Ear and Hearing.* Vol 28, no 2, 3s-6s

Colletti V, Carner M, Miorelli V, Guida M, Colletti L, Fiorino FG. (2005). **Cochlear Implantation at under 12 months: report on 10 patients.** *Laryngoscope, 115(3):445-9*

Dettman, S (2004) **Speech Perception Results for Children Using Cochlear Implants Who Have Additional Special Needs.** *Volta Review; 361-392*

Dettman, SJ; Pinder, D; Briggs, RJ.; Dowell, RC.; Leigh, JR. (2007) **Communication development in children who receive the cochlear implant younger than 12 months: risks versus benefits,** *Ear & Hearing: Vol 28 - Issue 2 - 11S-18S*

Edwards, L. (2007). **Children with cochlear implants and complex needs: A review of outcome research and psychological practice.** *Journal Deaf Studies and Deaf Education.* 12 (3): 258-268.

McCracken, W & Turner, O. (2012). **Deaf Children with Complex Needs: Parental Experience of Access to Cochlear Implants and Ongoing Support.** *Deafness and Education International,* 14 (1): 22-35

TAIT, M. (2010) **Bilateral versus unilateral cochlear implantation in young children.** *IntJnl Paed Ototorhinolaryngology.*74; 206-211

Fitzpatrick E, Mcrae R, Schramm, D. (2006) **A retrospective study in cochlear implants in children with residual hearing.** *Ear, Nose and Throat Disorders.*

Speers A, Jeffers E, McCready V, Toner J, McAnallen C. (2010). **Challenges Faced in the Management of Cochlear Implanted Children with Severe Learning Difficulties.** *Cochlear Implants International;* 11(s2):74-79

Quality Standards

National Deaf Children's society (NDCS)

Quality Standards: Cochlear Implants for Children and Young People (2005), Joint Revision by The National Deaf Children's Society & British Cochlear Implant Group. www.ndcs.org.

Quality Standards for the use of personal FM systems (2008). www.ndcs.org.

National Institute for Clinical Excellence (NICE)

Cochlear implants for children and adults with severe to profound deafness (2009).

Newborn Hearing Screening Programme (NHSP)

NHS Newborn Hearing Screening Programme. Quality Assurance Report 2006-2008 (2008).

University of Manchester.hearing.screening.nhs.uk

Newborn hearing screening; Cochlear Implant referral- Care Pathway 7.

Development of Guidelines

The original document was published in 2003 and distributed to Teachers of the Deaf via the BATOD Magazine and freely from BCIG via the Implant Centres.

The Guidelines were written by Implant Centre Teachers of the Deaf (ICTODs) in consultation with British Association of Teachers of the Deaf (BATOD) and British Cochlear Implant Group (BCIG) and revised in 2014.