Quality standards for habilitation of young deaf children receiving cochlear implants

Objective

These quality standards for habilitation of young deaf children receiving cochlear implants are developed within the European KA202 Erasmus+-project 'VOICE', Ref. no.: 2020-1-RO01-KA202-080059.

The main objective of the VOICE-project was to offer vocational education and training for speech and language therapists (SLT) and parents for teaching children with cochlear implants (CI) how to speak. One of the aims was also to identify guidelines for good practice that will help service providers to maintain and improve their standards and quality service provision for young deaf children receiving CI.
Although the term 'rehabilitation' is often used in scientific publications, we decided to use the term 'habilitation', because young deaf children receiving cochlear implants don't regain skills or abilities, but they will acquire these skills for the first time. Habilitation refers to health care services that help a person acquire, keep or improve, partially or fully, skills related to communication and activities of daily living. These services address the competencies and abilities needed for optimal functioning in interaction with their environments. Rehabilitation refers to regaining skills, abilities, or knowledge that may have been lost or compromised as a result of illness, injury, or acquiring a disability. (1)

The aim of habilitation of young CI-children is to ensure optimal benefit of the cochlear implant system for each child; to develop listening, speech perception, speech and functional communication skills. We now see huge variabilities in outcomes, depending on the knowledge and expertise and on the service delivery model employed by the team and on the individual needs of the child. Habilitation can be provided on an individual basis and through group work, in a live session or by using tele-practice.

Vocational education and training for speech and language therapists and parents for rehabilitation of children with cochlear implant on how to speak

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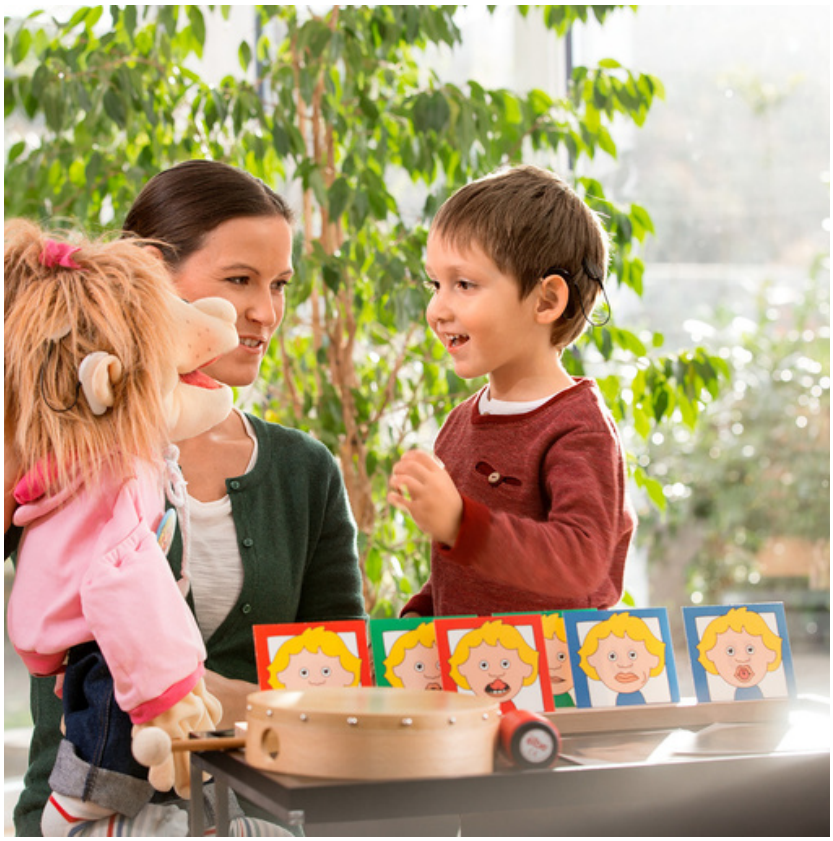

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Methods

To develop these quality standards we used the input from the interviews of of 11 local habilitation experts (2) from the 4 partner countries and the outcomes of a systematic review and on the outcomes of a systematic review of 848 publications retrieved from 6 databases: Pub Med, Psych Info, CINAHL, Scopus, Eric and Cochrane.

Based on all this information, we created a list of 32 quality standards over 4 domains: general quality standards, quality standards on fitting, quality standards on habilitation, quality standards for staff.

Further on, the Delphi method approach was used by 18 international habilitation specialists (3) to discuss and agree on these quality standards. Finally > 90% of the international experts agreed on 28 quality standards, of which most of them contain some subcategories.

Results

These quality standards on habilitation of young deaf children receiving CI propose the optimal provision of young deaf children receiving CI: the expertise necessary for their staff and describe important facilities and resources that CI-teams should possess or have access to. They focus on different aspects of habilitation: the multidisciplinary team, their expertise and knowledge, important habilitation topics to focus on, programming issues related to habilitation, etc.

This set of quality standards for habilitation of young children receiving CI's can help health care systems and more specific the CI-teams to provide comprehensive and state-of-the-art post-operative care for young deaf children receiving cochlear implants. By using these quality standards, they will be able to improve their quality service provision for young deaf children receiving CI, which will result in better outcomes.

Notes:

(1)New York State Speech, Language and Hearing Association, 2012, adapted from Fed. Reg. 52530; NAIC Glossary of Health Insurance and Medical Terms: 3

(2) Local experts: Martine de Smit (Belgium); Marlies Oyen (Belgium); Kirsten Gennotte (the Netherlands); Pedro Brás da Silva (Portugal); João Eloi Moura (Portugal); Camelia Oana Radu (Romania); Ady Cristian Mihailov (Romania); Crăescu Adina (Romania); Elena Macovei (Romania); Mariana Pop (Romania); Theodor Sirbuletu (Romania)

(3) International experts: Cheryl Dickson (Australia); Diana Zegg (Austria); Mila de Melo (Canada); Uwe Martin (Germany); Shirly Kaplan (Israel); Anneke Vermeulen (the Netherlands); Camelia Rusu (Romania); Mihaela Alexandru (Romania); Gal Katalina (Romania); Ion Mihaela (Romania); Theodor Sirbuletu (Romania); Mariana Pop (Romania); Luciana Frumos (Romania); Louise Ashton (South Africa); Manuel Manrique(Spain); Teresa Amat (Spain); Tricia Kemp (UK); Mihaela Fotescu Zamfir (UK).

1.GENERAL QUALITY STANDARDS FOR PAEDIATRIC COCHLEAR IMPLANTATION IN RELATION TO HABILITATION

Voice COCHLEAR IMPLANT REHAB

1. Providing a child with a cochlear implant requires a dedicated multidisciplinary team consisting of at least an ENT-surgeon, audiologist and a speech and language therapist.

- Ideally there should also be a psychologist and social worker included in the team.
- The multidisciplinary team should work interprofessionally (not next to each other but together) and in close cooperation with the parents/carers.
- The multidisciplinary team will liaise and work with the child's local professionals.

2. The CI-team of the hospital should coordinate the selection, surgery, fitting, habilitation and after care (equipment maintenance, spare materials).

3. Parents/carers need balanced and unbiased up-to-date information about cochlear implants and the fitting/habilitation process.

- Ideally in their language.
- Parents/carers should get appropriate counselling from the CI-team and other professionals to have appropriate expectations from the CI, depending on several variables such as age at implantation or additional disabilities.
- Parents/carers should have the opportunity to meet other families with CI children.
- Parents/carers also need psychological support: taking care of their emotions and stress.

4. Habilitation should be delivered by the CI-team in close cooperation with a local expert (team) in listening and spoken language development. (see quality standard # 28).

5. Habilitation is not possible without parent/family/caregiver involvement.

- In case parents or legal guardians are not able to be actively engaged in the child's habilitation due to very low Social Economical Status, mental health matters, or cognitive delays, other family members or carers should be involved.
- Professionals should use a child/family centred approach.

6. The cochlear implant surgery should take place as soon as a child is identified as a candidate and should ideally be done by the age of 12 months or sooner, preferably under the age of 36 months, without excluding children who are older than 37 months.

7. A child with a bilateral severe to profound hearing loss should be fitted bilaterally with cochlear implants, preferably before the age of 18 months.

- We expect all countries to follow the principles and guidelines of the Joint Committee on Infant hearing to have early hearing screening (before age 1 month), diagnosis (before 3 months) and start with habilitation (fitting hearing aids and early intervention) before 6 months of age.

8. The CI-team will issue or dispatch replacements for faulty external equipment within two working days.

- There should be a written policy regarding who is responsible in the event of loss/ damage and what spares can be provided as a matter of routine.

9. Arrangements should be in place to upgrade each child's sound processor every 5 years.

10.The implant programme should perform and publish yearly audits and comply with the requirements of the responsible national authorities.

- Audits should cover: clinical activity, staffing levels of expertise, child's performance outcomes, medical and surgical complications, device failures, research outcomes and child and family/caregiver feedback on the service provided.
- The audits should become freely available to interested parties.

2.QUALITY STANDARDS ON FITTING/PROGRAMMING IN RELATION TO HABILITATION

11.The fitting of the sound processor should be carried out by qualified paediatric audiologist preferably in clinic, face-to-face rather than remotely.

12.There should be a liaison between the audiologist of the CI-team and the local habilitation expert (and vice versa) to exchange information about the progress of the child's auditory skills.

- It is recommended that local professionals receive written reports on the child's auditory performance.

13. Instructions on the use of the sound processor must be given to the parent/caregiver on or before the day of activation, and should be repeated at least twice within the six months following activation.

- This is within the role of the audiologist and the habilitation therapist.
- Supporting materials on the handling, operating and care of the sound processor should be issued to the parent/carer.
- The recommended use of assistive listening accessories (eg AudioStream, Mini mic, Roger,...) should be explained to the parent/carer by the CI team (see Quality standard #1) before the CI surgery and the information reviewed after the activation.

14. Appropriate audiological, standardised speech perception tests and functional hearing assessment (by questionnaire) should be performed at 6 months intervals to enable hearing to be monitored.

- It is recommended to assess speech perception with standardised tests and a functional hearing questionnaire. Ideally: every 6 months in the first 2 years after the cochlear implant activation and then every year minimum of once a year.
- Measuring speech perception of soft speech and in noise should begin after two years of CI use.
- The results should be shared with the child's parents/carers and local professionals.

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3.QUALITY STANDARDS ON HABILITATION OF YOUNG CHILDREN RECEIVING COCHLEAR IMPLANTS

15. Habilitation should begin before implantation and at the latest immediately after initial fitting, according to the individual needs of the child.

- Even if habilitation does not start until initial fitting, written material about the content of habilitation should be shared with the parent/carer well before initial fitting, so that they have a good idea of what is needed to stimulate the child's listening and spoken language development.

16. Parents/carers are considered and valued as equal partners in the habilitation process of their child.

- Parents/carers must have equal access to information on CI in their preferred language.
- CI companies should make their brochures available in the preferred language of the parents/carers.

17. Appropriate measures should be performed yearly (ideally every 6 months) to monitor progress in language, communicational and educational outcomes the first 3 years after implantation.

- Standardised assessments for typical hearing children should be used for comparisons.
- Additional habilitation and/or referrals should take place where progress is slower than expected.

18. A diagnostic coaching approach to CI habilitation yields the most efficient and best benefit, both to children and to parents/carers and teachers.

- Additional needs should be identified as soon as possible, so habilitation and expectations can be adapted to the special needs.
- Additional specialists in other fields can be incorporated into the team to share their expertise.

19. The audiologist and habilitation therapist together with the parents should decide on the frequency of specialist contact sessions for fitting and for habilitation based on the individual needs of the child and their family.

- As the recommended approach of services is family-centred, it is understood that habilitation therapy sessions can take place weekly or fortnightly, considering that most listening and spoken language experience will occur at home between the sessions.

20. Children with cochlear implants should have annually the opportunity to trial and assess assistive listening devices (FM-systems, Bluetooth accessories,...).

21. Habilitation of young CI-children should involve collaboration between the CI Centre, local professionals and parents/carers to cover the following areas:

- Listening skills / functional listening / speech perception; Speech intelligibility, voice quality and prosody; Communication skills including repair strategies; All aspects of language development; Theory of Mind development; Ability to troubleshoot and maintain external equipment; Using assistive listening devices; Music; Literacy (reading); Cognitive skills (Executive Functions); Mainstream education (inclusion); Advocacy.

22. Although services differ based on each child's current level of performance, it is recommended that children receive listening and spoken language therapy after implantation to maximize benefit from the cochlear implants, even those who benefit little from CI and who are anticipated to still be sign reliant.

- Among all auditory-based early intervention approaches for children receiving CI, evidence based practice has proven that an approach focusing on listening and spoken language has the most impact on the child's speech perception skills and expressive spoken language development.
- The decision to add signed support or sign language in the habilitation therapy will be discussed among parents and professionals so parents can make an informed decision.

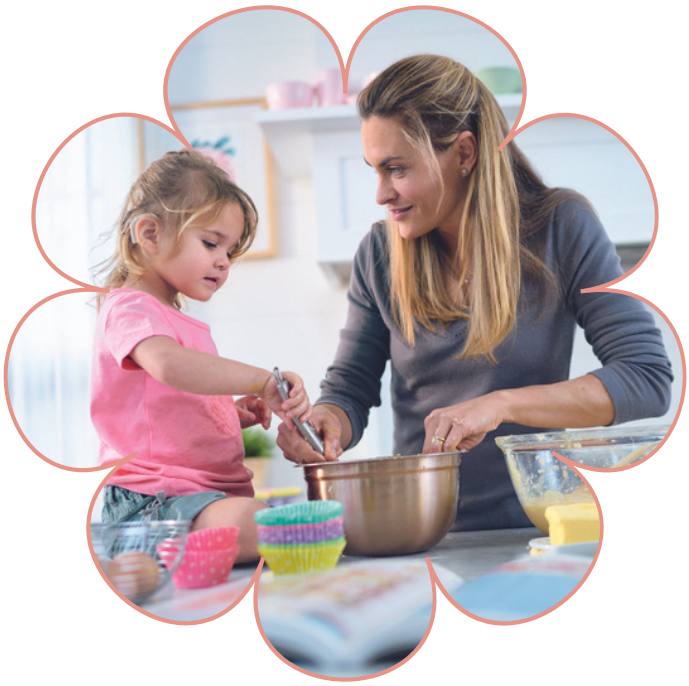
23. Habilitation therapists and parents/ carers will collaboratively generate measurable and appropriate goals in all areas of the child's development.

- auditory, receptive and expressive language, speech, cognition, and social skills should be measured, and therapist should identify ways to integrate the goals and strategies to achieve them in a nurturing and rich language.

24. Music should be integrated in the habilitation of young children using cochlear implants, particularly as a home based fun activity rather than in a formal setting.

4.QUALITY STANDARDS FOR PROFESSIONALS IN RELATION TO HABILITATION

25. Every country should have training opportunities for professionals in the various communication approaches (from auditory verbal to sign bilingualism) to become an expert in the field of habilitation and education of CI-children.



26. The staff of the CI team in the hospital and local habilitation therapists should have the knowledge and expertise that enables them to work effectively with children wearing cochlear implants, including those with additional needs in addition to their hearing loss.

- Some very complex children may need a very specialist service.

27. Habilitation of young CI-children should be carried out by an expert in promoting listening, speech and spoken language development, in managing the technology and the environment.

- The therapist should also have expertise in coaching and counselling parents.
- The therapist should also have expertise in a family-centred approach.

28. The expertise of the habilitation therapist/habilitation team should include the following skills:

- Expertise and skills working with infants and very young children (for paediatric services).
- Expertise in auditory development and listening skills.
- Knowledge on how to manage the technology.
- Knowledge on how to manage the acoustics of the environment and on how to address challenging listening situations (e.g., assistive listening devices).
- Understanding of the impact of deafness on the child's overall development (e.g., mental health, language, speech, cognition, social, and literacy) and on how to support these skills.
- Understanding of the impact of deafness on communication development, mental health, social and emotional well-being.
- Understanding and knowledge of communication support teams i.e. note takers, speech to text or sign language interpreters.
- Knowledge of audiology and assistive listening technology.
- Insight into the culture and language of the Deaf community.
- Knowledge on how to coach/guide families.
- Knowledge on inclusion of a CI-child (in education and in the local environment).

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