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SOCIAL AND ENVIRONMENTAL FACTORS AFFECTING COMMUNICATION HEALTH IN CHILDREN WITH COCHLEAR IMPLANTS: REPORT OF A PILOT STUDY

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Abstract

Introduction: This report summarises the pilot phase of a project, conducted at the World Hearing Center, Warsaw, Poland, on the role of social and environmental factors in the development of communication health in children with congenital deafness following cochlear implantation. This study validated the interview protocol, assessed the ICF-CY framework (International Classification of Functioning, Disability and Health, Children & Youth version), and identified preliminary social determinants.

Material and methods: The pilot study employed in-depth interviews (IDI) with 21 children with a CI and 20 of their parents. The interview framework was developed based on the ICF-CY framework. Qualitative analysis enabled the identification of key areas relevant to the development of communication health in children with a CI, including the school environment, social functioning, self-perception of disability, and parental involvement. The sample was selected using knowledge of the patient population attending the World Hearing Center, taking into account age at implantation, gender, and the absence of comorbid conditions.

Results: Development and validation of the research tool: an interview framework for children with a CI and their parents or caregivers is presented. Data indicate that the school environment, including peer relationships and teacher support, was the most frequently identified factor affecting the quality of the children's daily functioning. The children perceived their disability in varied ways, with most not identifying themselves as disabled, which highlights the need to reconsider traditional definitions of disability. Parental involvement and technical challenges related to the use of speech processors also emerged as important themes in user responses.

Conclusions: The pilot study confirms the value of using the ICF-CY as a framework for examining social factors that affect communication health in children with a CI. It also highlights the importance of an interdisciplinary approach and the need to incorporate psychosocial and environmental factors into the care of children with a CI. The findings point to the necessity of further research and the development of holistic support models tailored to this specific patient population.

Keywords: cochlear implant • interdisciplinary research • children with congenital deafness • ICF-CY • pilot study

ŚRODOWISKOWE CZYNNIKI SPOŁECZNE W KSZTAŁTOWANIU ZDROWIA KOMUNIKACYJNEGO U DZIECI Z IMPLANTAMI ŚLIMAKOWYMI: RAPORT Z BADANIA PILOTAŻOWEGO

Streszczenie

Wprowadzenie: Niniejszy raport podsumowuje wyniki pilotażowego etapu projektu „Rola społecznych i środowiskowych czynników w rozwoju zdrowia komunikacyjnego po wszczepieniu implantu ślimakowego u dzieci z wrodzoną głuchotą”, realizowanego w Światowym Centrum Słuchu (WHC) w Warszawie/Kajetanach, na temat roli czynników społecznych i środowiskowych w kształtowaniu zdrowia komunikacyjnego u dzieci z wrodzoną głuchotą po wszczepieniu implantu ślimakowego (CI). Badanie pilotażowe służyło walidacji i dopracowaniu scenariusza wywiadu, ocenie przydatności koncepcji ICF-CY jako podstawy metodologicznej badania oraz uzyskaniu pierwszych wyników dotyczących czynników społecznych wpływających na zdrowie komunikacyjne dzieci z CI.

Materiał i metody: Wywiady przeprowadzono z 21 dziećmi i 20 rodzicami. W badaniu zastosowano pogłębione wywiady (IDI) z 21 dziećmi z CI i ich 20 rodzicami. Scenariusz wywiadów został opracowany w oparciu o koncepcję ICF-CY. Analiza jakościowa umożliwiła identyfikację kluczowych obszarów mających znaczenie w kształtowaniu zdrowia komunikacyjnego dzieci z CI, w tym środowiska szkolnego, funkcjonowania społecznego, samooceny niepełnosprawności i zaangażowania rodziców. Próbkę do badania wybrano na podstawie wiedzy o populacji dzieci poddanych implantacji w Światowym Centrum Słuchu (WHC) z uwzględnieniem wieku w chwili implantacji, płci oraz braku współistniejących chorób i zaburzeń.

Wyniki: Dopracowanie i walidacja narzędzia badawczego: scenariusz wywiadu z dzieckiem z CI oraz jego rodzicem/opiekunem. Dane uzyskane podczas badania pilotażowego wskazują, że środowisko szkolne, w tym relacje z rówieśnikami i wsparcie nauczyciela, było najczęściej identyfikowanym czynnikiem wpływającym na jakość codziennego funkcjonowania dzieci z CI. Dzieci w zróżnicowany sposób postrzegały swoją niepełnosprawność, a większość nie określała siebie jako osoby z niepełnosprawnością, podkreślając potrzebę redefinicji tradycyjnego rozumienia pojęcia niepełnosprawności. Z wypowiedzi użytkowników wynika, że istotnymi czynnikami są również zaangażowanie rodziców i wyzwania techniczne związane z wykorzystaniem procesorów mowy.

Wnioski: Pilotaż potwierdza użyteczność wykorzystania ICF-CY jako ramy w badaniach czynników społecznych wpływających na zdrowie komunikacyjne dzieci z CI. Podkreśla także znaczenie podejścia interdyscyplinarnego oraz potrzebę uwzględniania czynników psychospołecznych i środowiskowych w opiece nad dziećmi z CI. Wyniki wskazują na konieczność prowadzenia dalszych badań i opracowania holistycznych modeli wsparcia dostosowanych do tej populacji pacjentów.

Słowa kluczowe: implant ślimakowy • badania interdyscyplinarne • dzieci z wrodzoną głuchotą • ICF-CY • badania pilotażowe

Introduction

This report presents the results of the pilot phase of an interdisciplinary project “The Role of Social and Environmental Factors in the Development of Communicative Health after Cochlear Implantation in Children with Congenital Deafness,” conducted at Poland’s World Hearing Center (WHC) in Kajetany. The pilot study’s aims were three-fold: to test a new interview framework for children with cochlear implants (CIs) and their caregivers; to assess the applicability of the ICF-CY framework developed by the United Nations as the methodological foundation of the study, and to gather initial data on factors affecting the development of communication health in young CI users. Insights gained from the pilot will guide further refinement of the interview protocol and of an online questionnaire.

Our project combines audiological, medical, and sociological aspects to provide a multidimensional assessment of the communication health of children with CIs. Future phases will expand the study sample and analyse the impact of each dimension on long-term outcomes. In this way we aim to develop comprehensive guidelines for practitioners, schools, and families for maximising CI benefits and for developing communication health.

Project context

To better understand our approach, we first outline current knowledge regarding cochlear implantation in children. Research confirms that early implantation, especially before 3 years of age, significantly increases the likelihood of developing typical language, perception, and social interaction [1,2]. Children implanted early generally have better speech comprehension and production, and perform better in social settings compared to those implanted later [3,4].

However, even when children have similar medical profiles, there is considerable variability in outcomes, affected not only by technical and medical factors but also by psychosocial and environmental conditions [5]. Key influences include age at implantation, family environment, peer and school support, communication methods at home, and parental involvement. Recent studies highlight that social relationships – with parents, teachers, and peers – strongly affect language development and psychosocial well-being in children with a CI [6,7].

A holistic approach is increasingly recognised as essential, considering functional outcomes alongside psychosocial and environmental factors. The International Classification

of Functioning, Disability and Health (ICF) [8] and its Children & Youth Version [9] offer valuable frameworks for assessing and planning rehabilitation of CI recipients [10]. Important determinants of CI outcomes include age at implantation, medical comorbidities, social determinants of health, and bilateral versus unilateral implantation [11]. Early implantation and bilateral hearing are associated with better results.

According to the ICF and ICF-CY, good functioning requires not only an intact auditory system but also activity and social participation, which are shaped by environmental factors such as social engagement and system-wide support [12]. Previous research on adults with CIs has used the assessment protocol based on the ICF model to gauge CI outcomes and has demonstrated that CIs improve auditory performance, communication, and well-being [10,13,14].

Communication health and the social environment

Following the American Speech-Language-Hearing Association (ASHA), which defines communication health as an individual's or a group's collective speech, language, and/or hearing health and well-being [15], we propose a related concept of communication health. In the ASHA definition, communication health is extended from the individual to the population level, going beyond discrete biological processes to include social and ecological factors, so that optimal communication health is achieved through preventing and mitigating communication disorders while promoting effective communication. Building on this framework, we define communication health to be the individual's ability to use speech, language, and hearing to participate fully in social life. Within a modern public health model, this construct sees communication as a key determinant of health and not merely a clinical deficit. Reflecting this view, a recent paper calls for integrating speech, language, and hearing sciences into a systems-based approach in order to overcome communication barriers and promote social participation [16].

Impaired development of communication in early childhood poses significant risks to a child's health and well-being, limiting their social and relational engagement [17]. In other words, a child's language and communication skills are closely linked to their psychological and social functioning. According to the ICF framework, communication involves not only auditory function but also activity and participation, so that it depends on personal and environmental factors. Thus, communication health will encompass sensory and linguistic proficiency as well as the ability to engage in family life, schooling, and social interactions.

Children with CIs

For children with a CI, communication health is a complex, multidimensional construct having audiological, social, and psychological components. Despite technological advances and generally positive outcomes, children with CIs can still face communication challenges and limitations in social participation [18,19]. Parents and professionals share the challenge of supporting a child to achieve its full personal, educational, and social potential [20,21].

All this underscores the need for flexible, individualised support and making use of comprehensive assessments that include audiological, environmental, and psychological factors [6]. However, prior research has mainly focused on audiological and medical factors, often neglecting the social and environmental aspects. To date, the ICF-based protocol has not been systematically used to assess outcomes in children with CIs.

Our project uses the ICF-CY framework to analyse the social and environmental factors that affect the outcomes of cochlear implantation in children with congenital deafness. Our study employs a 360-degree interdisciplinary approach, combining audiological, medical, and sociological data.

Key dimensions

Based on the ICF-CY framework in the context of communication health (see **Table 1**), we identified four key conceptual dimensions for the study. (1) *School environment* – analysis of educational conditions and the availability of specialised support revealed the significant impact of the school environment on children's communication skill and emotional development (in the ICF framework: environmental factors). (2) *Social functioning* – sociological studies have highlighted the role of a child's peer interactions and participation in extracurricular activities in shaping their sense of belonging and social competence (in the ICF framework: activity and participation). (3) *Perception of one's own disability* – conversations with children indicated that many young patients do not identify with the concept of “a person with a disability.” This redefinition of self-identity is crucial for their self-esteem and motivation for further rehabilitation (in the ICF framework: personal factors). (4) *Parental involvement* – family support, both emotional and organisational, also emerged as a fundamental factor enhancing therapy effectiveness and overall satisfaction with implantation outcomes (again, in the ICF framework, these are environmental factors).

We hypothesise that social environmental variables – family and peer relationships, school and leisure functioning, and community engagement – significantly affect the benefits available from using a CI. Our 360-degree research strategy was to collect data from diverse respondents through in-depth interviews (IDI), focus groups, and computer-assisted web interviews.

Assumptions and expected outcomes

Our research was based on three core assumptions: (1) that social factors, such as support from family and friends, significantly affects CI outcomes over and above medical factors; (2) that active engagement in school and peer environments, combined with a positive self-identification, helps overcome limitations associated with deafness and hearing loss; and (3) that the ICF-CY framework provides an accurate and multidimensional assessment of functioning in children with CIs. We hope that our findings will contribute to the development of practical recommendations for families, educators, and professionals, while also promoting participatory approaches in pediatric research. Furthermore, adapting the ICF-CY tools to a

Table 1. Main conceptual dimensions and how they can be operationalised into a questionnaire

Dimension	ICF-CY concept	Details	Operationalised questions
Social activity and social functioning	Activity is a person's performance of a task or taking an action; activity limitations are the difficulties a person may have in acting	Includes verbal and nonverbal communication, coping with everyday life situations, and functioning at home, school, and within peer environments	<ul style="list-style-type: none"> • Communication patterns, the quality of communicating with others • The way free time is spent (alone or with others): e.g., watching movies, listening to music, sports • Dealing with usual and unusual situations • Functioning at home and outside the home (e.g., school, with peers) • Responsibilities at home and outside the home • Identifying what is easy, and what is difficult (when alone or with others), and why
Social participation	Participation is a person's involvement in certain life situations. Limitations to participation are problems that hinder a person. Engaging in life situations. Being included in a particular area of life, being accepted, or having access to needed resources	Involvement in family, school, and extracurricular events, participation in additional activities, as well as functioning in situations requiring increased auditory effort	<ul style="list-style-type: none"> • Involvement in family events • Involvement in school • Extra-curricular activities • Situations requiring auditory "effort"
Self-identification and identification by others	Two dimensions to understand the "if" and "why" disability is used in the way respondents describe themselves and how others describe them	Seeing oneself as a person with or without a disability. Perception by others from the perspective of disability	<ul style="list-style-type: none"> • Is a child with an implant a person with or without a disability? • What makes the child see/define himself this way? • How do others see the CI processor in the respondent? • What is a CI processor? (a body part or something artificial)

Polish context will help establish a common terminology for describing how children with CIs function, facilitating comparisons across centers and borders and improving support networks.

Ethical considerations

A full-scale research project "The Role of Social and Environmental Factors in the Development of Communicative Health after Cochlear Implantation in Children with Congenital Deafness," is scheduled for implementation at the World Hearing Centre between 2024 and 2027, and has received prior approval from its bioethics committee. Approval covers the study design, participant recruitment procedures, consent forms for parents/caregivers, and the data management protocol. Prior to each interview, parents or legal guardians provided written consent on behalf of both themselves and their child.

Material and methods

Study design

As part of the preparations for the full multi-year research project (2024–2027), an exploratory pilot study was conducted with the primary aim of developing, testing, and preliminarily validating an innovative research tool. This study, reported here, constitutes the first phase of the "360-degree" research strategy involving a comprehensive assessment of the functioning of children with CIs and incorporates perspectives from both patients and their parents.

This pilot was conducted at the World Hearing Center, a large clinical and scientific facility in Warsaw specialising in the diagnosis, treatment, and rehabilitation of hearing disorders. The pilot study took place from 2–5 September 2024 and involved a carefully selected group of 41 participants who met the inclusion criteria for the main project.

Special care was taken to create a welcoming and safe environment. Interviews were conducted in familiar spaces within the WHC. Children were given the option to participate in the interview either by themselves or in the company of their parent or caregiver.

The pilot involved several key stages:

- (1) *Development of the research tool.* Based on a literature review and consultations with experts, the structure of in-depth interviews and questionnaires was developed. They were grounded in the ICF-CY guidelines and the latest trends in hearing rehabilitation research.
- (2) *Tool testing in clinical settings.* Individual interviews were conducted with children and their parents, analysing the audiological, psychosocial, and environmental aspects of daily life.
- (3) *Preliminary qualitative and quantitative analysis.* The collected data was analysed to identify the strengths and weaknesses of the tool, assess the clarity of questions, and detect potential difficulties in

interpretations as well as in reactions of interviewers with related questions.

- (4) *Gathering feedback from participants and experts.* Following the initial work, consultations were held with participants and the research team, enabling improvements to be made to the tool before the main study is implemented.

The pilot study made it possible not only to verify the practical usability and validity of the research tool but also to identify key strengths, areas for improvement, as well as potential methodological barriers that might occur in the main project. The pilot results serve as a basis for optimising research procedures and ensuring the quality and reliability of data in the main project.

Participants

The pilot study involved 41 participants – 21 children with congenital hearing loss and 20 parents or legal guardians. The inclusion criteria for the children were congenital total deafness, age between 7 and 18 years, and at least 5 years of experience of using a CI. Additionally, to eliminate other factors that might affect the results, children with comorbid disabilities (such as neurological, intellectual, or motor disorders) were excluded. The children were divided into four groups, allowing for analysis that aims at understanding the functional development across stages of childhood and adolescence [22]: 7–9 years (children of early school age, at a stage of intensive development of basic language and social skills); 10–12 years (prepubescent period, characterised by increased independence and development of interpersonal skills); 13–14 years (early adolescence, a time of intense emotional and social changes); 15–18 years (late adolescence, preparation for adulthood and independence). **Table 2** shows the number of children in each age group.

Selection of participants was based on purposive criteria, using the patient database of the World Hearing Center, which ensured that the group was representative of children with congenital deafness who use CIs in Poland. We did not gather parents' ages; that will be gathered in the main study.

The range of ages allowed for a diverse range of experiences related to implantation and daily functioning to be captured, both in educational and social contexts. Parents and guardians involved in the study played a key role in providing information about the family environment, support, and observations of the child's development. They gave a complementary view of the child's situation and the factors impacting the effectiveness of implantation.

Research tools

To assess the functioning of children with CIs, an original structure for in-depth interviews was developed. It uses the methodological framework and guidelines of the International Classification of Functioning, Disability and Health – Children & Youth Version (ICF-CY). We focused on three key areas of functioning. The main conceptual dimensions are shown in **Table 1**, with examples of how

Table 2. Gender balance of completed pilot study interviews

Age group [years]	Girls	Boys
7–9	2	3
10–12	2	3
13–14	2	3
15–18	3	3
All	9	12

these were operationalised into a questionnaire. Detailing the whole tool requires further work, which is being done; here we describe it in general using only high level terms.

The interview structure was designed to enable a multidimensional analysis of the experiences of both children and their parents, considering audiological, psychosocial, and environmental aspects. The in-depth interview consisted of six logically connected stages, allowing for a gradual introduction of the participant to the research topic and an open exploration of key areas of functioning: (1) *Warm-up* – introductory questions aimed at building an atmosphere of trust, learning about the child's interests, and reducing stress related to participating in the study; (2) *Free time* – exploration of preferred ways to spend time outside of school, including recreational, sports, and social activities, as well as barriers to and opportunities for social participation; (3) *School* – analysis of educational experiences, relationships with teachers and peers, identification of hearing challenges in the school environment, and strategies used to manage them; (4) *Hearing situations* – detailed discussion of everyday situations requiring auditory effort, such as conversations in noisy environments, participation in group activities, and use of assistive devices; (5) *Child's "relationship" with the implant* – questions about the child's subjective perception of the implant, its role in daily life, feelings about using it, and any technical challenges; (6) *Conclusion* – summary of the conversation, opportunity for open expression about personal experiences, and suggestions regarding support and needs.

The tool is designed to collect rich qualitative data, allowing for a multifaceted analysis of factors surrounding the effectiveness of cochlear implantation, as well as the identification of individual and environmental barriers and resources supporting the development of children with implants.

Data analysis

Data analysis used a qualitative approach, utilising a carefully developed codebook consisted of two layers:

- (1) *Code categories (general topics)* – covering the main thematic areas emerging from the interviews, such as school functioning, peer relationships, leisure activities, social participation, perception of disability, technical challenges, and family support.
- (2) *Analytical codes (detailed)* – precise identifiers relating to specific aspects of participants' statements,

e.g., coping strategies in noisy environments, preferred forms of activity, particular technical difficulties related to the implant, or ways the child perceives themselves.

The interview transcripts were systematically coded. This enabled the identification of recurring themes as well as the most frequently mentioned topics and the unique, individual experiences of the participants.

Since a mixed-method approach was in place, quantitative analysis was also possible. A frequency analysis was conducted to identify the occurrences of specific categories and analytical codes. This allowed most significant topics and themes to be identified and allowed comparisons to be made between different age groups and between children and parents.

Finally, the data analysis was enriched through triangulation – comparing results obtained from different sources (children vs parents) – which improved the reliability and validity of the interpretations. This approach allowed the main analytical categories to be identified as well as capturing relationships and contexts that may help understand the factors influencing the outcomes of cochlear implantation in children.

Results

The pilot study enabled the development and preliminary testing of the interview framework specifically designed for children with CIs and their parents/caregivers. Assessment was also made of the applicability of the ICF-CY model as the appropriate methodological foundation. In this way, we were able to obtain valuable initial data on the social determinants of communication health in children with CIs, as follows.

Topics discussed

The content analysis of the in-depth interviews with children with CIs identified seven key topics that reflected the most important aspects of daily life and its challenges.

The most frequently mentioned topic was *school* (165 mentions). The children gave detailed descriptions of their experiences with learning, the relationships with teachers and peers, and strategies for coping with hearing difficulties at school. School-related topics encompassed both educational and social aspects, including their participation in lessons, school breaks, and extracurricular activities. Children mentioned classes they liked, such as: “I don’t like classes where you must write a lot, but computer science and P.E. are fine.” They mentioned issues they faced at school: “Sometimes I can’t hear well when the room is noisy, I have to concentrate more then.” Both were then subject to closer study among the research leaders to understand how it was possible to deepen understanding of how such answers can be used to increase the children’s quality of life (such as by increasing care).

The second most frequently discussed area was *leisure time* (63 mentions), during which children talked about their interests, favorite recreational and sports activities, as well

as how the implants affect their ability to participate in social life outside school. They mentioned that some activities required auditory effort while others provided a break from acoustic stimuli. For example:

- (a) “I’m putting together Lego, the latest set has 3000 parts. A couple of days it takes. Even when I went to a semi-college and ended at 5 p.m. It’s from 5 to 7 p.m. every day that’s how I put together for a week.”
- (b) “Well, yes, paint something on a piece of paper, make something out of boxes, some structures. Now we made such a house that you can enter it from a cardboard box, only it has already crumbled.”
- (c) “I [...] dance – a lot of people now do that on TikTok and that’s how they dance all these dances – so I do the same: I prepare the choreography and perform it, record it, and post it on TikTok.”
- (d) “Well a lot... I also train aerial acrobatics for example. I had my first class yesterday. But three years I’ve been training, only that the first classes sort of this year, from this school year. [...] In acrobatics there are such hanging wheels and still such sashes, on them you hang... we learn various flips, star without hands and such things.”

As with the previously described cases, the answers were the subject of robust discussion to see how they could be used in the ongoing study as well as improving quality of life and raise awareness (e.g. in parents and doctors).

Further relevant topics occurring in interviews included:

- *The child’s “relationship” with the implant* (54 mentions). This covered subjective feelings about using the device, the level of acceptance, technical challenges, and the implant’s role in daily life.
- *Perception of disability* (46 mentions). Here, children shared reflections on their identity, sense of difference (or lack thereof), and how they were perceived by others.
- *Peer relationships* (46 mentions). This focused on interactions with friends, experiences of inclusion or exclusion, and support from peer groups.
- *Hearing situations* (45 mentions). Children described everyday challenges related to sound perception, understanding speech in noisy environments, navigating various acoustic settings, and adapting to changing auditory conditions.
- *Technical aspects related to CI usage* (16 mentions). Children addressed practical issues such as operating the speech processor, managing technical difficulties, charging batteries, and maintaining the device.
- *Family* (12 mentions). Children highlighted support from close relatives, the role of parents in the rehabilitation process, and the importance of the home environment for their development.

- *The future* (5 mentions). Children shared their dreams, plans, and concerns about their future lives with an implant.

Such a broad spectrum of topics highlighted the complexity that children with a CI experience and the multidimensional nature of the factors affecting their functioning. The collected data provided a rich source of insight for further analysis, making it possible to identify both universal and individual needs and challenges.

Functioning at school

Functioning in the school environment emerged as the most frequently discussed topic in interviews with children with CIs, highlighting the significant role of school in their daily lives and social development. Participants were especially eager to talk about their favorite subjects, most commonly mentioning mathematics, English, and computer science (a total of 27 mentions). The children related how they performed well in these subjects, and their satisfaction with learning contributed to a positive attitude toward school.

Nevertheless, a significant portion of their responses described the hearing difficulties encountered in the school setting (15 mentions). The children pointed to challenges related to understanding speech in noisy classrooms, during lessons held in large groups, and in activities that required quick information exchange. They noted the need to use various compensatory strategies, such as asking teachers to repeat instructions, choosing seats closer to the teacher, or using additional learning aids. Some said that openness and understanding from teachers and classmates played a crucial role in overcoming communication barriers and building a sense of acceptance.

Many respondents also pointed to physical activity, especially sports and physical education classes, as their most enjoyable school activities. Sports were seen as a space where they could demonstrate skills that were independent of hearing, build peer relationships, and develop self-confidence. The children said that participating in sports activities allowed them to integrate more fully with the group and give them a sense of equality with their peers.

In summary, school for children with a CI is, on the one hand, a source of joy and satisfaction, and on the other, an area where they must face hearing-related daily challenges. Coping strategies, support from teachers, and the openness of the school environment to their needs are crucial.

Leisure time and activities

Analysis of the children's statements showed that time outside of school is a significant aspect of their daily lives, promoting both personal development and the formation of social relationships. The most frequently mentioned leisure activity was playing computer games (19 mentions). The popularity of this activity can be explained by its visual appeal, the ability to adjust the difficulty level to the individual, and – particularly important for children with CIs – the reduced need for intensive auditory interaction. Computer games offer children an opportunity to

engage in a virtual world where hearing barriers are less prominent, and success relies mainly on manual dexterity, reflexes, and logical thinking.

Among physical activities, soccer (12 mentions) was the most popular, as it not only supports motor development but also facilitates peer integration and the development of teamwork. Swimming (7 mentions) was another frequently chosen form of exercise, although some children pointed out technical limitations relating to non-waterproof processors, which sometimes hinder full participation.

Among activities that foster creativity and manual skills, children mentioned drawing and building with Lego bricks (6 mentions each). These activities allow for self-expression, the development of imagination, and spending time in a calm and relaxing way, regardless of hearing ability.

It is worth noting that the leisure activities chosen by children with CIs were quite similar to those preferred by their hearing peers, though they often consider specific needs and abilities related to their experience of deafness and implant use. These activities serve an important compensatory function, allowing children to develop in areas independent of hearing while also helping to build a sense of competence and belonging.

Perception of disability

One of the most important and surprising findings of the study was the significant diversity in how children with CIs perceive their own disability. Analysis of the statements revealed that the largest group of participants – eight children – did not identify themselves as individuals with a disability. These children said that, thanks to the CI, they could function in everyday life almost like their hearing peers, and that the differences resulting from their hearing loss are insignificant or even invisible to them. Their narratives included expressions indicating a sense of normality and full social integration, reflecting a high level of acceptance of their own health condition and technological support. For example, when asked “Do you see yourself as a person with a disability?” the children said: (a) “No. Because the people I’ve met don’t even notice it in me. And most people forget about it. Teachers are the same, because they even forget that I have it, because I function in such a way that it’s not visible.” (b) “No, but I know that I am a disabled person because I have implants. So I don’t consider myself to be an able-bodied person, but I know that I am disabled because I have implants. Well, I consider myself to be an able-bodied person.”

A second group, consisting of six children, displayed an ambivalent attitude, expressed in responses such as “both yes and no.” These children recognised certain limitations related to the implant and hearing loss but did not clearly define themselves as individuals with a disability. They often said their experiences were complex and context-dependent – in some situations, they felt “normal,” while in others, they encountered barriers or difficulties that could be perceived as expressing a disability. For example:

- (a) “Yes and no. That’s not a very good answer. Because yes and no, maybe I’ll start with no. No, because thanks

to that, thanks to my parents, thanks to everything they've done for me, I feel like a normal person who just comes here every year. It's like the only sign, and I function normally like my peers, sometimes better than them, sometimes worse than them. It's like thanks to that I feel normal, in the sense that I don't see myself as that kind of person. But when it comes down to it, for example, if someone starts pointing it out during an argument or discussion, or if I simply see such a situation and find myself in a situation where I am unable to do something because of these processors or this defect, then yes, I see myself as such a person."

- (b) "On the one hand, you could say yes, but on the other hand, I've learned a lot, so it's fifty-fifty. Well, for example, I can't do certain things, like swimming with the device, or I won't be able to hear, or... There's also the fact that some of my friends envy me because when I go to sleep, I can take off the device and go to sleep peacefully. Is that so cool? Sometimes my mom told me that it's dangerous because something could fall or start burning and I wouldn't hear it. But when my brother sleeps, I look at him and he sleeps like a log. But... You don't know if he would hear anything. Most of the time it's like that, but when I look at my parents, when I was little, I always shouted to my mom that I wanted to pee, or something else, or a drink, and my mom always got up. I often watch her, and she falls asleep, and is asleep in five seconds. I say, how do you do it, Mom? I don't know."

Only a small group – three children – unequivocally identified themselves as individuals with a disability. These children frequently pointed to specific challenges and limitations they experienced in daily life, both in terms of communication and social functioning. Their statements reflected an awareness of differences and difficulties that, despite technological support, continue to impact on their lives.

This diversity in how children perceive their own disability highlights the need to redefine traditional concepts of disability in the context of modern rehabilitative technologies such as CIs. It also underscores the necessity of an individual approach to psychosocial support that considers children's subjective experiences and self-identification, rather than relying solely on objective medical criteria. Understanding how children view their situation is crucial for effectively planning therapeutic and educational interventions that promote their development and social integration.

Technical challenges

Statements from the children clearly indicate that despite the significant benefits of using CIs, daily life with the device also involves several technical challenges. The most frequently reported issue was the lack of water resistance of the speech processors (16 mentions). This limitation effectively excludes children from many water-related activities, such as swimming, playing in the pool, or spontaneous play in the rain. For many young implant users, having to remove the processor before coming into contact with water is not only uncomfortable but also leads

to feelings of exclusion from their peer group, especially during school activities or group trips.

The second significant technical challenge was the need for frequent charging or battery replacement in the processor (8 mentions). Children pointed out that the device running out of power during the school day or while engaged in activities outside the home can lead to a sudden loss of connection to the world of sounds, causing stress and a sense of uncertainty. This required both them and their caregivers to constantly monitor the battery level and carry spares, which can be inconvenient and limit the spontaneity of daily life.

Another set of problems involved difficulties securing the processor (5 mentions). Children reported that the device can slip or shift during movement or physical activity and can be uncomfortable when worn for extended periods. These issues are especially noticeable during sports, active play, or when wearing headgear, which can negatively affect comfort and willingness to participate.

These technical challenges demonstrate that although cochlear implants provide new opportunities for development and social integration for children with congenital deafness, there is still a need for further technological improvements. Enhancements in water resistance, extended battery life, and improved ergonomics of the processor's attachment could significantly enhance the quality of life for young users and enable them to participate more fully.

Parents' perspective

Interviews conducted with parents and caregivers of children with CIs provided insight into a range of highly important aspects of treatment and rehabilitation that often lie beyond the direct experience of the children themselves. The parents emphasised the crucial role of early diagnosis, highlighting the importance of both newborn hearing screening and genetic testing, which enable the identification of causes of hearing loss and the prediction of the risk of hearing impairments in other family members. Many parents also shared their own experiences related to the history of hearing loss in their families, which affected their vigilance, prompt decision-making, and active pursuit of the best therapeutic solutions for their child.

A strong theme was the tremendous involvement of parents in the development of their CI-wearing child. Caregivers not only actively participated in rehabilitation but also undertook numerous actions to support the development of their children's communication, social, and emotional skills. They expressed the necessity for continuously monitoring progress, motivating their child to engage in work, and building a positive sense of self-worth.

Parents also shared their own strategies for coping with the challenges associated with hearing impairment within the family. These strategies included seeking support in parent groups for children with implants, utilising specialist consultations, and actively participating in their child's school and social life. Some parents highlighted the importance of educating themselves about implant technology, children's rights, and available system support.

A strong conviction was the need to implement comprehensive therapy that went beyond traditional speech therapy. Parents described the need to collaborate with a wide range of specialists: psychologists, educators, special educators for the deaf and hard of hearing, as well as sensory integration therapists. Many caregivers stressed that effective rehabilitation required a holistic approach, encompassing not only speech development but also emotional support, building social relationships, and developing coping skills for everyday challenges.

The parents' perspectives add valuable insight into how a child with a CI functions, extending over medical and genetic factors as well as psychosocial and organisational ones. Their experiences and involvement constitute a valuable source of support and inspiration for creating individualised and effective therapy programs.

Discussion

Use of the ICF in research on CI users

The ICF, together with its child-specific version (ICF-CY), constitutes a universal framework that encompasses all dimensions of human health and selected aspects of well-being. It is not restricted to individuals with disabilities; rather, it applies to all people, providing a comprehensive and standardised language for describing the full spectrum of health-related states. Notably, it conceptualises health in a positive sense, as the overall well-being of an individual, rather than merely as the absence of disease. It organises information in a structured, meaningful, and accessible manner for a broad range of users. The conceptual framework developed by Lorens et al. in 2014 [10] has been internationally validated and thoroughly reviewed by members of the HearRing Group – an international consortium of leading clinical and research institutions specialising in hearing disorders. In collaboration with Melissa Selb from the ICF Research Branch, this work has resulted in the development of a structured methodology for applying the ICF in a comprehensive and standardised manner within international, multicenter research studies [10].

Findings from previous studies [13,14] have demonstrated that the selected ICF categories and associated measurement tools provide a standardised and holistic framework for evaluating outcomes in adult CI users. This ICF-based protocol offers a common language that facilitates consistent assessment across both clinical practice and research contexts, enabling meaningful comparisons at national and international levels, as well as across individual and group cases. The clarity and universality of ICF-based outcome descriptions make them accessible to professionals beyond the field of cochlear implantation, thereby promoting interdisciplinary collaboration and enhancing the understanding of each patient's rehabilitation needs. Integrating this approach into routine clinical care supports a truly patient-centered rehabilitation model, one that considers not only impairments in body functions and structures, but also activity limitations, participation restrictions, and environmental factors. All of this ultimately contributes to improved outcomes for adult CI users.

At the same time, ICF-CY provides an adapted framework specifically suited for capturing the developmental and contextual complexities of pediatric populations. The ICF-CY enables a systematic evaluation of functioning at multiple levels, including body functions and structures (e.g., hearing ability, speech perception, sound localisation), activities (e.g., communication competencies), and participation (e.g., engagement in educational settings and family life). Crucially, it also highlights the role of environmental factors – both facilitators and barriers – that significantly affect the daily experiences, development trajectories, and rehabilitation outcomes of children with CIs. Therefore, in the current project, we are aiming to incorporate the ICF-CY into outcome assessments so as to promote a comprehensive understanding of a child's functioning. In this context, a child with a CI may be viewed as having a physical disability (unable to hear or hard of hearing without the implant), yet, with appropriate social, educational, and family support, they can achieve communication and social competencies comparable to those of their hearing peers. As a result, the concept of "disability" is redefined; it is no longer seen as a permanent limitation but rather the outcome of a dynamic interaction between the individual and their social environment. The ICF-CY categories selected for cochlear implantation provide a structured overview of key domains of functioning that should be assessed; importantly, however, they do not specify corresponding measurement tools [23,24], and this is where our project aims to fill the gap.

Conclusions

Our pilot study demonstrates how interdisciplinary assessment based on the ICF-CY model can be used to evaluate the way in which children with CIs function in daily life. Combining insights from children, their parents, and professionals can yield a rich, holistic view of children's experiences and, crucially, reveal important environmental factors that shape communication health after implantation. These factors go well beyond standard medical and audiological metrics and underscore the pivotal roles that social, emotional, and family contexts play in rehabilitation.

Our preliminary findings suggest that the success of a CI in fostering effective communication is linked, among other things, to:

- (1) *Parental involvement in the child's development.* The parents' active engagement, emotional support, and consistency in following through with therapy are essential for achieving the full benefits of an implant.
- (2) *Balance in leisure activities.* Leisure allows a child to pursue a variety of interests (both individual and group-based), promotes social integration, and helps build self-esteem.
- (3) *Strategies for coping with school challenges.* Support from teachers and the school environment helps minimise communication barriers and fosters full participation in classroom life.

- (4) *Redefinition of the concept of disability.* Modern rehabilitation technologies mean that an increasing number of children with implants do not perceive themselves as disabled, and this calls for a new perspective on what is needed to support them.

The next phases of the project, planned for 2024–2027, will involve a deeper analysis of the ways by which family, school, and peer environments affect long-term CI outcomes. It is hoped that the results will contribute to the

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