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## EARLY HEARING IDENTIFICATION AND INTERVENTION PROGRAMS: AN ITALIAN ANALYSIS

by *Eva Orzan*

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scale: introduction to an Italian study

Improving regional universal newborn hearing screening programmes in Italy

Childhood hearing surveillance activity in Italy: preliminary recommendations

Early definition of type, degree and audiogram shape in childhood  
hearing impairment

Aetiologic diagnosis of hearing loss in children identified through newborn  
hearing screening testing

Achieving effective hearing aid fitting within one month after identification  
of childhood permanent hearing impairment

Achieving early functional auditory access  
in paediatric cochlear implantation

Early care in children with permanent hearing impairment

Follow-up of permanent hearing impairment in childhood

Empowering the family during the first months after identification of permanent  
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# Early hearing identification and intervention programmes: an Italian analysis

## Preface

G. PALUDETTI

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Permanent deafness is the most common sensorial defect in childhood and predisposes to communicative-behavioural problems and impaired psychosocial conditions that can persist in adolescence and adulthood.

Universal Hearing Loss Screening (UNHS) programmes have already demonstrated their efficiency and quality. Many papers in the international literature have been published that demonstrate the efficacy of universal auditory screening in terms of quality of the child's life, economic costs and social consequences. It is necessary to ensure that every infant has an equal chance to receive an early diagnosis of hearing loss and early audiological rehabilitation to prevent disabilities related to auditory impairment and eventual general handicap.

At present, UNHS can be considered in most Italian regions as a major health advance. However, this screening the five not been uniformly and fully realised in all Italian regions. Many problems are related to the organisation of auditory screening and several criticisms remain to be resolved.

In March 2014, the CCM (Centro Controllo Malattie or Disease Control Centre) of the Italian Ministry of Health funded a project entitled "Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children". The project involved five tertiary centres with UNHS programmes formally approved by the Region of belonging. The centres involved in the projects are the following: (1) Audiology and Otolaryngology Unit, Department of Paediatrics, Research Institute and Hospital for Maternal and Child Health - IRCCS "Burlo Garofolo" – Trieste (Head of the Unit, Scientific coordinator and local supervisor of the project: dr. Eva Orzan); (2) Department of Head and Neck Surgery, Department of Head and Neck Surgery – Otorhinolaryngology Catholic University of the Sacred Heart "A. Gemelli" Hospital, Rome (Local Supervisor of the project prof. Guido Conti, Director of Department: prof. Gaetano Paludetti,) (3) Otorhinolaryn-

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The aim of the project is to ameliorate public healthcare practices on childhood deafness with special attention to diagnostic and treatment innovations, family empowerment, treatment alliance and interdisciplinary approach. The final purpose is to establish an integrated regionally-based public healthcare model for identification, diagnosis and intervention of childhood deafness.

The study group used SWOT analysis in order to identify current organisation's Strengths, Weaknesses, Opportunities and Threats. SWOT analysis is a structured planning method used to evaluate the strength (characteristic of a project that give an advantage over others), weakness (characteristic that place the project in a disadvantage if compared to others), opportunities (element that the project could exploit for an advantage) and threats (elements in the environment that could cause troubles) of the project. This kind of analysis serves to specify the objective of the project and to identify the internal and external factors that are favourable and unfavourable to reach the objective.

The first phase of the project, described in the following articles, investigates the state of the art of UNHS and leads to recommendations and standardisation to improve the identification, diagnosis, therapy and care of deaf children.

A specific target for SWOT analysis was identified for each area of childhood deafness. A group of competent professionals from the five tertiary referral centres performed nine different SWOT analyses to evaluate the or-

ganisational capacities and realistic possibilities for implementation of the project, especially concerning early intervention in all Italian regions.

The present monograph is divided into nine different chapters corresponding to the nine SWOT analyses performed by the different groups: planning early audiological programmes, screening, surveillance, audiological diagnosis, aetiologic diagnosis, hearing aid fitting, cochlear implantation, early care, follow-up and family support.

Each chapter has been written with great accuracy by a panel of experts and with an updated review of the literature. The result is a critical full paper for the reader who wants to learn more about the topic.

The requirements for effective organisation of the professional network have been detected in all nine analyses, stressing that communication and education are the fundamental strengths of organisational healthcare management for childhood deafness.

It is a privilege for me to be the Editor of this important monograph, and I appreciate the effort made by the working Italian group from five Italian research groups. I hope that this monograph will be useful to the Italian societies of otolaryngology and audiology, and to all specialists involved, in order to guarantee the implementation of early intervention programs in every Italian region and to improve the management of deaf children at all levels.

# Planning early childhood audiologic intervention programs on a regional scale: introduction to an Italian study

## *Pianificare su base regionale un programma di intervento audiologico precoce dell'ipoacusia infantile: introduzione a uno studio italiano*

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### SUMMARY

Non-uniform, late, or inappropriate care of childhood with permanent hearing impairment (PHI) predisposes many children to develop communicative-behaviour problems and impaired psychosocial adjustment that can persist in adolescence and adulthood. In March 2014, the CCM (Centro Controllo Malattie or Disease Control Centre) of the Italian Ministry of Health funded a project entitled "Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children". The project involved 5 tertiary centres with UNHS programs formally approved by the Region. The main purpose of the project is to define and launch an integrated regionally-based public health model for identification, diagnosis and intervention of childhood PHI. The first phase of the project investigated the state of art and produced recommendations for positive changes in identification, diagnosis, therapy and care of childhood PHI in Italy, taking into account diagnostic and treatment innovations, family empowerment, treatment alliance and an interdisciplinary approach. Recommendations drawn from this initial phase will represent the basis for a regional system for early intervention that is validated, integrated and shared between the five regions.

**KEY WORDS:** Universal newborn hearing screening • Childhood auditory surveillance • Early intervention program • Health service planning • SWOT analysis

### RIASSUNTO

*Una presa in carico non uniforme, tardiva o inappropriata dei bambini con deficit uditivo aumenta il rischio di sviluppare difficoltà comunicative-comportamentali e psicosociali che possono persistere fino all'adolescenza o all'età adulta. Nel Marzo 2014 il Centro di Controllo Malattie (CCM) del Ministero della Salute Italiano ha finanziato il progetto "Programma regionale di identificazione, intervento e presa in carico precoci per la prevenzione dei disturbi comunicativi nei bambini con deficit di udito". Il progetto coinvolge 5 centri di III livello in cui il programma di screening uditivo neonatale è stato approvato dalla regione di appartenenza. Lo scopo principale del progetto è quello di definire e proporre un modello di salute pubblica su base regionale per l'identificazione delle ipoacusie infantili permanenti, la diagnosi e l'intervento. La prima fase del progetto prevede di indagare lo stato dell'arte e di produrre raccomandazioni che possano portare a cambiamenti positivi nell'identificazione, nella diagnosi, nella terapia e nella presa in carico dei bambini con deficit uditivo, tenendo presenti le innovazioni diagnostiche-riabilitative, il sostegno e l'alleanza terapeutica con la famiglia, un approccio interdisciplinare. Le raccomandazioni emerse da questa prima fase rappresenteranno le basi per un sistema regionale di intervento precoce che sia valido, integrato e condiviso da tutte le cinque regioni coinvolte.*

**PAROLE CHIAVE:** Screening uditivo neonatale • Sorveglianza uditiva pediatrica • Programma di intervento precoce • Pianificazione del servizio sanitario • Analisi SWOT

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### Introduction

Permanent hearing impairment (PHI) is the most common sensory defect in childhood. A significant degree of PHI occurs in 1-3 per thousand births in industrialised countries. Its prevalence can double by age of school entry and can increase by 3 to 10 times in at-risk paediatric populations or in poor countries<sup>1,2</sup>.

A childhood auditory deficit is typically of cochlear origin and is severe to profound in about a third of cases,

and eventually requires cochlear implantation. The condition harbours a high risk of language learning impairment and language-based learning disabilities because functional development of the auditory cortex critically depends on auditory experience<sup>3</sup>. Sensory deprivation during periods of maximal receptiveness (known as sensitive periods) impairs the auditory system function and compromises cortical and cognitive development, affecting the mutual interaction of the cortical areas<sup>4</sup>. As



a result of the decoupling of the auditory system from other systems in the brain, there is a compromise of key cognitive functions, such as working memory, attention and sequence learning<sup>5</sup>.

Fortunately, developments in scientific, clinical and medical technology have shown remarkable progress in the last 15-20 years. Valid diagnostic and intervention procedures linked with fitting of sophisticated hearing aids or cochlear implants have outlined courses and processes that are today applicable, feasible, effective and sustainable<sup>6</sup>. Timing, appropriateness and quality of interventions have been shown to be crucial factors: the better conceived, the greater the chances of avoiding the negative impact associated with PHI<sup>17</sup>. This knowledge has internationally encouraged the development of newborn hearing screening (UNHS) and surveillance programs with the aim of identifying congenital and delayed-onset PHI within the first 3 months of life or immediately after occurrence<sup>12,8,9</sup>. Several Italian regions have now regional policies specifically aimed at detection of childhood PHI<sup>10-14</sup>. The majority have been demonstrated to be highly practical, and excellent results in terms of coverage and reduced age of hearing impairment identification have been reported<sup>15-17</sup>. Yet, at this point, it is necessary to build an integration with further steps of diagnostic, therapeutic and rehabilitative intervention, in order to not miss the opportunity to achieve early management as well. This achievement is still problematic in most national and international programs. As an example, an audit on the effects related to US UNHS programs published in 2010 reported excellent result in terms of national coverage, but also showed that about 40% of infants who screened positive did not get the required audiologic evaluation within 3 months, thus producing a high percentage of children that could not initiate early management<sup>18</sup>.

Diagnostic, treatment, rehabilitative and educational interventions are often late or inappropriate in Italy, predisposing many children to communicative-behaviour problems and impaired psychosocial adjustment that can persist into adolescence and adulthood. In addition to clinical and educational issues, this highly jeopardised situation restrains rehabilitation, educational and legislative interventions, forcing them towards a *support-based* rather than *prevention-based* approach<sup>10-14</sup>.

In March 2014, the CCM (Centro Controllo Malattie or Disease Control Centre) of the Italian Ministry of Health funded a project entitled "Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children". The vision of the project is to lessen and prevent communication delays that typically occur in the event of late care. The program's policy is to upgrade and uniform current public health practices, taking into account diagnostic and treatment innovations, family empowerment and treatment alliance, and an interdisciplinary approach. The main purpose of the project is to define and launch an integrated,

regionally-based public health model for identification, diagnosis and intervention of childhood PHI. The project will be carried out in five Audiology and Otolaryngology Units that coordinate and represent a tertiary centre for UNHS programs approved by each participating Region and that provide audiologic assessment, cochlear implant surgery and rehabilitation. The centres are the following: (1) Audiology and Otolaryngology Unit, Department of Pediatrics, Research Institute and Hospital for Maternal and Child Health - IRCCS "Burlo Garofolo" – Trieste (Head of the Unit, Scientific coordinator and local supervisor of the project: Dr. Eva Orzan); (2) Department of Head and Neck Surgery, Department of Head and Neck Surgery – Otorhinolaryngology Catholic University of the Sacred Heart "A. Gemelli" Hospital, Rome (Local Supervisor of the project Prof. Guido Conti, Director of Department: Prof. Gaetano Paludetti,) (3) Otorhinolaryngology Clinic, University of Perugia, Perugia (Local Supervisor of the project and Director of the Clinic Prof. Giampietro Ricci); (4) Otology and Cochlear Implant Unit, Santobono-Pausilipon Children's Hospital, Naples (Local project Supervisor and Head of Unit Dr. Antonio Della Volpe; project collaborator Dr. P. Siani) (5) Operative Unit of Otorhinolaryngology, Audiology and Phoniatrics, University of Pisa, Pisa (Local Supervisor of the project and Head of Unit: Prof. Stefano Berrettini).

The first phase of the project included the identification of areas for which it is necessary to plan innovative organisation. Overall and specific objectives were set for each area of activity and a structured planning method was employed to identify the internal and external factors that are favourable and unfavourable to the aims, i.e. evaluate the capabilities of the organisation and to identify where the greatest opportunities lie within a realistic context. This phase has been carried out using the principles of a SWOT analysis. Recommendations drawn from the strategic analysis will represent the basis for a regional system for early intervention that is validated, integrated and shared between the five regions. The results of this first stage of the project are conveyed in this series of articles.

## Materials and methods

SWOT analysis can help identifying an organization's Strengths, Weaknesses, Opportunities and Threats. It was developed at the Stanford Research Institute in the 1960's and was designed to engage all staff who affect a company's achievements in systems for positive change<sup>19</sup>. Although it was originally designed to provide a thorough analysis of private sectors, its benefits have prompted its use in health-care organisations as well<sup>19,20</sup>. In principle, SWOT analysis offers a model to systemise compilation and assessment of key data, such as present status of medical technology, sources of professional training and state of the art, to obtain recommendations to be considered for future planning.

**Table I.** Overall and specific objectives for the 9 SWOT analyses performed.

Themes	Overall objective	Specific objective for SWOT analysis
Newborn hearing screening	Optimise UNHS processes	Universal screening and re-screening test to be done by 1st month of age, preferably before hospital discharge
Hearing surveillance activity	Recognise childhood PHI that are not identified by the UNHS	Minimise loss to follow up cases and achieve an early identification of late onset or progressive PHI
Aetiologic diagnosis	Obtain an early aetiological diagnosis through the implementation of uniform and timely procedures, particularly with regards to common causes (CMV, GJB2 mutations/GJB6, inner ear malformations)	Apply a shared diagnostic protocol that can identify the cause in at least 70% of PHI
Audiologic diagnosis	Obtain an audiologic definition of PHI through the implementation of uniform and timely audiometric protocols, functional to the subsequent early hearing aid fitting.	Define the type, severity and morphology of PHI within 3-6 months of life if the child has been referred from the UNHS, or within one month if the child has been referred from hearing surveillance activity
Hearing aid fitting	Achieve an early amplification in all cases of significant PHI	Achieve an optimal hearing aid fitting in case of significant bilateral PHI within one month after audiologic diagnosis
Follow-up	Harmonise criteria for outcome evaluation	Schedule a follow-up protocol that supports an effective feedback within tertiary centres and primary care
Family support	Foster the natural communicative development of the child by strengthening the therapeutic alliance and the empowerment of the family	Coordinate professional activities that involve and empower families in the first three months after identification of PHI
Rehabilitation	Promote the global development of children with PHI by means of an early rehabilitation project based on shared knowledge and scientific evidence	Define the features and modes of access to a precise and specialised rehabilitation project for the small hearing-impaired child within three months from audiologic diagnosis
Cochlear implant fitting	Early cochlear implantation for children with severe to profound PHI	Obtain a hearing threshold within 35 dB HL within 3-6 months from the cochlear implant activation

A SWOT facilitator was identified for each analysis. The first step involved formulating overall and specific analysis objectives to help focus thinking and problem-solving, as listed in Table I. A group of professionals working in the aforementioned 5 tertiary care referral centres for childhood PHI was asked to report at least two strengths, weaknesses, opportunities and threats for each of the 9 themes of discussion. The facilitator introduced the SWOT matrix, which is divided into four quadrants, labeled “Strengths”, “Weaknesses”, “Opportunities” and “Threats”.

Strengths and weaknesses can be defined as internal to the setting. Internal factors at the healthcare centre include resources and experience. Human resources encompass staff, volunteers and the centre’s target population. Physical resources include location, building and equipment. Financial resources may cover grants and other sources of income. Experience may involve the centre’s successful

programs and even the centre’s reputation in the community. Opportunities and threats are external. Opportunities are external to the setting and can involve the future. Some examples include collaborations with different healthcare organisations, development of new healthcare programs and increased funds for better healthcare informatics. Factors that could harm the performance of healthcare organisations are considered threats. Examples include economic or political insecurity, increased demand for expensive medical technology, budget deficit and increased pressure for reductions in healthcare costs.

Participants were asked to write down their initial ideas on paper and to suggest items from their own lists to favour discussion, revisit the list and consolidate related suggestions. Table II lists possible questions that helped participants to identify strengths, weaknesses, opportunities and threats for each discussion theme.

**Table II.** SWOT matrix with useful questions for identifying strengths, weaknesses, opportunities and threats.

<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• What do we do well?</li> <li>• What advantages do we have?</li> <li>• What relevant resources do we have access to?</li> <li>• What do others see as our strengths?</li> </ul> <p><b>Opportunities</b></p> <ul style="list-style-type: none"> <li>• What good opportunities are facing us?</li> <li>• What trends might be helpful to observe?</li> </ul>	<p><b>Weaknesses</b></p> <ul style="list-style-type: none"> <li>• What aren’t we doing well?</li> <li>• What can we improve?</li> <li>• What should we avoid?</li> </ul> <p><b>Threats</b></p> <ul style="list-style-type: none"> <li>• What obstacles do we face?</li> <li>• Is technology changing faster than we are adapting to the changes?</li> </ul>
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Next, the SWOT facilitator summarised priorities by calculating the frequency of items collected during SWOT analysis. The review of the most frequently cited items were used to make a TOWS (Threats-Opportunities-Weaknesses-Strength) matrix, which matches the external threats and opportunities with internal weaknesses and strengths of the specific activity <sup>20</sup>.

A TOWS matrix compares strengths-opportunities, weaknesses-threats and weaknesses-opportunities:

(1) S-O strategy: Strengths can be used to employ the opportunities offered by external elements; (2) W-O strategy: Weaknesses internal to the system can be overcome by empowering and taking advantage of opportunities offered by external elements; (3) S-T strategy: The risks from external elements can be minimised by employing the strengths points efficiently; (4) W-T strategy: A good plan to minimise internal weaknesses can be useful to prevent the effects of risks arising from external elements.

This type of analysis makes it possible to extrapolate recommendations and guidelines for each theme. Analysing and discussing the data, some main recommendations were obtained that can represent food for thought for tertiary care audiology centres, to optimise resources and generate positive changes.

## Results

The flow diagram of the SWOT and TOWS analysis processes is outlined in Figure 1.

A SWOT analysis facilitator was selected between the members of the working group for each of the theme of discussion (see also Table I). The facilitator conducted a preliminary literature search on the assigned topic. Subsequently, before beginning SWOT process, the facilitator explained and focused the overall and specific objectives (see also Table I) that should drive the strategic study to the working group. For three themes (Hearing aid fitting, Family support and Rehabilitation) the facilitators decided to run a “first round” analysis that was proposed also to other professionals or families not included in the working group, to foster a subsequent discussion that could better reflect the Italian reality. This preliminary survey was conducted by mail with the same principles of the SWOT analysis or with questionnaires specifically developed to assess positive and negative aspects of the procedures or protocols available at the tertiary care centres. The working group included from 17 to 24 professionals involved in prevention, diagnosis, treatment and rehabilitation of childhood PHI, all working in the 5 above mentioned tertiary care centers. All analyzes were conducted at project

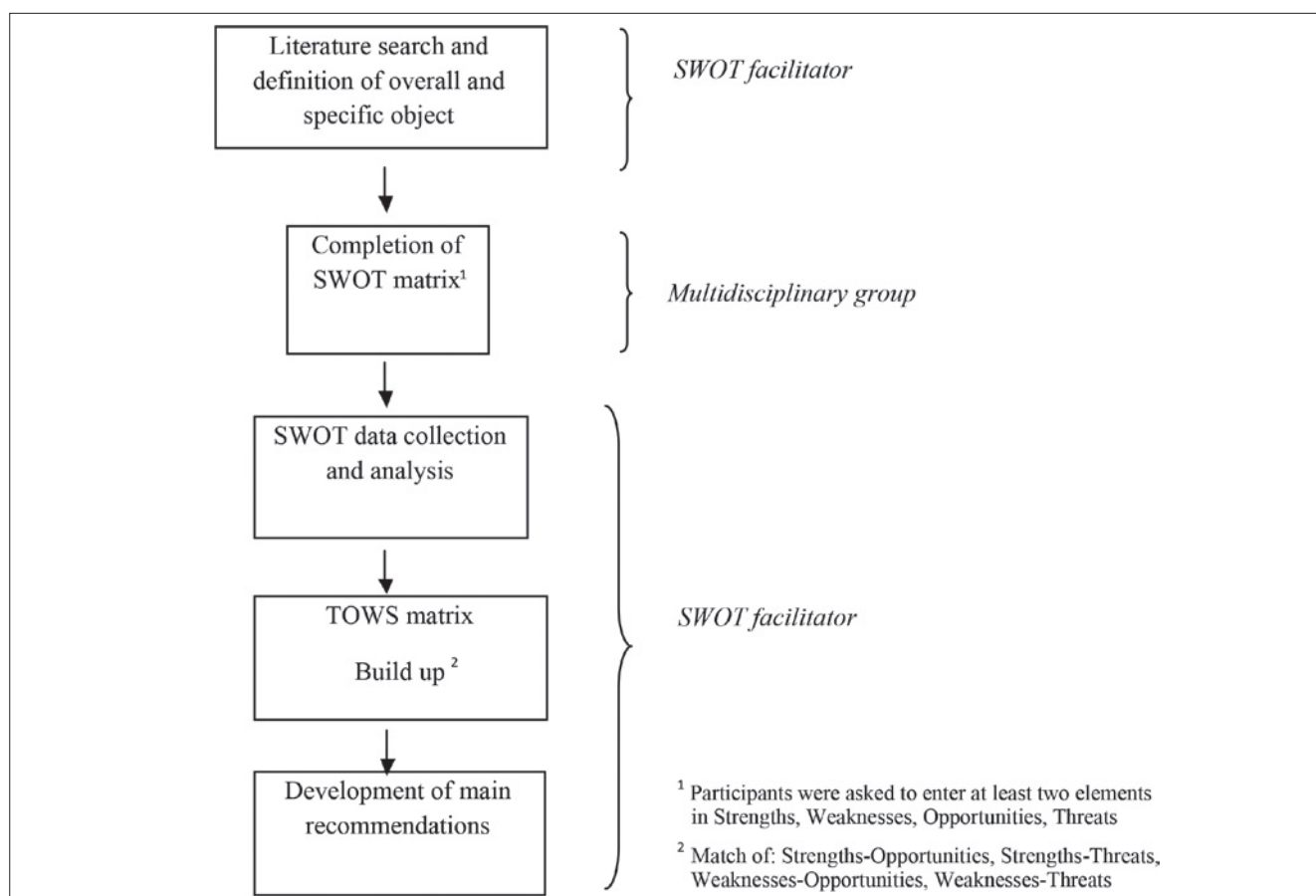


Fig. 1. Flowchart with all the steps of collecting, processing and discussing the details of each work area.

meetings, with all participants present, each one completing his or her own SWOT matrix. After completion of the matrices, the facilitator collected all the data. Overall, 486 items were identified for Strength (S) category, 513 items in the Weakness (W), 421 items in the Opportunity (O) and 434 items in the Threats (T) category, for a total of 1854 items. Subsequently all items were reviewed and grouped in main key points. Finally, a TOWS matrix was created for each theme, which compares and combines Strengths with Opportunities (S-O), Weaknesses with Opportunities (W-O), Strengths with Threats (S-T) and Weaknesses with Threats (W-T), eventually offering recommendations and directions that can constitute an effective starting point for prospective planning and innovation, in particular for tertiary care centres. A total of 103 suggestions or proposals were obtained as to the best course of action for the 9 fundamental themes and objectives of early childhood hearing loss care.

## Discussion

Implementation of UNHS programs in most Italian regions has been a major healthcare advance<sup>21,22</sup>. An additional step consists in systematising an early intervention process that can facilitate language, social and cognitive skills development, eventually allowing children to fully achieve educational and social opportunities<sup>7,23</sup>. This potential has not been uniformly and fully realised in Italy. The team of professionals involved in the project is convinced that it is necessary to improve the system of services needed to serve hearing impaired children and their families according to centres' experiences, along with the evolution of technology and in parallel with the application of healthcare reforms.

Restructuring of the healthcare sector is taking place in many Italian regions, and healthcare organisations face many new challenges: defining services, securing the means and understanding expectations and sustainability. UNHS programs have already been demonstrated to be efficient with a high level of quality. It is now necessary to ensure that every child with PHI has an equal chance to receive access to all critical care within a realistic context: timely identification; follow-up diagnostic testing; communication of results to family and other involved professionals; start of auditory stimulation; early rehabilitative intervention; long-term follow-up.

When planning services it is advisable to define and agree on the goals and objectives, analyse the current situation (including resources and obstacles), predict trends and finally define the activities and strategies to reach the desired goal. To do this, there are several options. One is SWOT analysis. This method is advantageous mainly because it encourages proactive and "positive" thinking, rather than reacting to actions in habitual ways<sup>19</sup>.

The outcome of our SWOT analyses are the main recom-

mendations for specific goals and will be used within the CCM national project as a call to action plan: activities to be undertaken, who should be responsible for each activity and when and how the activity should be completed. A strength of this project is that all units involved coordinate and/or represent a tertiary centre for UNHS programs formally approved by each Region. Moreover, all centres take care of children and families from first diagnosis, hearing aids fitting and potential cochlear implant surgery, up to evaluation of outcomes. The analysis and implementation of procedures, since they are carried out by the units that are actually involved in the realisation of the project, can guarantee the transfer of results at the local, regional and supra-regional levels. The healthcare models developed, agreed and implemented will be made available to other regions or organisations for similar programs. Other Regions will be added to the activity.

The present work in the course of the project has some limitations. SWOT analysis is only one way to generate ideas for improvement. It is a subjective instrument that depends on points of view, experiences and biases of those who participate. Sometimes, participants confused "strengths" and "opportunities" and "weaknesses" and "threats". Strengths are considered internal to the organisation, and opportunities are external. The coordinators and facilitators of SWOT analyses placed the suggestion in the appropriate quadrant when necessary, keeping in mind that the "correct" placement was always considered less important than capturing the idea. SWOT analysis is most effective if as many stakeholders as possible are involved in the process<sup>19</sup>. Each person on staff has a different perspective about the strengths and weaknesses of the health centre's efforts. On this occasion, it was an interdisciplinary group of professionals working in tertiary centres with daily experience in early childhood PHI management. There are, however, other professionals that can provide a useful contribution such as healthcare coordinators and policy makers. These individuals may provide other ideas for networks, need of cooperation, with a clear distinction between internal and external factors.

A further drawback can be that regions, albeit with regional laws, initiated their programs with different organisational backgrounds. Therefore, the strengths of one group can be seen as weaknesses of another group. This aspect highlighted a strong need for interdisciplinary training as a requisite for future effective networks. All contributors to SWOT analyses indeed favoured greater collaboration and communication between the various professionals that are involved with the child and also between the team and the family, especially if the child and the family live far away from the tertiary centre. A team that is affected by ambiguous competence assignments, uneven sharing of information and lack of working meetings, not only is ineffective, but also leads to incoherent information given to families.

The early intervention system involves the partnership of many professionals, hospital and primary providers, associations and specialised teams to monitor and assure proper functioning of all aspects of the system. Audiologic services operators, rehabilitation technicians, family and later even the school must share the needs and solutions aimed at achieving overall well-being of the child. As for other healthcare organisations, even the paediatric PHI care system needs to transform itself into professional network organisations that are influenced by many stakeholders. Resources should be available, and SWOT analyses foresee that resources can be found not only within the organisation itself, but also in its network. Finally, the following SWOT analyses should not be viewed as a conclusion, but rather as a starting point within a specific “historical moment” of Italian childhood PHI care. It can help healthcare managers and policy makers to know what the expectations of their stakeholders are now and in the near future in order to prioritise them and, hopefully, fully realise the promise of UNHS.

## Conclusions

Non-uniform, late or inappropriate care of childhood PHI predisposes many children to develop communicative-behaviour problems and impaired psychosocial adjustment that can persist in adolescence and adulthood. In Italy, this highly jeopardised situation is still confining rehabilitation, education and legislation towards a *support-based* rather than *prevention-based* approach.

In March 2014, the CCM (Centro Controllo Malattie or Disease Control Centre) of the Italian Ministry of Health funded a project entitled “Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children”. The program policy aims to upgrade and harmonise current public healthcare practices, taking into account diagnostic and treatment innovations, family empowerment and treatment alliance, and an interdisciplinary approach. The first phase of the project, described in the following series of articles, is intended to investigate the state of art and produce recommendations for positive changes and innovation in identification, diagnosis, therapy and care of childhood PHI. A specific target that can drive SWOT analysis has been identified for each area of childhood PHI management process. A group of professionals working in tertiary centres performed 9 SWOT analyses to evaluate capabilities of the organisation and to identify opportunities within a realistic context. Recommendations were identified for several themes regarding the early PHI intervention process, and will represent the basis for a region-based early intervention system that is integrated and shared between stakeholders. The need for an effective professional network organisation has been highlighted in all 9 analyses presented, emphasizing that

communication and training are the most effective levers in healthcare organisations.

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# Improving regional universal newborn hearing screening programmes in Italy

## *Raccomandazioni per perfezionare i programmi regionali di screening uditivo neonatale universale in Italia*

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### SUMMARY

The Universal Newborn Hearing Screening (UNHS) programme aims at achieving early detection of hearing impairment. Subsequent diagnosis and intervention should follow promptly. Within the framework of the Ministry of Health project CCM 2013 “Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children”, the limitations and strengths of current UNHS programs in Italy have been analysed by a group of professionals working in tertiary centres involved in regional UNHS programmes, using SWOT analysis and a subsequent TOWS matrix. Coverage and lost-to-follow up rates are issues related to UNHS programmes. Recommendations to improve the effectiveness of the UNHS programme have been identified. The need for homogeneous policies, high-quality information and dissemination of knowledge for operators and families of hearing-impaired children emerged from the discussion.

KEY WORDS: Newborn hearing screening • Early intervention • SWOT analysis

### RIASSUNTO

*L’obiettivo dello screening uditivo neonatale universale è di ottenere una diagnosi precoce di ipoacusia congenita. Non appena confermata la perdita uditiva, è necessario intervenire dal punto di vista riabilitativo. Nell’ambito del progetto del Ministero della Salute CCM 2013 “Programma regionale di identificazione, intervento e presa in carico precoci per la prevenzione dei disturbi comunicativi nei bambini con deficit uditivo” un gruppo di professionisti appartenenti a centri di terzo livello con un programma regionale di screening uditivo neonatale, ha analizzato i limiti e i punti di forza dell’attuale impostazione dei programmi regionali di screening uditivo neonatale mediante l’analisi SWOT e la realizzazione di una matrice TOWS. Alcune criticità sono rappresentate dalla copertura dello screening e dal numero di persi allo screening. Sono state sviluppate raccomandazioni volte a migliorare l’efficacia di tali programmi. Sono emerse la necessità di una regolamentazione uniforme dei programmi di screening a livello regionale e nazionale, e il bisogno di ricevere informazioni e formazione aggiornate, di alta qualità, e condivise per familiari e operatori.*

PAROLE CHIAVE: Screening uditivo neonatale • Intervento precoce • Analisi SWOT

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## Introduction

The Universal Newborn Hearing Screening (UNHS) programme aims at enhancing the child’s communicative, social and academic development through early identification of permanent hearing impairment (PHI). Many regional programs in Italy have improved the detection rate and timing <sup>1</sup>. Before the introduction of UNHS in the Umbria region, mean age at identification of PHI was about 32 months <sup>2</sup>. Amplification was applied at least 2 months later <sup>2</sup>. Since 2010, the Umbria region has implemented a UNHS programme with the aim to obtain wide coverage, low re-screening rates, high adherence to follow-up and early intervention <sup>3-5</sup>.

UNHS becomes effective if the diagnosis prompts early and adequate intervention <sup>6</sup>. It is reported that up to 50% of infants referred from UNHS may not receive a timely diagnosis and intervention, or are not included in the tracking system. Quality services for the child and its family are important to take advantage from UNHS. Actually, parents may become distressed when confirmation of hearing loss is not followed by immediate support, and can consequently impair the therapeutic alliance with professionals <sup>7,8</sup>. Considerable efforts are now being employed at a regional and national level to ensure that infants and families receive the best support from UNHS. In the framework of the Italian Ministry of Health project



CCM 2013 “Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children”, a multidisciplinary team of professionals established a strategic analysis with this specific aim: universal screening and re-screening test to be done within the 1st month of age, preferably before hospital discharge. This study aims to highlight the strengths and weaknesses of current assets in order to achieve preliminary recommendations to optimise UNHS processes.

## Materials and methods

Seventeen professionals involved in the field of prevention, diagnosis, treatment and rehabilitation of paediatric PHI (i.e. audiologists, otorhinolaryngologists, audiometry technicians, speech and language pathologists, psychologists, hearing aids professionals, cochlear implant technical specialists) and working in 5 third level centres running UNHS programmes were involved in the strategic analysis. The data obtained were used to complete a SWOT analysis with this specific aim: universal screening and re-screening test to be done within the 1st month of age, preferably before hospital discharge. Next, a reverse process was undertaken, the TOWS matrix, to match the external threats and opportunities with internal weaknesses and strengths of the newborn hearing screening programme. The detailed description of the SWOT and TOWS matrix analysis procedure can be found elsewhere in this issue.

## Results

All participants completed the SWOT questionnaire; overall, 201 answers were collected. Fifty-seven answers were obtained for the S category, 51 for the W category, 451 for the O category and 42 for the T category. The answers were grouped according to the field of interest (Table I).

### *Strength key points analysis*

Three fields emerged from the strength points analysis (Table I).

#### *Ease and effectiveness of the procedure*

This category includes all the answers about technical specifications of equipment in use, either from the clinical aspects, or from cost point of view. An ideal screening test is inexpensive ( $n = 6$ ), reliable and easy to use ( $n = 10$ ), tested and validated ( $n = 4$ ), straightforward to teach and learn from neophytes ( $n = 3$ ) and regulated by clear policies at a regional level ( $n = 8$ ).

#### *Third-level centre organisation*

In this category, answers regarding organisation in terms of accessibility, facilities and dedicated staff have been

included. Strength derives from competent ( $n = 9$ ) and collaborative ( $n = 3$ ) personnel, adequate facilities ( $n = 2$ ) and staff ( $n = 1$ ), effective procedures ( $n = 2$ ), shared databases ( $n = 2$ ), short waiting lists ( $n = 2$ ), compelling connection with hospital nurseries ( $n = 2$ ) and with a nominated person who is responsible for screening ( $n = 1$ ).

#### *Good family involvement in the diagnostic and rehabilitative process*

The chance to involve families of deaf children in the identification process is a strength. This entails, on one hand, that families are informed adequately on the importance of early intervention ( $n = 1$ ), and on the other, that the staff is skilled ( $n = 1$ ) and prepared to give adequate and homogeneous answers about the following diagnostic and rehabilitative path ( $n = 1$ ). The possibility to retrieve “missing” patients is considered important ( $n = 1$ ).

### *Weakness key points analysis*

Three fields emerged from the weakness points analysis (Table I).

#### *Difficult coverage*

The problem of the drop-out from the scheduled re-screening and referral programme is reported ( $n = 11$ ), especially for non-Italian families. One of the causes can be inadequate staff personnel, either in term of numbers ( $n = 6$ ) or ineffective communication among referral centres ( $n = 4$ ). This can be related to excessive personnel turnover ( $n = 3$ ) and to higher workload resulting in shallow evaluations ( $n = 1$ ). Unreliable testing devices can cause delays in the screening process ( $n = 3$ ). Unilateral referral cases can be overlooked in some centres ( $n = 1$ ).

#### *Local policy problems*

In this category, answers regarding policy differences and controversies among regions ( $n = 6$ ), that prevent homogeneity and promptness of actions ( $n = 5$ ), as well the opportunity to manage data in a shared database ( $n = 4$ ), have been included. Lack of funding ( $n = 1$ ) and uncertainty or controversies on the specificity/sensibility of tests and procedures ( $n = 3$ ) are also considered.

#### *Communication problems*

Weak points have been attributed to communication problems, i.e. insufficient communication with the families about results and importance of the screening procedures ( $n = 2$ ), or lack of feedback on program implementation ( $n = 1$ ).

### *Opportunity key points analysis*

Three fields were recognised about opportunities.

#### *Information and formation*

This category includes the dissemination of knowledge



about UNHS programmes (n = 12) directed both to families of deaf children and to general population. The opportunity to improve the newborn hearing screening programme also comes from continuing education including distance learning and mentoring (n = 10), efficient organisational support as dedicated administrative office (n = 2) and telematic facilities, e.g. shared online databases (n = 3), online communication of screening results (n = 4).

#### *Policy opportunities*

Answers in this category entailed the introduction of homogeneous policies and protocols among regions, centres (n = 12) and areas (n = 1), in order to improve screening and surveillance programmes, extend screening instruments to all hospital nurseries (n = 1), external collaborations with third level centres (n = 1), verification by the paediatrician about completion of screening (n = 1).

#### *Technical and technological aspects*

The foundation of a regional network is an opportunity to improve technological homogeneity (n = 1) and mutual advice from a technical point of view (n = 3).

#### *Threats key points analysis*

Threats points have been grouped in three categories (Table I).

**Table I.** Main key points extrapolated from questionnaires.

**Table Ia.** *Strengths.*

Strength key points	N (%)
Ease and effectiveness of the procedure	31 (54.4)
Third-level centre organization	22 (38.6)
Good family involvement	4 (7)

**Table Ib.** *Weaknesses.*

Weakness key points	N (%)
Difficult coverage	29 (56.9)
Policy problems	19 (37.2)
Communication problems	3 (5.9)

**Table Ic.** *Opportunities.*

Opportunity key points	N (%)
Information and formation	31 (60.8)
Policy opportunities	16 (31.4)
Technical and technological aspects	4 (7.8)

**Table Id.** *Threats.*

Threats key points	N (%)
Cultural, ethnical and territorial differences	25 (59.5)
Lack of information and dissemination of knowledge	11 (26.2)
Resources and equipment	6 (14.3)

#### *Cultural, ethnical and territorial differences*

There are issues about the universality of newborn hearing screening, because of cultural, ethnical and territorial differences, leading to misunderstanding or lack of confidence (n = 9), and about the territorial complexity and healthcare organisation weakness (n = 3). Threat points are also attributable to the lack of homogeneity and equity (n = 9), and of national policies about UNHS (n = 2), with overload of a few centres (n = 2)

#### *Lack of information and dissemination of knowledge*

This category includes the lack of information (n = 2) and education (n = 1) of professionals regarding the screening/re-screening protocol (n = 2) and about the specific responsibilities of the professionals involved in the programme (n = 1). This can lead to incomplete or erroneous information given to patients (n = 3). The awareness level about hearing problems is low in the general population (n = 1). The problem of mild-to-moderate PHI can remain underrated (n = 1).

#### *Resources and equipment*

Lack of funds (n = 3), unreliable instruments (n = 1), and poor knowledge of their characteristics, maintenance and employment (n = 2) were included.

## Discussion

Several issues regarding screening and rescreening newborns have been reported in past years: coverage of the programme, loss to follow-up between first and second screening test, false positive cases, inclusion of unilateral PHI in the detection procedure, homogeneity in procedures between birthing centres within the same region and within the country, 2nd and 3rd level appointments, management of the non-functioning screening instruments, clear roles in the programme, data management<sup>5 9 10</sup>.

A TOWS matrix has been developed on the bases of the SWOT analysis (S-O, S-T, W-O and W-T strategy). Thanks to the good organisation of services and information, the SO strategy will improve the employment of electronic databases for the collection and share of UNHS data. The W-O strategy will overcome the coverage issues of the UNHS by means of the introduction of regional policies. The S-T strategy will improve UNHS effectiveness thanks to the increased ease of the procedures. The W-T strategy will enrich available funds directed to improve UNHS outcomes, based on a better organisation of the programme. Applying the TOWS matrix to the themes of internal and external factors, as identified by UNHS coordinators with the SWOT analysis, 8 recommendations, or “strategic plans” for hospitals and audiology tertiary care referral centres have been developed (Table II). The 8 items can be summarised in 2 main strategies, which are interconnected and are in accordance with the current international

**Table II.** TOWS matrix (see text for explanation).

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	<b>SO strategy</b> 1. Keep updating the UNHS program through a regional network to improve the procedures while developing homogeneous protocols and assistance. 2. Set up an efficient network among centres and territory, in order to improve the involvement of families, education of professionals, involvement of families and sharing of information.	<b>WO strategy</b> 1. Use continuing education to improve the quality of the shared informations, also with the support of new technologies and media. 2. Introduce homogeneous national laws regulating UNHS in order to improve diagnosis and rehabilitation pathways, increasing funds and a common database.
	Threats (T)	<b>ST strategy</b> 1. Demonstrate that thanks to the ease of the procedure and the effectiveness of the organisation, logistic and cultural barriers can be overcome. 2. Use policies to close cultural and information gaps among operators, unaware of the population, and to receive adequate resources.	<b>WT strategy</b> 1. Improve the UNHS and re-screening coverage identifying specific paths and policies to enlarge the staff and the resources. 2. Make aware the institutions that changing the policies about UNHS can improve paediatric population monitoring and assimilate databases in a national registry.

guidelines inspiring UNHS<sup>4,5</sup>. These strategies are directed to: a) improve policies related to UNHS and b) provide information of high quality to families and professionals. The reorganisation of the policies involved in the UNHS is mandatory. It includes the sensitisation of the institutions and the introduction of adequate job descriptions, with the aim to improve UNHS and surveillance effectiveness, optimise resources, improve continuing education, inform the population and achieve a good and sustainable monitoring of the paediatric population<sup>9</sup>. UNHS should become the object of a nation-wide applied policy in Italy, in order to carry out homogeneous evaluation and ensure uniform levels of care. National policies should be introduced to make the UNHS mandatory, to make plain cultural contrasts and to give adequate resources, including management and supervision offices.

The second strategy entails the dissemination of high quality information through online networks and information exchange for professionals, families and children, in an appropriate language. Information should be given before delivery to parents, highlighting the importance of early identification of hearing impairment, and about the screening path, follow-up process and impact rehabilitation<sup>10</sup>. Basic information about anatomy, physiology, pathology, rehabilitation and instrumentation used for hearing assessment and on the specific role of the different professionals will be also provided. Parents will be driven through the rehabilitation path by leaflets, books, videos, distance learning, distance mentoring and other resources. Counseling and communication issues between parents and professionals, or between parents and children professionals and children will be addressed<sup>11</sup>. Dissemination of information to the general population should be provided at different levels (in the hospital, on the territory). Dedicated secretarial staff will address the needs of families and patients, and receive suggestions by users. High levels of therapeutic alliance must be

achieved. Training of operators should be either theoretical and practical (e.g. nurses should be aware of screening goals, congenital hearing causes, and trained on earbuds positioning), and provided by professionals<sup>12,13</sup>. Updated protocols need to be periodically discussed, highlighting the pros and cons of the program organisation. A clinical updated is to be included<sup>14</sup>. A periodic scientific with all the informative material for parents and professional, and the critical aspects emerged in teaching and training should be collected and published<sup>15</sup>.

## Conclusions

Two main recommendations have been identified, which are useful to improve UNHS programmes, i.e. the need for homogeneous policies in Italy and for high-quality information and dissemination of knowledge for operators and families of hearing-impaired children. This approach is consistent with current paediatric audiology guidelines<sup>4,5</sup>.

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# Childhood hearing surveillance activity in Italy: preliminary recommendations

## *L'attività di sorveglianza audiologica pediatrica in Italia: raccomandazioni preliminari*

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### SUMMARY

Following the positive outcomes of the newborn hearing screening programmes already underway in several Italian regions, it is now necessary to address the identification of childhood hearing impairments that missed the neonatal screening programme or have delayed onset. Within the framework of the Ministry of Health project CCM 2013 “Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children”, a group of professionals identified three main recommendations that can be useful to improve hearing surveillance activity within the regional and state Italian Health System. The family paediatrician is recognised as having a key role in ongoing monitoring of hearing capacity and development of the growing child.

KEY WORDS: Health surveillance • Hearing loss children • Paediatrician • Paediatric primary care • Regular health visits • SWOT analysis

### RIASSUNTO

*Sulla base dei risultati dei programmi di screening uditivo neonatale attivi in diverse regioni italiane, si è resa necessaria una riflessione riguardo all'identificazione delle ipoacusie sfuggite al programma di screening neonatale, delle ipoacusie progressive o insorte dopo la nascita. Nell'ambito del progetto del Ministero della Salute CCM 2013 “Programma regionale di identificazione, intervento e presa in carico precoci per la prevenzione dei disturbi comunicativi nei bambini con deficit uditivo” un gruppo di esperti ha identificato tre principali raccomandazioni utili per ottimizzare l'attività di sorveglianza audiologica pediatrica nell'ambito del Servizio Sanitari Nazionale. Il pediatra di famiglia è riconosciuto come la figura chiave per il monitoraggio delle capacità uditive e dello sviluppo del bambino.*

PAROLE CHIAVE: Sorveglianza sanitaria • Ipoacusia infantile • Pediatra di famiglia • Pediatria di base • Bilanci di salute • Analisi SWOT

Acta Otorhinolaryngol Ital 2016;36:15-20

## Introduction

In many countries and in most Italian regions hearing screening tests are routinely carried out in all newborns to detect and treat permanent hearing impairments (PHI) as early as possible. Research has shown that congenital hearing problems are usually diagnosed much sooner if newborns are routinely screened<sup>1,2</sup>. Moreover, children whose PHI was diagnosed through universal newborn hearing screening (UNHS) receive earlier treatment and have better early language development than in children whose PHI was diagnosed and treated later<sup>3,4</sup>. Yet the prevalence of confirmed childhood PHI increases with age and concerns have been expressed about hearing impaired children not picked up by the newborn screen<sup>5</sup>. There are many factors that may contribute to the increase

in cumulative prevalence of PHI with age. Some are related to the limitations of the UNHS system, i.e. cases that missed the neonatal screening test, false negative cases and cases loss to follow-up<sup>6</sup>. Other factors are related to the unpredictable timing of onset and the different aetiologies responsible for late-onset or progressive cases. This is, for example, the case of some genetic forms of PHI or of other PHI in “at risk” children such as, for example, after meningitis, chemotherapy or CMV infection<sup>7</sup>. Unfortunately, many young children may not have another hearing screening test after the newborn period, and previous investigations have shown that a large proportion of children with PHI have undiagnosed delayed-onset hearing loss<sup>8</sup>. The frequent timeliness of service delivery (in diagnostic audiologic evaluations, hearing aid fitting

or early intervention services) is an additional important issue for late-identified children with PHI. Walker et al. advised that children referred from the UNHS should receive earlier intervention than those identified later<sup>9</sup>.

In summary, literature data convey important implications for paediatric primary audiology service providers. Many critical issues on the efficacy of current childhood PHI detection programmes have been identified<sup>10,11</sup>, while few healthcare organisation system proposals provide for effective management of the problem<sup>9</sup>. To our knowledge, there are no studies that have explored the efficacy of the childhood hearing surveillance (CHS) activity in Italy. This study aims to highlight the strengths and weaknesses of current assets in order to achieve preliminary recommendations that can minimise the loss to follow-up cases and identify as early as possible delayed-onset or progressive PHI in preschool children in Italy.

## Materials and methods

A group of professionals working in tertiary care referral centres for childhood PHI was asked to complete a survey. To examine issues related to CHS activity in Italy, the survey asked participants to report at least 2 strengths, weaknesses, opportunities and threats for use in strategic planning. This phase has been conducted with the principles of a SWOT analysis. The acronym SWOT stands for Strength (S), Weaknesses (W), Opportunities (O) and Threats (T), and corresponds to what the comments of the participants have pointed out. The responses obtained were reviewed by the specialists responsible for this work's area. To generate recommendations from the SWOT analysis, a TOWS matrix was used to match the external threats and opportunities with internal weaknesses and strengths of the organisation or programme<sup>12</sup>. The detailed description of the SWOT and TOWS matrix analysis procedure can be found elsewhere in this issue. The study and the survey was focused on this specific aim: minimise the *loss to follow-up* cases and obtain early identification of *late onset* or progressive PHI in early childhood.

## Results

The study group included 24 professionals with specific roles in the prevention, diagnosis and treatment of paediatric hearing loss (especially in tertiary care referral centres where there is an active UNHS programme) (Table I). All participants completed the SWOT questionnaire. The 219 open-ended answers (S = 56, W = 58, O = 48, T = 57) were reviewed by the authors and grouped in main key points (Table II).

### Strength key points analysis

*Effectiveness of Family Paediatrician (FP) activity and FP regional network activity*

**Table I.** Duties of the rehabilitation professionals (n = 24) involved in the survey.

Professional duty	n
Otolaryngologist/Physician in Audiology	10
Audiologist/Hearing Acoustician	4
Physician in Neonatology	1
Speech and language therapist	2
Psychologist	1
Cochlear implant technical specialist	1
Parent/Association	2
Primary Care Paediatrician	3

In this category answers regarding a complete, uniform and shared education and activity of FP (n = 14) were included: guarantee that the UNHS is carried out and correctly reported (n = 7), correct administration of parental questionnaires aimed to support the observation of child's auditory capacity (n = 3), organisation of a FP network covering the entire territory to ensure homogeneity of the service offered (n = 5). In some areas, FP education

**Table II.** Main key points extrapolated from the questionnaires.

**Table IIa.** Strengths.

Strength key points	N (%)
Effectiveness of FP activity and FP regional network activity	29 (52%)
Strong organisation and procedures	22 (39%)
Public awareness	5 (9%)

**Table IIb.** Weaknesses.

Weakness key points	N (%)
Inefficient system organisation	36 (62%)
Inefficiency of FP CHS activity	13 (22%)
Inefficient communication	9 (16%)

**Table IIc.** Opportunities.

Opportunity key points	N (%)
Development of innovative and efficient healthcare organisation	18 (38%)
CHS awareness and knowledge	15 (31%)
Up-to-date technology	14 (29%)
Other	1 (2%)

**Table IId.** Threats.

Threats key points	N (%)
Cultural, ethnical and territorial differences	25 (59.5)
Scarce equity of service and non-homogeneous training	30 (53%)
Multiculturalism	9 (16%)
Conflict of interest	10 (17%)
Lack of funds	7 (12%)
Other	1 (2%)



is proposed at least every two years. FPs regularly visit infants and children and become the key figure that can share parental concerns related to child's hearing and language development. They ascertain UNHS results and subsequent delivery steps, and monitor and follow-up auditory, language and behavioural development.

#### *Strong organisation and procedures*

This category includes all the themes concerning the organisation and procedures for screening and surveillance governance: effective and systematic collaboration among I, II and III level centres (i.e. integration between hospitals and FP, facilitation of procedures, easy access to useful contacts and to professionals) (n = 7); correct and efficient organisation of data processing within the regional program that also includes retrieving missed appointments and communication of results to the family (n = 7); the organisation of dedicated administrative reference points for easy access to II and III level centres (n = 8).

#### *Public awareness*

This category includes the themes regarding the presence of family associations that are aware of and support CHS activity. By acting at the territorial level, associations can further support the tertiary referral centre and the FP in providing the correct information to families (n = 5).

#### *Weakness key points analysis*

##### *Inefficient system organisation*

In this category, we entered all the answers that reported various issues related to an ineffective organisation of CHS activity. In particular, the network activity can be compromised by scarce communication between the tertiary referral centre and the FP: i.e. inadequate sharing of audiologic evaluations outcomes and scarce awareness regarding CHS within paediatrician's community (n = 11). Difficulties in recalling patients who do not show up at to FP visits or who missed UNHS and second level appointments (n = 8). Other issues relate to difficulties in aligning CHS activity. This is the case when a regional FP network is missing, when there are no guidelines regarding the CHS role of the FP or when there is no FP coverage in the territory (n = 6). Finally, this category includes lack of dedicated administrative offices or excessive workload of professionals (n = 6).

##### *Inefficiency of FP CHS activity*

This theme includes the answers related to the lack of professional education or professional training in paediatric audiology addressed to the FP (n = 6) and to the presence of insufficient and inefficient evaluation tools for CHS (n = 7).

##### *Inefficient communication*

This theme includes the answers concerning the insufficient information given to families about the importance

of CHS in childhood (n = 9), and in particular information on late onset or progressive hearing loss and information on the meaning of a positive UNHS result.

#### *Opportunities key points analysis*

##### *Development of innovative and efficient healthcare organisation*

This category includes all the remarks that can help to ameliorate the organisational set up: interdisciplinary work-up for a complete evaluation of the child (n = 4); shared education and training for professionals and parents (n = 4); stronger involvement of FP in CHS programmes (n = 4); use UNHS models as a source for CHS programme planning (n = 2); obtain a FP assignment for the newborn before the hospital discharge or link screening results to vaccination data (n = 2).

##### *CHS awareness and knowledge*

This category includes the themes regarding CHS awareness within families, institutions and associations (n = 15). There is, for example, the possibility to publicise information by means of posters or brochures displayed in FP waiting rooms, schools, vaccinations centres, etc. Other opportunities can emerge from successful experiences of the UNHS.

##### *Up-to-date technology*

This theme includes the answers regarding utilising technological advances that can ameliorate databases and software in order to ease collection/reaching/sharing of data within professionals and clinics (n = 8). This theme also includes the opportunity to develop and design new audiologic tools to FP CHS activity (n = 6).

Other answers in this field of the key points analysis are unspecified (n = 1).

#### *Threats key points analysis*

##### *Scarce equity of service and non-homogeneous training*

This category includes answers concerning the lack of shared education and training of FP, with inadequate knowledge about epidemiology of non-congenital PHI, about auditory deprivation effects and the role of the FP in CHS activities (n = 11). The lack of shared education can predispose to communication difficulties between stakeholders (n = 6).

Some answers also pointed out the lack of national uniformity (legislations, medical report models...) (n = 7) and the lack of general awareness on the problem (n = 2).

##### *Multiculturalism*

In this category, participants raised concerns regarding the interaction with families belonging to different cultures: cultural and linguistic barriers can sometimes be a serious obstacle for acceptance of CHS activities (n = 9).



*Conflict of interest*

Since the FP receives economic reimbursement when performing the Boel Test during regular visits, in Italy some concerns have raised the risk that this observational tool will continue to be used even if ascertained as having scarce sensibility and specificity (n = 8). Other conflicts of interest have been identified in the possible overlap in diagnostic activity between II and III level services, or between different III level centres, especially in regions with a higher number of III level centres (n = 2).

*Lack of funds*

This category includes the answers concerning the lack of funds and projects aimed at paediatric audiology and CHS research, with subsequent reduced staff and scarcity of funds for research projects (n = 7). Other answers in this field of the key-points analysis are unspecified (n = 2).

**Discussion**

The JCIH outlined risk factors registries that can be used in association with parental and professional concerns to identify infants and small children with HI missed by UNHS (“infants who pass the neonatal screening, but have a risk factor should have at least 1 diagnostic audiology assessment by 24-30 months of age”) <sup>7</sup>. In practice, several critical matters emerged regarding the efficacy of these registries and considerable debate exists over the most effective method for PHI detection post-UNHS <sup>13 14</sup>. The following issues were preliminarily considered by the working group:

- within 7-9 years of age, the prevalence of PHI is about twice that expected from the results of the UNHS <sup>10</sup>;
- some children who develop PHI have no risk factors and have no discoverable cause <sup>15</sup>;
- there is a high lost contact rate in CHS and children with only a single risk factor are more likely to not attend a CHS appointment <sup>14</sup>;

- sometimes it is difficult to establish a good alliance with the family. This situation can lead to late recognition of risk factors and poor adherence to CHS appointments;
- delayed onset of PHI is linked to a limited ability to achieve early diagnosis and early cochlear implantation of a significant number of children <sup>16</sup>;
- a single additional hearing screening at primary school entrance (5-7 years of age) could not detect new cases early enough, possibly leading to a lack of timeliness of service delivery <sup>8</sup>;
- there is no consensus about the most suitable methodology to screen auditory capacity in the preschool age <sup>14</sup>;
- the FP represents a key figure for childhood health CHS in the Italian National Health System. The FP visits regularly carried out at 1, 3, 6, 8, 12, 18, 24 and 36 months of the growing child, place the FP in an optimal position to ascertain the UNHS results and subsequent service delivery steps, to monitor and follow-up auditory, language and behavioral development and to screen the child’s hearing capacity. In some areas and regions, FP education is already established and regularly proposed <sup>17</sup>.

Following the SWOT analysis, a TOWS matrix was created, which compares Strengths-Opportunities, Weaknesses-Threats, Weaknesses-Opportunities. Analysing and discussing the data obtained from this research, 10 recommendations were obtained (Table III). These recommendations can represent the starting point for focusing the attention on population needs, on optimising resources and on generating positive changes. With this point of view, the strategic analysis identified three main themes or recommendations that may contribute to an efficient CHS system in Italy. These are:

1. Reassessment of the role of the FP though continuing

**Table III.** TOWS matrix (see text for explanation).

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	<p><b>SO strategy</b></p> <ol style="list-style-type: none"> <li>1. Develop an innovative organisation that exploits the good coverage of the FP on the territory, its training, a common database and the use of an objective screening tool.</li> <li>2. Take advantage of the good organization of the UNHS to increase awareness of families, FP, institutions and associations on CHS.</li> </ol>	<p><b>WO strategy</b></p> <ol style="list-style-type: none"> <li>1. Leverage on the current cultural awareness to organise effective public CHS activity.</li> <li>2. Use technological developments to improve tools, methods and systems for effective CHS and cooperation between FP and III level centres.</li> </ol>
	Threats (T)	<p><b>ST strategy</b></p> <ol style="list-style-type: none"> <li>1. Capitalise on well trained FPs to become regional referents for CHS activity on the territory and favour paediatric networks.</li> <li>2. Endorse FP and III level centres as having an effective role and awareness to promote tools and protocols that can overcome conflicts of interest.</li> <li>3. Take advantage of the most efficient existing programs to convey financial supports and national uniformity.</li> <li>4. Overcome multicultural issues raising cultural awareness.</li> </ol>	<p><b>WT strategy</b></p> <ol style="list-style-type: none"> <li>1. Identify ineffective FP activity in order to minimize risk of pitfalls and non-uniform service.</li> <li>2. Set up a system for prompt identification of service course weaknesses and their revision.</li> </ol>

- education within the hearing screening national system/programme;
2. UNHS and CHS community awareness and attendance;
  3. Organisational set-up and procedural uniformity of childhood CHS activity within the Italian National Health System.

The first theme is considered essential for a successful CHS regional or national programme: permanent and effective education and training of the FP needs to be consistent in the entire territory, formally included within the UNHS programmes and operationally linked with I, II and III level activities. The recognition and establishment of the role of the FP for the CHS within early identification and intervention programmes will “naturally” replace ineffective CHS activity<sup>8 10 11</sup>.

There have been some initial network experiences for pediatric audiology in Italy, promoted by Italian Paediatrician Federation (FIMP). This initiative also includes training and educational courses taught by audiologists and otolaryngologists. New cost-effective tools and procedures of audiological screening to be used in primary care are currently tested in an ongoing study at IRCCS Burlo Garofolo in Trieste<sup>19</sup>.

The second main theme can partially integrate the first. The FP is indeed in the role of educating caregivers to be alert and sensible observers of their child’s development. Moreover, the FP can increase family cooperation to attend appointments offered by the CHS programme. Several methods that can maximise the FP’s role were identified: posters that highlight and advise essential information can be displayed in clinics and FP waiting rooms; a cooperation with the National Health Service and FP/family associations can popularise leaflets and short videos that inform the community about the critical issues on auditory development and deficit; interdisciplinary events and meetings can raise awareness and publicise the opportunities and benefits of early intervention. It is the belief of the working group that all the projects aimed to strengthen CHS actions within the FP activity should be agreed between the parties, i.e. National Health System, FP organisations, family associations, and UNHS programmes.

The third main recommendation relates to the national CHS set-up, in order to make its activity more practical. This theme is also linked to the first regarding the FP’s role, and specifically the CHS audiologic screening tools and methods to be used by the FP. Current FP referral procedures comprise parental and professional concerns, questionnaires, high-risk lists and subjective observational tools, i.e. the Boel Test which, similar to the Distraction Test, observes the gaze orientation after a sound stimulus. The first three did not achieve national uniformity and the Boel test yields only a very inaccurate global estimate of

the child’s hearing capacity in the best case, with many false positive and false negative results<sup>5</sup>.

Few scientific studies have reported on alternative methods and tools that would be effective at the level of the FP CHS<sup>18 19</sup>.

Finally, this working group endorses a public health CHS structure, in terms of an ongoing systematic collection, analysis and interpretation of data, closely integrated with UNHS programmes and with the timely dissemination of these data to professionals responsible for preventing and treating the disease<sup>8 10 11 20 21</sup>.

## Conclusions

Postneonatal routes of identification are today considered essential. While being aware of their current ineffectiveness, they need to be maintained and improvements investigated in order to obtain an operative policy for detection and an early management for children not identified by the UNHS program. The Italian National Health System recognises the FP as a key figure for childhood health and CHS. The FP ascertains the UNHS results and the following delivery steps. The regular visits to the FP place the FP in an optimal position to monitor auditory capacity of the growing child. New audiologic tools for FP CHS activities should be developed and designed. The FP should be included in interdisciplinary education and training. It is indeed necessary to implement a public health system in parallel to the UNHS that can more effectively empower early referral and identification of hearing impaired children not identified by newborn screening.

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# Early definition of type, degree and audiogram shape in childhood hearing impairment

## *La diagnosi audiologica precoce dell'ipoacusia dell'età pediatrica*

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### SUMMARY

In the context of permanent childhood hearing loss, early audiological diagnosis is a prerequisite for activation of an adequate rehabilitation program to prevent or limit the known effects that auditory deprivation determines on language development and cognitive skills in neonates. Audiological diagnosis consists schematically of three phases: identification of subjects at risk, definition of hearing loss and/or children features, verification of appropriateness of diagnosis itself and a rehabilitation programme. Strategies and methods of audiological diagnosis are well defined and include an integration of data coming from objective methods with clinical and behavioural data. Although the substantial effectiveness of procedures and a general consensus on their use and interpretation have been defined, there are several critical issues concerning the achievement of this objective, which will be discussed in this paper.

**KEY WORDS:** Infant hearing impairment • Early audiological diagnosis • Auditory pathways maturation • Universal newborn hearing screening (UNHS) • ABR • SWOT analysis

### RIASSUNTO

*Nell'ambito delle ipoacusie infantili permanenti, la diagnosi audiologica precoce rappresenta il presupposto per l'attivazione di un adeguato programma abilitativo, in modo da prevenire o limitare i noti effetti che la deprivazione uditiva determina sullo sviluppo del linguaggio e delle abilità cognitive nel bambino. Nella diagnosi audiologica possono riconoscersi schematicamente tre fasi: l'identificazione dei soggetti a rischio, la definizione dei caratteri dell'ipoacusia, la verifica dell'appropriatezza della diagnosi stessa e dell'abilitazione. La strategia ed i metodi della diagnosi audiologica sono ben definiti e prevedono l'integrazione dei dati provenienti dai metodi obiettivi, con quelli clinici e comportamentali. A fronte di una sostanziale efficacia delle procedure e di un diffuso consenso sul loro impiego e sulla loro interpretazione, esistono varie criticità rispetto al conseguimento di tale obiettivo, che saranno affrontate in questo lavoro.*

**PAROLE CHIAVE:** Ipoacusia infantile • Diagnosi audiologica precoce • Maturazione vie uditive • Screening audiologico neonatale universale • ABR • Analisi SWOT

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## Introduction

Audiological diagnosis is the prerequisite to activate appropriate measures in order to prevent or limit the effects of permanent bilateral childhood hearing loss (PBHL), either on language development or cognitive skills<sup>1</sup>. Three steps are schematically recognised in the process of audiological diagnosis<sup>2,3</sup>. The first step is the identification of subjects at risk for hearing loss, and corresponds to the newborn hearing screening and to the surveillance programme; the second step is the audiological diagnosis itself, which must confirm the severity of hearing loss and define its features, before choosing the most suitable hearing aid parameters; a third phase is the follow-up during rehabilitation and hearing aid fitting process, to verify the

appropriateness of care and with the option, if needed, of coming back to the second step.

After referral from newborn hearing screening, the adherence to the timeline of the diagnostic work-up allows achieving audiological diagnosis of PBHL at 3-6 months of age<sup>4,5</sup>. Late onset hearing loss or lost-to-follow up cases, as well as children carrying audiological risk factors and children suspected for hearing loss by parents or caregivers should also be addressed to an adequate audiological evaluation and/or to follow up.

In confirmed cases of PBHL, the objective of diagnosis is to ascertain hearing loss and define its characteristics in view of the best prosthetic strategy through either amplification or cochlear implantation. Audiological diagnosis must therefore define the entity, nature (conductive, senso-



rineural, mixed), audiometric shape and pathophysiology/dynamic range of hearing, and which are requirements to define the type and operating parameters of hearing aids. Strategy and methods of audiological diagnosis are well defined and are essentially based on integration of data coming from objective methods (electrophysiology/auditory evoked potentials, impedance audiometry, otoacoustic emissions), with clinical data (medical history, otoscopy, clinical examination) and behavioural data<sup>126</sup>. Although the substantial effectiveness of diagnostic and the general consensus on its use and interpretation is established, there are still several critical issues concerning the attainment of diagnosis. The present paper mainly discusses these issues using the methods of SWOT analysis. The present topic has been assigned to the Department of Head and Neck Surgery - Otorhinolaryngology Catholic University of the Sacred Heart “A. Gemelli” Hospital, in the framework of the Italian Ministry of Health project CCM 2013 “Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children”.

## Materials and methods

A group of professionals working in tertiary care referral centres was asked to complete a survey on the issues of paediatric hearing impairment evaluation. The survey asked the participants to report at least 2 strengths, weaknesses, opportunities and threats for their strategic planning. This phase was conducted by means of the principles of SWOT analysis. The acronym SWOT stands for Strength (S), Weaknesses (W), Opportunities (O) and Threats (T), and corresponds to what the comments of the participants have pointed out. The responses obtained were reviewed by the specialists responsible for the working group of the appropriate field of interest. A TOWS matrix was used to match the external threats and opportunities with the internal weaknesses and strengths of the SWOT analysis to generate recommendations. The detailed description of the SWOT and TOWS matrix analysis procedure can be found elsewhere in this issue. The study and the survey were focused on this specific aim: how to define type, severity and morphology of PBHL within 3-6 months of age if the child has been referred from the universal newborn hearing screening, or within one month if the child has been referred from the hearing surveillance programme.

## Results

The respondents identified 34 items in the strength category, 43 items in the weaknesses category, 31 items in the opportunities category and 32 items in the threats category, accounting for 140 responses. Based on these responses, several specific themes were generated for each category (Table I).

**Table I.** Main key points extrapolated from the questionnaires.

**Table Ia.** *Strengths.*

Strength key points	N (%)
Performing audiological evaluation structured with all of the diagnostic procedures	13 (38.2%)
Having a qualified, competent and motivated team	13 (38.2%)
Having a standardised diagnostic workup	4 (11.8%)
Having rapid evaluation times /good outpatient care services	3 (8.8%)
Presence of anaesthesiologic care	1 (3%)
Total	34 (100%)

**Table Ib.** *Weaknesses.*

Weakness key points	N (%)
Technical difficulty in identifying severe-medium frequencies	10 (23.3%)
Lack of resources	7 (16.3%)
Lack of paediatric anaesthesiologic care	7 (16.3%)
Limited technical and specific skills	6 (14%)
Problems linked to late maturation / electrophysiological responses unreliable	6 (14%)
Difficult management of late onset or lost to follow-up	4 (9.3%)
Difficult communication with parents	2 (4.6%)
Difficult management of large volumes of diagnostic procedures	1 (2.3%)
Total	43 (100%)

**Table Ic.** *Opportunities.*

Opportunity key points	N (%)
Improvement of technologies	13 (42%)
Presence of dedicated and competent team	11 (35.5%)
Presence of a standardised diagnostic protocol	3 (9.5%)
Better collaboration with the territory	2 (6.5%)
Implementation of data collected by informal assessments	2 (6.5%)
Total	31 (100%)

**Table Id.** *Threats.*

Threats key points	N (%)
Limited economic resources	7 (21.9%)
Technical limits (false positives-long execution)	6 (18.8%)
Difficult relationship with families for limited cooperation	5 (15.6%)
Difficult management of extraterritorial patients/cultural background	5 (15.6%)
Legal aspects	4 (12.5%)
Difficult management of patient “late onset” or “lost to follow-up”	2 (6.2%)
Inadequate hearing aid	1 (3.1%)
Difficult execution of behavioural tests in children with cognitive deficit	1 (3.1%)
Misinformation	1 (3.1%)
Total	32 (100%)

**Strength key points analysis**

The 4 most frequently cited strengths points were: being able to perform complete audiological evaluation with all the worthy diagnostic tools (38.2%), having a qualified, competent and motivated team (38.2%), having a standardised diagnostic workup (11.8%), having short waiting lists for evaluation plans thanks to good organisation of services and with easy access to a suitable environment (8.8%) (Table Ia).

We describe and discuss the main themes below.

*Performing an audiological evaluation enclosing all the worthy diagnostic procedures*

In this group, we included all the answers that pertained to the correct evaluation of hearing function (n = 4) and, if PBHL is present, of its pathophysiological features. Evaluation should be quick, based on reliable instrumental equipment (n = 4), matched with an adequate and competent clinical examination (n = 3), and using objective and subjective measures (n = 2).

*Having a qualified, competent and motivated team*

In this group, we counted all the answers that refer to the presence of a medical/technical staff that is qualified and motivated (n = 7), which operates with devotion (n = 3) and specific competence in paediatric audiology (n = 3).

*Having a standardised diagnostic workup*

In this group, we enclosed all the answers that refer to the use of an efficient and accepted diagnostic protocol (n = 2), with the preparation, when necessary, of specific and adequate laboratory regulations (n = 1), that allows to obtain audiological diagnosis within a period compatible with an effective rehabilitation programme. We included an individual answer which emphasised that diagnostic procedures should be non-invasive and inexpensive (n = 1).

*Having rapid evaluation times/good outpatient care services*

In this group, we gathered all the answers that refer to the presence of good organisation of services, with suitable environments for medical procedures (diagnostic, assistance) and counselling, with short waiting lists (n = 2) and easy access to the structure (n = 1). In addition, when available, the strength of the availability of specific anaesthesiological care is reported (n = 1).

**Weakness key points analysis**

The six most frequently cited weaknesses were: technical difficulty in identifying audiological threshold for middle and low frequency range frequencies (23.3%), lack of resources (16.3%), lack of paediatric anaesthesiological care (16.3%), limited technical and specific skills (14%), problems linked to late maturation/unreliability of electrophysiological data (14%), difficult management of late onset cases or lost to follow-up (9.3%) (Table Ib).

We describe and discuss the main themes below.

*Technical difficulty in identifying hearing loss at middle and low frequency range*

In this group, we gathered all the answers that refer to the lack of a methodology that allows accurate definition of audiometric configuration. We reported the difficulty of an objective diagnosis threshold, for middle and low frequencies (below 1-2 kHz), and the consequent risk of overestimation (in down-sloping thresholds) or underestimation (in up-sloping thresholds) of overall hearing loss (n = 10).

*Lack of resources*

In this group, we included all the answers that refer to the lack of funds available for the recruitment of a competent and dedicated team (n = 4), and for adjusting and maintaining a complete and technologically updated instrumentation. Lack of funds (n = 2) also cause a shortage in logistical and organisational aspects (e.g. secretarial and archive management) and prolonged waiting lists, as well as poor accessibility to structures (n = 2).

*Lack of paediatric anaesthesiological care*

In this group, we included all the answers that refer to the conditions of absence of a dedicated staff of paediatric anaesthesiology (n = 6), which is considered crucial when performing objective hearing tests, to ensure appropriate sedation and reliable and early diagnosis (n = 1).

*Limited technical and specific skills*

In this group, we counted all the answers that refer to the limited technical competence of the staff assigned to the management of paediatric hearing impairment (n = 4), such as in performing behavioural hearing tests (n = 4).

*Problems linked to late maturation/unreliable electrophysiological data*

In this group, we embraced all the answers that refer to the topic of the interference of auditory pathway maturation (n = 5) and transient middle ear conditions (e.g. otitis media) (n = 1) with accurate and timely diagnosis.

*Difficult management of late onset hearing loss or lost to follow-up*

In this group, we gathered all the answers that refer to the complex management of “late onset” hearing loss and “lost to follow-up” patients (n = 2), especially in hospitals where the user comes from distant areas (n = 2), living very far from the referral audiological centre.

Other weaknesses reported are issues in the communication with parents (n = 2), especially in the absence of reference professionals (paediatrician, psychologist, child psychiatrist) and the management of large volumes of diagnostic procedures (n = 1).

**Opportunity key points analysis**

The five most frequently cited opportunities were: possible improvement of technology (42%), presence of



dedicated and competent team (35.5%), presence of a standardised diagnostic protocol (9.5%), improved collaboration among healthcare professionals (paediatricians, speech therapists, hearing care professionals, etc.) of the area (6.5%) and implementation of data collected by informal assessments (6.5%) (Table Ic).

We describe and discuss the main themes below.

#### *Improvement of technologies*

In this group, we included all the answers that refer to the elaboration and implementation of new diagnostic technologies (n = 9), through collaboration among companies, basic and clinical research centres (n = 2), in order to improve completeness and reliability of objective audiological diagnosis (n = 2), with the development of new subjective procedures to be implemented as early as possible.

#### *Presence of dedicated and competent team*

In this group, we gathered all the answers that consider the availability of a dedicated and specifically trained team (n = 7), with the improvement of an internal program of organisation (n = 2), with better secretarial and logistical services, and easier access to the structure (n = 2).

#### *Presence of a standardised diagnostic protocol*

In this group, we enclosed all the answers that refer to the realisation of homogeneous standardised and accepted diagnostic pathways within a regional/national audiological “network” (n = 3).

#### *Better collaboration in the territory*

In this group, we took all the answers that refer to the opportunities to strengthen the connections between audiological centre and territorial network (n = 1), highlighting the role of families and paediatricians (n = 1). We also report, in addition to audiological measures, the data collected by informal assessments [information from parents (n = 1), observations of caregivers about auditory behaviour (n = 1)].

#### *Threats key points analysis*

The five most frequently cited threats are: limited economic resources (21.9%), technical limits (false positives, prolonged time of execution) (18.8%), difficult relationships with families and limited cooperation (15.6%), difficult management of extraterritorial patients and of families with different cultural backgrounds (15.6%) and legal aspects (12.5%) (Table Id).

We describe and discuss the main themes below.

#### *Limited economic resources*

In this group, we enclosed all the answers that refer to the lack of funds available to ensure establishment and strengthening of training and updating courses (n = 3) for all operators involved, to promote and support (n = 3) awareness-

raising and information (families, paediatricians), to ensure an adequate technological support (n = 1) and to sustain the efficient organisation of referral centres.

#### *Technical limitations*

In this group, we enclosed all the answers that refer to the limitations of current available diagnostic technologies, meaning either the uncertainty of the audiometric threshold for the middle and low frequencies (n = 3), or the need to use sedation during objective tests (n = 3).

#### *Difficult relationship with families for limited cooperation*

In this group, we incorporated all the answers that refer to the management of relationship with families that do not always allow an ideal setting for performing subjective tests (n = 2) and or to perform sedation when needed (n = 3).

#### *Difficult management of extraterritorial patients/cultural background*

In this group, we gathered all the answers that refer to the difficulties encountered in achieving diagnostic information on the family, which is not always willing to accept the audiological diagnosis or the diagnostic workup. This could be an issue in centres where users are often multicultural (n = 2), with the difficulties encountered in the management of diagnostic pathway for the extraterritorial patient (n = 3), considering the lack of a good internal and territorial organisational network.

#### *Legal aspects*

In this category, we included all the answers concerning the improvement of the policies (n = 4) that are prerequisites to obtain the necessary legal and economic support. In addition, other reported threats are: difficult management of patient “late onset” cases or “lost to follow-up” patients (n = 2), inadequate fitting of hearing aid (n = 1), low reliability of behavioural tests in children with cognitive deficits (n = 1) and misinformation (n = 1).

## **Discussion**

The objective of this analysis was to obtain general recommendations regarding the activity of “defining the type, degree and audiogram shape of hearing impairment within 3-6 months of life if the hearing loss was identified through the UNHS, or within one month from hearing impairment identification if the child was referred after a neonatal age”. Starting from the SWOT analysis data, a TOWS matrix was created, which compares Strengths-Opportunities, Weaknesses-Threats, Weaknesses-Opportunities, eventually offering recommendations and directions that can constitute an effective starting point for prospective planning and innovation, in particular for tertiary care audiology centres.

Analysing and discussing the data obtained from this research, 16 recommendations were obtained (Table II), grouped in four main areas, which identify strategies directed to minimise external obstacles and enhance opportunities:

1. To have a competent and dedicated working group, constantly updated, able to make a comprehensive audiologic evaluation, supported by all reference professional.
2. To use a validated diagnostic protocol, with reference to scientific progress and national and international standards, which includes integration of clinical and instrumental data; to promote the development of clinically available procedures through collaboration between companies and research centres, in order to obtain improvement and spreading of diagnostic technologies.
3. To improve collaboration and communication between tertiary care audiological centres and territorial references (families, family paediatrician, territorial rehabilitation), promoting awareness and information at the local level, thus facilitating the access to tertiary care audiology centres for families.
4. To obtain or to improve legislation and regulations regarding early hearing impairment detection and interventional programmes, in order to create conditions that facilitate economic and organisational support by institutions.

The first strategy includes establishing and maintaining of a competent and dedicated working group that is able

to comprehensively and reliably manage the audiologic evaluation of a newborn or a young child, which respects the time needed to activate the rehabilitative programme. The audiologic team needs to be supported in the diagnostic phase by other referral professionals (i.e. clinical geneticist, paediatric neuropsychiatrist, anaesthesiologist) who are skilled in childhood audiologic and developmental issues. The anaesthesiologist is often essential in audiologic diagnosis to ensure adequate conditions of examination, especially in complex cases. The importance of presence/availability of a paediatric anaesthesiologist was strongly emphasised by the participants of this SWOT analysis.

Having a competent and cohesive working group that operates in logistically and structurally appropriate conditions is the foundation for the second most complex strategy: implementation of a validated diagnostic protocol, which refers to scientific evidence and to national and international standards, and that is based on integration of clinical and instrumental data. Clinical data essentially include general clinical and otoscopic examination and medical history, paying special attention to audiological risk factors revision and to parental observations about the child's auditory behaviour.

Regarding instrumental data, it is widely accepted that audiologic evaluation in the first year of life must be based on all objective data gathered from the following measurements: immittance measures (including tympanometry, preferably with probe tone of 1000 Hz in the first 6 months of life,

**Table II.** TOWS matrix (see text for explanation).

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	<p><b>SO strategy</b></p> <ol style="list-style-type: none"> <li>1. Having a competent and dedicated working group that is able to perform a complete audiological evaluation, with presence of anaesthesiologic care</li> <li>2. Using a validated diagnostic protocol, with reference to national and international standards, that includes integration of clinical and instrumental data</li> <li>3. Implementation of connections between audiological centre and territorial network and easy access to audiological centre</li> </ol>	<p><b>WO strategy</b></p> <ol style="list-style-type: none"> <li>1. Encouraging collaboration between companies and research centres for the improvement of diagnostic technologies (determination of audiometric threshold including medium/severe frequencies)</li> <li>2. Improvement of service organisation and of access to the diagnostic pathway, through a territorial network, in collaboration with families and paediatricians</li> <li>3. Obtaining adequate anaesthesiologic assistance</li> <li>4. Development of appropriate regulations for the control of variability "non-pathological" factors (maturation/structural development) of results, to increase reliability and reduce diagnostic timing</li> <li>5. Promoting the development of new diagnostic subjective procedures to apply in the first year of life</li> </ol>
	Threats (T)	<p><b>ST strategy</b></p> <ol style="list-style-type: none"> <li>1. Obtain or improve legislation and regulations of early detection programme of hearing loss</li> <li>2. Encourage and support awareness and information at local level, intending families and paediatricians</li> <li>3. Promoting/soliciting the increase of economic resources</li> <li>4. Introducing other professional figures into the "audiological" team (psychologist, child psychiatrist) with specific expertise for audiological problems, also improving integration with families</li> <li>5. Establish or strengthen forms of training and updating for all operators involved</li> </ol>	<p><b>WT strategy</b></p> <ol style="list-style-type: none"> <li>1. Improving internal expertise and follow strictly decisional diagnostic pathways</li> <li>2. Presence of a dedicated staff and of a constant good organisation of referral centre to optimise diagnosis</li> <li>3. Obtaining greater resources to organise educational days would minimise the effects of multiculturalism</li> </ol>

and ipsilateral and contralateral cochleo-stapedial reflexes thresholds); diagnostic oto-acoustic emissions (transients or distortion products, i.e. TEOAEs or DPOAEs); electrophysiology (i.e. electrocochleography, auditory brainstem responses (ABR), and cortical auditory potentials). An ABR is obtained by air conducted transient stimuli (click), eventually integrated by bone conduction testing, when there is a doubt about the conductive component/nature of hearing loss. The examination should include the use of frequency-specific stimuli (low frequencies) when there are doubts or it is necessary to better define the audiometric configuration. This aspect can become critical both in hearing impairment with differential high- or low-frequency involvement, in which click ABR measurements can cause false positive (overestimation of hearing threshold) or false negative results (underestimation of hearing threshold), respectively. Along with tone-burst stimuli<sup>7,8</sup>, the results obtained with the recently introduced “CHIRP”, spectral default composition stimuli, appear promising<sup>9,10</sup>.

The specific informative content of each diagnostic procedure contributes to a comprehensive audiologic evaluation that allows in most cases the definition of the main characteristics of hearing impairment that are propedeutic to the therapeutic choices<sup>11</sup>.

This SWOT analysis emphasised the possibility of potential ambiguity and complexity in diagnostic evaluation, which can be attributed to various conditions. The first and most common problem is the coexistence of a conductive component of the hearing loss, which is a frequent condition in early childhood, this condition can be evidenced by otoscopy and tympanometry. The condition does not represent a significant problem if the estimated ABR hearing threshold is measured within 40 dB HL. Beyond this limit, electrophysiological data cannot always differentiate the main type of hearing impairment, i.e. the distinction between a conductive or sensorineural hearing loss or the amount of the conductive component of a mixed hearing impairment. The ambiguity is not always easy to overcome in these cases, and can lead to wrong therapeutic choices or delayed diagnosis.

An additional aspect of variability and diagnostic error (mainly overestimation of hearing impairment) involves the “development” of the hearing system, especially in its neural component and electrophysiological data. Maturational phenomena involve the whole auditory system, from the periphery to the cortex, but they are especially supported by processes of myelination and synaptogenesis of neural structures<sup>12</sup>. These phenomena are well known and demonstrated in many studies<sup>13,14</sup> concerning the effects on evoked potentials in time domain in normal subjects.

In the neonatal period, in particular in pre-term infants or in infants hospitalised in intensive care units (ICU)<sup>15-17</sup> various conditions are frequently associated with alterations of electrophysiological epiphenomena of maturational processes (increased the latency and threshold of evoked potentials).

Other conditions of possible “interference” during audiologic diagnosis are represented by cases of “downstream sensory function” compartment (cyto-neural junction, VIII nerve, central auditory pathways) dysfunction, where the impairment of temporal and dynamic characteristics of afferent neural activation may cause important clinical effects on verbal perception and a deterioration or disappearance of electrophysiological responses. These audiologic profiles were initially named “auditory neuropathy”<sup>18</sup> and later included in the group of diseases described as “synaptopathy” or “dyssynchrony”. They are also found in the neonatal period and, again, most commonly in pre-term infants usually hospitalised in the ICU. These conditions are able to sustain a mismatch between good peripheral capabilities (middle ear-cochlea) and an abnormal function of afferent pathway “downstream” to the cochlea. It may cause a wrong diagnosis of hearing impairment or its even extreme overestimation<sup>6</sup> that is not always predictable by medical history.

The presence and the possible coexistence of these interfering conditions can complicate audiologic diagnosis. An extreme situation is represented by cases with no ABR responses that lead to a diagnosis of a severe/profound sensorineural hearing impairment, with an estimated threshold equal to or higher than 90 dB HL. This result may, in fact, match several conditions: a profound hearing impairment that represents a primary indication for a cochlear implantation; a cochlear hearing impairment rapidly decreasing for frequencies beyond 500/1000 Hz; a moderate or moderate-severe hearing impairment associated with a coexistent conductive component or neural dysfunction. These uncertainties may not be always resolved, even with careful integration of results by different diagnostic methods. It is therefore mandatory to apply careful clinical/audiologic tools and frequent subjective and objective audiometric monitoring. It is author’s opinion that severe/profound hearing impairment cases should be considered for a cochlear implant selection process after 6-8 months of age in infants without associated audiologic risk factors, and by 70-85 weeks of corrected age in pre-term infants<sup>17</sup>. Complex cases should be considered for electrocochleography (ECochG) with trans-tympanic derivation, as a second choice procedure. The trans-tympanic optimises the assessment of auditory periphery level and provides unique information for differential diagnosis of cytoneural/neural compartment dysfunctions<sup>6,19,20</sup>. At this stage of audiological childhood diagnosis, we must also consider the steady-state auditory evoked potentials, which are able to provide a high frequency specificity in estimating the audiometric threshold (80-100 Hz SSR), even if there are no data concerning reliability and applicability of this time consuming method<sup>21,22</sup>.

Audiologic centres of second or, even more, third level (where comprehensive diagnosis is performed) must be able to apply and interpret all diagnostic procedures. While in most cases test is obtained in spontaneous sleep, it is nec-

essary that the structure provides conditions for pharmacological sleep induction or narcosis for children in whom there is a higher risk of diagnostic delays. This is, for example, the case of patients with critical clinical conditions, or those coming a long way off.

Audiologic centres should adhere to strict standards<sup>4</sup> and it is hoped that initiatives are taken at national level to define shared practices. The centre should, however, take all measures (development of own rules, calibration and maintenance of instruments) aimed at controlling the biological (age/maturity, etc.) and non-biological factors (type and method of acoustic stimulation, etc.) which can be a source of diagnostic errors.

Current procedures of subjective behavioural audiometry are considered as having a limited role in early audiological diagnosis, although their value grows in the first year of life and acquires a decisive role in the diagnostic and rehabilitative process, especially in cases selected for CI. There is a strong need to develop new and reliable behavioural evaluation procedures that can be appropriate since the first months of life. Improvements and further developments of subjective and objective procedures is expected, although there are methodologies that guarantee adequate reliability in early audiological diagnosis. They can be achieved only by enhanced collaboration between clinical and basic research centres, and companies of diagnostic equipment production and distribution.

Another recommendation involves the diagnostic “formalisation” and professional-family alliance. A full audiological diagnosis should include the results and their significance in a complete and clear style, including explicit indications for rehabilitation. The report should be given to the family and to the operators involved in the prospective management of the young patient (hearing aid professional, speech therapist, paediatrician etc.)<sup>5,23-25</sup>. Clear and complete information is the core of childhood audiological diagnosis and is the foundation of the management alliance among all those professionals (healthcare operators, pedagogical and social workers, family) who are part of the rehabilitation programme. SWOT participants consider this approach as an appreciated and an essential element for its success.

The third identified strategy concerns access to the diagnostic process and services through an extensive network in the area, in cooperation with families and family paediatricians, which recalls the principle of an approach based on a well-founded alliance among all the figures and institutions involved in the diagnostic and intervention programme for hearing impairment. Having good internal organisation would reduce the number of “lost to follow-up” cases and obtain maximum accuracy and timeliness in diagnosing “late onset” hearing impairment cases. This has been reported as particularly important for the large referral centres that frequently treat children

and families that come from far away. Creating a single network between the third level centre and the territory resources would allow more effective management of medical treatment of common respiratory infections and associated conductive hearing impairment, or other conditions that affect the auditory system. Moreover, they can ease the organisation of training and update courses for healthcare professionals and public information and awareness campaigns. Diagnostic information has to be provided to the family in a clear and explicit manner, in terms of both therapeutic indications and prognosis and expectations. Diagnosis has to be accurate and formalised in an understandable report. It should be addressed to the family and the family paediatrician, whose cooperation is central for diagnosis, control of variability factors or diagnostic confusion, and of course future follow-up and treatment. The existence of an effective network can guarantee accurate information and ensure an easy access to audiologic centres, achieving the goal of making easier and faster the contact with the family.

The fourth strategy concerns legislative and regulatory issues that are the prerequisites for obtaining adequate legal and administrative support. It is certainly possible to achieve operational improvements through organisational and procedural adjustments inside the centres, although this analysis highlighted that substantial changes cannot be separated from normative, legislative and, accordingly, economic aspects. Enhancement of didactical aspects, improvement of information and connection methods, acquisition of new tools and validation of new procedures are all necessarily subordinated to economic aspects. Considering the current situation characterised by limited resources and a progressive contraction in healthcare expense, the group opinion emphasised the requirement of a commitment that can raise the awareness of national policymakers and administrative managers, of local authorities and in its operating area about the importance and the effectiveness of early diagnostic and treatment programs for childhood hearing impairment.

## Conclusions

In the field of audiological diagnosis, first of all diagnosis should come from a competent and constantly updated dedicated working group. Secondly audiological evaluation should be based on a validated diagnostic protocol, with reference to national and international standards, which includes integration of clinical and instrumental data. Thirdly collaboration and communication between the audiological centre and territorial referent should be optimised, lastly obtaining or improving legislation and regulations regarding the program of early hearing loss detection are necessary requirements to create the conditions to facilitate economic and organisational support by institutions.



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# Aetiologic diagnosis of hearing loss in children identified through newborn hearing screening testing

## *Diagnosi eziologica dell'ipoacusia nei bambini identificati attraverso lo screening audiologico neonatale*

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### SUMMARY

With the implementation of universal newborn hearing screening (UNHS) programmes and early diagnosis and treatment of hearing problems, the need has clearly emerged to implement and carry out a systematic and coordinated protocol for the aetiological diagnosis of permanent hearing impairment (PHI). Within the framework of the Italian Ministry of Health project CCM 2013 "Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children", it has been decided to consider the problems relative to aetiological diagnosis of child PHI within UNHS programmes. The specific objective was to apply a shared diagnostic protocol that can identify the cause in at least 70% of cases of PHI. For this part of the project, four main recommendations were identified that can be useful for an efficient aetiological diagnosis in children affected by PHI and that can offer valid suggestions to optimise resources and produce positive changes for third-level audiologic centres.

KEY WORDS: Aetiology • Hearing loss • Children • Newborn hearing screening • SWOT analysis

### RIASSUNTO

*Parallelamente alla attuazione dei programmi di screening audiologico neonatale e di diagnosi audiologica e trattamento precoci, si è resa evidente la necessità di mettere a punto e attuare un protocollo per la diagnosi eziologica della sordità, che sia sistematizzato e che si coordini, senza interferire, con il percorso diagnostico audiologico. Nell'ambito del progetto del Ministero della Salute CCM 2013 "Programma regionale di identificazione, intervento e presa in carico precoci per la prevenzione dei disturbi comunicativi nei bambini con deficit uditivo" è stata presa in considerazione la problematica relativa alla diagnosi eziologica della ipoacusia infantile nell'ambito dei programmi di screening audiologico neonatale. L'obiettivo specifico è quello di attuare il protocollo diagnostico per ottenere una definizione della causa della ipoacusia in almeno il 70% dei casi con diagnosi audiologica confermata. Nell'ambito di questa parte del progetto, sono state individuate quattro principali raccomandazioni utili nella ricerca di una diagnosi eziologica nei bambini affetti da ipoacusia, che possono costituire, per i centri audiologici di III livello, dei validi suggerimenti per ottimizzare le risorse e produrre cambiamenti positivi.*

PAROLE CHIAVE: *Eziologia delle ipoacusie infantili • Screening uditivo neonatale • Analisi SWOT*

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### Introduction

With the implementation of UNHS programmes and early diagnosis and treatment of hearing problems<sup>1,2</sup>, to implement and carry out a systematic and coordinated protocol for the aetiological diagnosis of permanent hearing impairment (PHI) has clearly emerged. In this respect, progresses in molecular genetics and in the treatment of pre- and perinatal infections have improved both diagnostic and therapeutic possibilities in the fields of congenital and prelingual PHI, so today an accurate and early

aetiological diagnosis plays an even more important and sometimes decisive role. Consequently, once the identification of PHI has been made, it is advisable to implement a well-structured programme for aetiological diagnosis based on a multidisciplinary approach<sup>3</sup>.

Concerning the treatment and management of children with hearing problems, the early identification of the causes of the disorder offers a number of advantages: it can avoid expensive and unnecessary tests, provide psychological benefits to relatives who are made aware of the causes of the impairment, offer important genetic infor-

mation both for the child and the family, and supply prognostic information, which can help identify risk factors, prevent complications, and allow an early diagnosis of associated problems, with the possibility to prevent the effects of the disorder. The information obtained from aetiological diagnosis can therefore be useful in the management of the child with PHI.

The importance of an aetiological diagnosis is underlined by the recent position statements of the Joint Committee on Infant Hearing of 2007 and 2013, in which it has been recommended that every newborn diagnosed with PHI should start a protocol for diagnostic assessment of the causes of the disorder<sup>1,2</sup>. However, in many of the newborn hearing screening protocols, the possibility of carrying out an aetiological diagnosis is not taken into account. Within the framework of the Italian Ministry of Health project CCM 2013 "Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children", it has been decided to consider the problems relative to the aetiological diagnosis of childhood PHI in UNHS programmes. As a result, one of the objectives was to obtain an early aetiological diagnosis through the implementation of uniform and timely procedures, in particular with regard to common causes (CMV, GJB2/GJB6 mutations, inner ear malformations). The specific aim was to apply a shared diagnostic protocol that can identify the cause in at least 70% of cases of PHI.

## Material and methods

A review of the international literature was made to collect information, aiming at a strategic analysis of the activities associated with aetiological diagnosis. The achieved data were then analysed, taking into account the current protocols and programmes of aetiological diagnosis for evaluation of the positive and negative aspects of the entire process.

This first evaluation allowed us to perform a preliminary SWOT analysis (Strengths, Weaknesses, Opportunities, Threats) on aetiological diagnosis. SWOT analysis was performed by reporting the following: Strengths, S; Weaknesses, W; Opportunities, O; and Threats, T in aetiological diagnosis. In SWOT analysis, Strengths and Weaknesses were referred to the inner aspects of the system under examination, while Risks and Opportunities regarded the external conditions that can affect system performance. The achieved data were examined, discussed and integrated by a team of 21 professionals involved in the prevention, diagnosis and treatment of newborn hearing impairment (audiological physicians, otolaryngologists, audiometrists, speech therapists, paediatricians, psychologists, audioprosthesis and clinical specialists for cochlear implants, families) in third-level centres in which UNHS programmes are available. In

order to obtain recommendations and general guidelines from SWOT analysis, a TOWS matrix was created, which allowed combining strengths with opportunities (strategy S-O), strengths with threats (strategy S-T), weaknesses with opportunities (strategy W-O) and weaknesses with threats (strategy W-T). The detailed description of the SWOT and TOWS matrix analysis procedure can be found elsewhere in this issue.

## Results

This article will discuss the problems of SWOT analysis carried out by the team of expert operators, and the final TOWS analysis constructed on the basis of the results obtained. The working team provided 32 answers for category S, 44 for category W, 30 for category O and 30 for category T, for a total of 136. These data were then grouped according to type and area of reference. The main key points obtained are listed in Table I.

### *Strength key points analysis*

Four main topics emerged from SWOT analysis, which represent the strengths featuring the area of aetiological diagnosis: the existence of a protocol for aetiological diagnosis (46.87%), multidisciplinary collaboration (34.37%), facilitated access to audiologic assessment (12.5%), communication to the families of the outcomes of diagnosis (6.25%). These strengths can be analysed in further detail:

#### *Existence of protocols for aetiological diagnosis used in some third-level audiologic centres*

This category contains all the replies concerning the possibility of structuring a shared protocol for the achievement of an aetiological diagnosis, starting from the protocols used in some structures. The presence of a shared protocol could allow third-level centers to standardise methods and procedures for aetiological diagnosis. The access to aetiological data is extremely important because it can help to better delineate future progress in child development, by addressing the therapeutic choices in a safer and more conscious manner. In order to optimise the procedure of aetiological investigation, a point of strength is represented by the possibility to carry out the diagnostic programme in a single centre in which all involved specialists are present (audiological physician, otolaryngologist, paediatrician, ophthalmologist, child neuropsychiatrist, geneticist, radiologist, etc). In order to favour participation, prenatal diagnostic protocols could be activated at the Departments of Neonatology to allow precocity of intervention.

#### *Multidisciplinary collaboration*

This category contains all the replies concerning multidisciplinary collaboration among the professionals involved

**Table I.** Main key points extrapolated from questionnaires.**Table Ia.** *Strengths.*

Strength key points	Frequency (%) (n = 32)
Existence of a protocol for aetiological diagnosis	15 (46.87%)
Multidisciplinary collaboration	11 (34.37%)
Facilitated access to audiologic assessment	4 (12.5%)
Communication to families of the outcomes of diagnosis	2 (6.25%)

**Table Ib.** *Weaknesses.*

Weakness key points	Frequency (%) (n = 44)
Lack of standardisation in the procedures	12 (27.27%)
Scarce multidisciplinary collaboration	9 (20.45%)
Difficulty of communication with the family	6 (13.63%)
Limited knowledges	6 (13.63%)
Management Difficulties	6 (13.63%)
Scarce information technology for data collection	5 (11.36%)

**Table Ic.** *Opportunities.*

Opportunity key points	Frequency (%) (n = 30)
Implementation of shared protocols for aetiological diagnosis	10 (33.3%)
Shared database for aetiological data collection	9 (30%)
Multidisciplinary collaboration	9 (30%)
Other	2 (6.6%)

**Table Id.** *Threats.*

Threats key points	Frequency (%) (n = 30)
Resources	9 (30%)
Scarce standardisation in the approach to aetiological diagnosis	9 (30%)
Difficulty in communication	7 (23.3%)
Lack of legal support	3 (10%)
Other	2 (6.6%)

Table I (a b c d) The table shows the frequency of the topics that emerged in the categories Strength, Weakness, Opportunity and Threat. (n = 231)

in the procedure of aetiological investigation, more or less systematic, currently adopted in some third-level audiologic centres.

Due to the variety of the investigation's multidisciplinary collaboration, this represents an important resource for the entire procedure of aetiological research. In particular, paediatric (dismorphological paediatrics) and genetic counselling have proven to be an important factor for early detection of PHI associated with other syndromes.

#### *Facilitated access to audiologic assessment*

This category contains all the replies concerning facilitated access to audiologic diagnosis. Facilitated access to au-

diologic assessment and short waiting times are essential for early identification of impaired hearing and to be able to rapidly start the entire process of aetiological research.

#### *Communication to the families of the outcomes of diagnosis*

This category contains all the replies concerning the communication of aetiological diagnosis to families. The identification of PHI aetiology is an important requirement for many parents, and for this the family should be informed about the outcomes of the various aetiological investigations, and on the possible prognosis of their child development.

#### *Weakness key points analysis*

Six main topics emerged from SWOT analysis, which represent the Weaknesses featuring the area of aetiological diagnosis: lack of standardisation in diagnostic procedures (27.27%), limited multidisciplinary collaboration (20.45%), difficulties in communication with the family (13.63%), limited knowledge (13.63%), management difficulties (13.63 %) and obstacles in data collection (11.36%) (Table IIIb). These weaknesses can be analysed in further detail:

#### *Lack of standardisation in procedures*

This category contains all the replies concerning the lack of standardisation in the procedures relative to implementation of an aetiological diagnosis, associated with the lack of a universally shared protocol (at least on a national scale). The identified weaknesses are mainly due to the absence of guidelines for the treatment of the patient, both regard to times and modalities, resulting in a "personal" management of aetiological diagnosis. Difficulties reported in the management of diagnostic protocols are even greater in patients with syndromic PHI.

#### *Scarce multidisciplinary collaboration*

This category contains all the replies concerning multidisciplinary collaboration among the team members participating in the definition of aetiological diagnosis. Collaboration problems are strictly connected to the difficulties in disseminating and sharing the results of the aetiological investigations submitted to the patient by the staff members (e.g. outcomes of post-natal virologic diagnosis), and to the obstacles in coordinating the different diagnostic activities, especially when the professionals involved are not working in the same structure. Communication with the territorial Service and Paediatric Neuropsychiatry has proved to be particularly difficult.

#### *Difficulty of communication with families*

This category contains all the replies concerning the difficulties in communicating with the family of the hearing impaired child. The first difficulty emerges from the fact

that the family is not always given a clear and complete explanation of the entire programme, and therefore parents cannot understand the importance of defining aetiological diagnosis and of the different steps involved in the diagnostic process. Another critical point is represented by transmission of the test results from the third-level laboratory (genetic and other tests) to the child's family. The communication difficulties increase when the patient's place of residence is distant from the audiologic centre of reference.

#### *Limited knowledge*

This category contains all the replies concerning the limited knowledge of some aspects of aetiological diagnosis. The availability of limited epidemiological data is associated with the partial knowledge of a definite aetiological diagnosis. There are also limited data in relation to the sensitivity and specificity of the various tools of aetiological investigation.

#### *General management difficulties*

This category contains all the replies concerning the general management difficulties concerning the process of aetiological diagnosis. The most relevant point of weakness is represented by the presence of long waiting-times to obtain diagnostic tests and consequently to obtain the necessary clinical data for an aetiological diagnosis. Other critical points concern the absence of dedicated staff and the costs necessary for diagnostic tests.

#### *Difficulty in collecting data*

This category contains all the replies concerning the collection of aetiological diagnostic data. The lack of uniformity in data collection standards, the impossibility of telematic data sharing and the absence of shared databases make the exchange of information between the problematic for the different specialists involved in the aetiological research to exchange information, determining an incomplete collection of the elements necessary to reach a diagnosis.

#### *Opportunities key points analysis*

Three main topics representing the Opportunities characterising aetiological diagnosis emerged from SWOT analysis: implementation of shared protocols for aetiological diagnosis (33.3%); shared database for the collection of aetiological data (30%); multidisciplinary collaboration (30%). These points of strength can be analysed in further detail:

#### *Implementation of shared protocols for aetiological diagnosis*

This category contains all the replies concerning the advantages of diagnostic aetiological protocols for the implementation of shared protocols. All third-level centres must be highly specialised, and possess the tools and competences for aetiological assessment in their institutes, or

within affiliated structures. The study of CMV represents a major field of investigation for the general protocol of aetiological research. Gynaecologist and parents should be sensitised on this issue so as to promote early aetiological diagnosis, by activating protocols of prenatal screening for the research of CMV during pregnancy.

#### *Shared database for the collection of aetiological data*

This category contains all the replies concerning the advantages of a database for the collection of aetiological data that could lead to the creation of shared databases. The availability of these databases could promote the exchange of information among the different specialists involved, and could allow the collection of useful epidemiological data, and to establish guidelines for treatment.

#### *Multidisciplinary collaboration*

This category contains all the replies concerning the advantages of multidisciplinary collaboration. The communication network represents a strong need within the process that will allow audiologists, otolaryngologists, neonatologists and family paediatricians (to mention only some of the specialists) to perform aetiological diagnosis. All professionals of the multidisciplinary team (physicians and paramedics) need to possess some basic knowledge on the main stages of the process: aetiology of PHI, investigation methods of the main causes and prognosis of development for each aetiological factor. The possibility to access training opportunities could be useful for knowledge standardisation.

#### *Threats key points analysis*

From the SWOT analysis four main topics emerged, which represent the risks characterising the area of aetiological diagnosis: lack of resources (30%), insufficient standardisation in the approach to aetiological diagnosis (30%), difficulties in communication (23.3%) and lack of legal support (10%). These risks can be analysed in further detail as follows:

#### *Resources*

This category contains all the replies concerning the risks derived from the lack of resources, associated with the difficulties in covering the healthcare costs necessary to conduct an aetiological investigation.

#### *Scarce standardisation in the approach to aetiological diagnosis*

This category contains all the replies concerning the risks derived from the limited standardisation in approaching aetiological diagnosis. The lack of uniformity is most evident considering the competences of the third-level centres situated on the national territory, and it is likely to be related to the lack of shared guidelines. The training and the preparation of centres involved in aetiological diagnosis is variable, and diagnosis can be underestimated.



Furthermore, the resources for detection may be invested in a partial and unorganised way.

*Difficulties in communication*

This category contains all the replies concerning the Risks derived from the difficulties of communication in the field of aetiological research. The lack of communication between the different professional figures involved represents a risk for aetiological diagnosis and for future management of outcomes. In particular, there is a risk correlated to partial communication of the results during aetiological tests performed in third-level centres.

The difficulties in communication involve not only professionals, but also impair communication between health-care operators and parents. Parents may sometimes show a scarce interest in the programme of aetiological diagnosis since they cannot understand its importance. The difficulties in communicating with the family are increased in all the situations in which there is social discomfort, and the lack of resources can make it even more difficult to adhere to the protocols of aetiological diagnosis. The cultural background is also important for an efficient communication. Difficulties in communication can also be enhanced by the presence of families with different cultural backgrounds. In these cases, the search for the causes of PHI may assume a more or less relevant connotation.

*Lack of legal support*

This category contains all the replies concerning the risks deriving from the lack of legal support. The lack of legal support defining requisites and competences of the third-level centres regard to aetiological diagnosis represents a risk for the standardisation of the approaches to aetiological diagnosis.

**Discussion**

The TOWS matrix, which relates Strengths-Opportunities, Strengths-Risks, Weaknesses-Opportunities, Weaknesses-Threats, was created starting from the data of SWOT analysis. An analysis of this type allowed to compare internal and external aspects to the system, to obtain specific recommendations and guidelines for the optimisation of the process of aetiological diagnosis. The recommendations can constitute an excellent cause for reflection for third-level audiologic centres, and can supply suggestions to optimise resources and produce positive changes. A total of 17 recommendations were obtained from the analysis and discussion of the data (Table II). From the strategic study performed it was possible to identify four principal areas representing the strongest elements of strength for aetiological diagnosis. The drawbacks should be minimised and the opportunities implemented:

- implementation of shared protocols for aetiological diagnosis of infant hearing loss and definition of a shared

**Table II.** TOWS matrix (see text for explanation).

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	<p><b>SO strategy</b></p> <ol style="list-style-type: none"> <li>1. Implementing shared protocols for aetiological diagnosis of infant hearing loss</li> <li>2. Defining shared timing of the different investigations included in the protocol of aetiological assessment</li> <li>3. Creating structured and formalised multidisciplinary teams for audiologic, medical and aetiological assessment of children with impaired hearing</li> <li>4. Implementing a database or information system for data storage and exchange of information among various professionals</li> <li>5. Optimising times and modes of communication to the families on the importance of aetiological diagnosis, investigation programs, results of tests and their meanings</li> </ol>	<p><b>WO strategy</b></p> <ol style="list-style-type: none"> <li>1. Establishing and standardising times and modes of access to the structures and specialists involved in aetiological diagnosis</li> <li>2. Optimising and standardising the collaboration of the multidisciplinary team</li> <li>3. Improving communication among the members of the multidisciplinary team by implementing databases or information systems, or moments of multidisciplinary meetings</li> <li>4. Promoting systems of information and training addressed both to the operators forming the multidisciplinary team and to the families on the importance and meaning of aetiological assessment</li> </ol>
	Threats (T)	<p><b>ST strategy</b></p> <ol style="list-style-type: none"> <li>1. Optimising resources for the implementation of standardised and shared protocols for aetiological diagnosis</li> <li>2. Optimising the modes of access to the structures/operators involved in aetiological investigations to streamline procedures and reduce waiting times</li> <li>3. Improving communication among healthcare operators, and between operators and families by exploiting, optimising and exporting database and information systems available in some regional realities and dedicated personnel of associations</li> <li>4. Identifying moments shared between operators and families to communicate the results of the aetiological examinations and of their meanings</li> </ol>	<p><b>WT strategy</b></p> <ol style="list-style-type: none"> <li>1. Motivating institutions and associations on the importance of operator training</li> <li>2. Involving the associations in informing the families on the importance and meaning of aetiological assessment</li> <li>3. Stimulating the institutions and associations on the need for legal support, by fostering the implementation and realisation of protocols for aetiological diagnosis</li> <li>4. Sensitising institutions and associations on the importance of databases and systems for the collection and exchange of information concerning aetiological diagnosis programmes</li> </ol>



timing program concerning the different investigations included in the protocol of aetiological assessment;

- creation of structured and formalised multidisciplinary teams for audiologic, medical and aetiological assessment of children with PHI;
- implementation of databases or information systems for data storage and exchange of information among various professionals;
- optimisation of times and modes of communication to families on the importance of aetiological diagnosis, investigation programmes, results of tests and their meaning.

The first recommendation concerns the necessity to include the child with confirmed diagnosis of hearing impairment in national protocols for aetiological diagnosis. Adherence to audiologic protocols for neonatal screening and consequent early diagnosis of child hearing impairment are associated with the need to reach an aetiological diagnosis within the first months of life<sup>1,2</sup>. In compliance with JCIH, every child confirmed with the diagnosis of impaired hearing should be included in a diagnostic protocol aimed at determining the cause of the problem<sup>1,2</sup>. The definition of the aetiology of deafness provides important prognostic information both for the evolution of the defect for global development of the child and for outcomes of prosthesis-rehabilitation. Furthermore, early aetiological diagnosis can favour the identification of problems associated with PHI, by facilitating the activation of a targeted and prompt recovery intervention, and provide important information for parent and family from both a genetic and prognostic point of view. No shared protocols currently exist (at a national level) for aetiological diagnosis in UNHS *referent* children, in which the presence of impaired hearing has been confirmed. Each Centre of Reference (III level) conducts the search independently using the means available.

From the study of the literature it appears evident that the UNHS programs envisage structured and shared protocols for aetiological and medical diagnosis, alongside the protocol of audiologic diagnosis. In this respect, Declau et al. have reported a protocol for aetiological diagnosis applied to *refer* newborns at UNHS for which the PHI presence was confirmed<sup>4</sup>. The screening allowed to identify the causes of PHI in around 50% of cases. Leenheer et al. proposed a step-by-step protocol for aetiological assessment of *referred* newborns at screening, with confirmed diagnosis of impaired hearing<sup>5</sup>. More recently, Lemmens et al. implemented a protocol of aetiological diagnosis which they applied to a group of 505 children with confirmed diagnosis of PHI, through which they managed to identify the cause of impaired hearing in approximately 1/3 of cases<sup>6</sup>. In 2014, the American College of Medical Genetics and Genomics published guidelines for clinical assessment and aetiological diagnosis of impaired hearing, and faced the problem of prelingual hearing impairment<sup>7</sup>.

The congenital infection from CMV represents a meaningful example of the importance of early aetiological diagnosis. At present, congenital infection from CMV seems to be the only significant infectious pre-natal cause of congenital or prelingual hearing impairment, owing to the fact that toxoplasmosis, epidemic parotitis and rubella have become rare thanks to the prevention performed during pregnancy and vaccination campaigns. In industrialised countries, moreover, congenital infection from CMV is estimated to be the most common congenital infection, with a prevalence at birth around 0.3-0.6%<sup>8</sup>; therefore, congenital infection from CMV is currently considered the major non-genetic cause of childhood hearing impairment. Approximately 10% of newborns with congenital infection are symptomatic at birth, and among these there is a high risk of developing neurological *sequelae*, including neurosensory PHI. Of the remaining 90% of asymptomatic newborns, around 6-23% have or will develop PHI<sup>8</sup>. In case of congenital infection from CMV, hearing impairment can be present at birth or can occur months or even years after birth, and in more than 50% of cases it has a progressive trend<sup>8</sup>. With regard to the possibility of treating newborns affected by this congenital infection, over the last few years evidence has emerged that antiviral therapy with ganciclovir (intravenous) or valganciclovir (oral) administered in the first month of life can be effective in reducing the risk of neurological problems, and in particular in preventing the progression of impaired hearing<sup>9</sup>. It is important to perform diagnosis of congenital infection of CMV as early as possible, in order to be able to distinguish between congenital and acquired infection, and to offer the child the possibility of pharmaceutical treatment. Today, the method considered to be the most effective is testing for viral DNA in urine or saliva within the first 21 days of life<sup>8</sup>.

To date, from the analysis of literature, there seem to be no neonatal screening programmes for this type of pathology. Within the framework of the general protocol for the research of the aetiology, the study of CMV thus represents an important field of investigation. Implementation of protocols for neonatal screening for CMV infection, restricted to *refer* newborns at neonatal audiologic screening, can be fundamental for early aetiological diagnosis. Recently, Williams et al. published a study on the feasibility of screening for congenital infection from CMV, concluding that saliva screening, aimed at UNHS *referred* newborns, is feasible and well accepted by families, and allows newborns with PHI from congenital CMV infection to benefit from pharmacological therapy with antiviral drugs<sup>8</sup>.

The protocol of neonatal audiologic screening of the Tuscany Region (obligatory from November 2007) expects that the congenital infection from CMV is investigated early in all *referred* newborns with otoemission at screening, through viral DNA testing in urine by PCR. This will

make it possible to distinguish any CMV congenital infection from other infections contracted later<sup>10</sup>. To our knowledge, this type of investigation is not yet routinely performed in other neonatal audiological screening protocols. Moreover, since congenital infection from CMV seems to be a factor predisposing to foetal death in the uterus, premature birth and low-weight conditions due to gestational age (SGA: small for gestational age), our working group has looked for the presence of CMV infection in all SGA newborns and in premature infants admitted to the Operative Unit of Neonatology at the University Hospital in Pisa from November 2005 to April 2009. In the study, an association was found between congenital infection from CMV, premature birth (3.03%) and SGA newborns (3.7%)<sup>11</sup>.

In addition to neonatal investigations for diagnosing congenital infections from CMV, another external possibility is the creation of a network for collaboration among gynaecologists. These specialists are the first to get in contact with the future mothers, and therefore could immediately sensitise them on the problem, favouring early diagnosis of maternal infections from CMV.

The implementation and performance of shared protocols of aetiological assessment would allow to obtain not only an early aetiological and medical diagnosis, with all the benefits mentioned above, but also a common approach among the various structures so as to guarantee greater uniformity of intervention. More precisely, the protocol should establish the times and ways of access to the structures and the various specialists involved, defining the timing of the various investigations. The definition of these aspects could streamline the researching procedures and positively affect healthcare costs. The absence of shared protocols sometimes leads to a useless repetition of the same diagnostic tests on the same child in different centres (e.g. genetic tests), in the event that a family decides to consult various audiological centres, with a waste of resources.

Each third-level audiological centre should possess the competences and means to manage the entire process of etiological research. The possibility of joining only one centre of reference would support the child and its family at the same time, and reduce the dispersion of clinical data.

The second recommendation identified within the field of aetiological diagnosis regards the possibility of structuring a formalised multidisciplinary team for audiological, medical and aetiological assessment of the hearing-impaired child.

The process leading to the definition of an aetiological diagnosis involves operators belonging to different disciplines. The protocol followed by our centre mainly involves the following specialists: audiological physician, geneticist, neonatologist, ophthalmologist, neuroradiologist, child neuropsychiatrist and paediatrician. In a later

stage, and according to the specific needs of the patient, other operators can be involved. Taking on global responsibility for the patient, with integrated interventions, is based on the synergy and collaboration of all the members of the multidisciplinary team, even when they belong to units that are located in different centres. It is important that the professionals involved in the team are connected by a solid and efficient communication network that is able to guarantee a constant and bi-directional exchange of information. Towards this end, the figure of the family paediatrician plays an important role: considering the continuous relation that paediatricians have with the family of the child, their collaboration is fundamental to monitor the development of the aetiological investigation process.

An important aspect of the second recommendation concerns the training of the members of the multidisciplinary team. Participation in a protocol of aetiological diagnosis requires the acquisition of basic notions that allow all the members of the team to understand the importance of the investigations and their prognostic outcomes. An opportunity in this field is represented by the participation in specific training courses. In this regard, we report the positive experience of the Tuscany Region, which organised compulsory training courses for the family paediatrician in the years 2009-2010. The course, divided into two days, faced the main themes of child with PHI, and included a session aimed at checking the knowledge that had been learned. This initiative allowed to give greater uniformity to the audiological knowledge of paediatricians, and had a positive impact on the procedures of management of all at-risk patients as well as of the patients with previously confirmed diagnosis. The possibility of involving institutions and associations, so that they may promote the realisation of specific training projects in the field of childhood hearing impairment, could represent a strategy designed to standardise the know-how of multidisciplinary team members. The third recommendation concerns the possibility for the members of the multidisciplinary team to access databases or systems for the data storage and the exchange of information.

Access to the data concerning aetiological investigations and outcomes by all the professionals of the team can stimulate multidisciplinary collaboration, thus facilitating the exchange of information. Update of information included in the database (tests performed, times, results of the investigations, evaluation gaps, future appointments, etc.) would allow the professionals responsible for the child to check whether the protocol of aetiological diagnosis has been followed correctly or whether further investigation is necessary. In addition, systematic data collection represents an opportunity for the realisation of future studies, both epidemiological, and on the aetiology of child hearing impairment. Within the framework of neonatal audiological screening in the Tuscany Region, a telematic

registry (database) has been established for the collection of data concerning newborns that were *referred* to UNHS. The database will report the audiologic and aetiological outcomes and prosthetic rehabilitation treatment undertaken. The registry will also contain the data concerning *referred* newborns at screening who present elements of risk for progressive hearing impairment, or for late onset, so that they can be followed-up. The registry will need to be constantly updated by the healthcare staff operating at the different levels (neonatology, audiology, third-level centres of reference).

The possibility of referring to a shared database clashes with the risk correlated to the lack of resources, influencing both the design and diffusion of the tool, as well as the scarce availability of the personnel destined to its compilation.

In the absence of a shared database, drafting of the written reports containing the results of the assessments and tests – and also the availability of telephone numbers and e-mail addresses of reference – could favour the exchange of information among healthcare operators.

Even in this case, a major external risk is represented by the impossibility to use the resources that could be exploited to involve the staff responsible for these activities. The final recommendation concerns the need to involve the parents in the plan of definition of aetiological diagnosis. Full adherence to any protocol of aetiological diagnosis requires good parental collaboration. The respect of all these passages is closely correlated to the possibility of understanding the importance of each step for a diagnosis and, in turn, the importance of the diagnosis for the implications it may have on a child's development. The external risks of this recommendation regard the difficulties in achieving clear and exhaustive communication with the family. The specialists will have to make sure that the family is fully aware of the types of investigation considered by the aetiological protocol and of the modes and times necessary for it to be performed. Once a diagnosis has been made, the results will have to be communicated to the family, by explaining the implications it may have in terms of prognosis for the progress of the disturbance and in general for the development of the child. The language used with the relatives will need to be adapted to their socio-linguistic characteristics (e.g. foreign parents with poor competence in Italian language), and the specialists will need to be sure that the parents have understood the contents of the message. In order to facilitate the entire process, it might be useful to plan moments of shared participation between operators and families during which the outcomes of the aetiological examinations and their meanings will be explained.

## Conclusions

With the implementation of newborn hearing screening programmes, the need to implement effective and stand-

ardised protocols for aetiological diagnosis has clearly emerged, to be carried out promptly, for the identification of the cause of PHI and the presence of any comorbidities or associated disabilities, so as to rapidly offer an optimal and customised treatment to each child affected by prelingual PHI. Within the framework of this project, following a first SWOT based on a review of the international literature, a second overall SWOT analysis was elaborated, resulting from an exchange and discussion among 21 experts in paediatric audiology. The data obtained were then used for the realisation of a TOWS matrix from which four main recommendations were identified, useful for the search of aetiological diagnosis for childhood PHI:

1. implementation of shared protocols for etiological PHI diagnosis in UNHS *referred* newborns, for whom the presence of PHI was confirmed and a shared programme of timing for several diagnostic investigations was defined;
2. creation of structured and formalised multidisciplinary teams for audiologic, medical and aetiological assessment of the hearing-impaired child;
3. implementing databases or systems for data storage and exchange of information among various professionals;
4. optimising the times and modes of communication to the family about the importance of aetiological diagnosis, investigation programmes, outcomes of tests and their meanings.

For third-level audiologic centres, the recommendations obtained from this process represent valid suggestions for the optimisation of resources and creation of positive changes.

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# Achieving effective hearing aid fitting within one month after identification of childhood permanent hearing impairment

## *Completare l'adattamento degli apparecchi acustici entro 1 mese dall'identificazione dell'ipoacusia di un bambino*

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### SUMMARY

Diagnosis of child permanent hearing impairment (PHI) can be made with extreme timeliness compared to the past thanks to improvements in PHI identification through newborn hearing screening programmes. It now becomes essential to provide an effective amplification as quickly as possible in order to restore auditory function and favour speech and language development. The early fitting of hearing aids and possible later cochlear implantation indeed prompts the development of central auditory pathways, connections with secondary sensory brain areas, as well as with motor and articulatory cortex. The aim of this paper is to report the results of a strategic analysis that involves identification of strengths, weaknesses, opportunities and threats regarding the process of achieving early amplification in all cases of significant childhood PHI. The analysis is focused on the Italian situation and is part of the Italian Ministry of Health project CCM 2013 "Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children".

**KEY WORDS:** Childhood hearing impairment • Early hearing aid fitting • Hearing aid professionals • Interdisciplinary collaboration • SWOT analysis

### RIASSUNTO

*Grazie al perfezionamento delle procedure diagnostiche e alla diffusione dei programmi di screening uditivo neonatale, la diagnosi di ipoacusia può essere posta con estrema tempestività rispetto ad un passato non troppo lontano. Diventa pertanto fondamentale giungere dalla diagnosi alla corretta applicazione dell'apparecchio acustico in tempi rapidi, in modo da ripristinare la funzione uditiva e consentire lo sviluppo del linguaggio. L'intervento abilitativo precoce di protesizzazione acustica o l'eventuale successiva applicazione dell'impianto cocleare offrono l'opportunità di un regolare sviluppo delle vie uditive centrali e delle aree cerebrali deputate alla ricezione dell'informazione sonora nonché delle relative connessioni con le aree motorie e articolatorie. L'obiettivo di questo articolo è presentare i risultati di un'analisi strategica che prenda in considerazione i punti di forza, i punti di debolezza, le opportunità e i rischi del percorso clinico da seguire per ottenere un'amplificazione precoce in tutti i casi di ipoacusia bilaterale permanente dell'età pediatrica. L'analisi è centrata sulla realtà italiana ed è parte del progetto CCM 2013 finanziato dal Ministero della Salute "Programma regionale di identificazione, intervento e presa in carico precoci per la prevenzione dei disturbi comunicativi nei bambini con deficit uditivo".*

**PAROLE CHIAVE:** Ipoacusia infantile • Protesizzazione acustica precoce • Audioprotesisti • Collaborazione interdisciplinare • Analisi SWOT

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## Introduction

Early amplification in childhood is aimed at giving access to auditory environment and hence lessen the effects of auditory deprivation related to permanent hearing impairment (PHI). Early hearing aid (HA) fitting and eventual cochlear implantation prompts the development of central auditory pathways connections. The HA rehabilitation process that is implemented during sensitive periods has therefore the objective to prevent the effects of PHI

on the plasticity of the entire central nervous system<sup>1,2</sup>. Maturation of auditory pathways is indeed closely linked to auditory stimulation. Restoring auditory function and fostering speech and language development during sensitive periods makes the central nervous system more effective in adapting to external inputs<sup>3</sup>. Thanks to availability of universal newborn hearing screening (UNHS) programmes the identification of PHI can be made with greater timeliness compared to the past. The improvements in audiological diagnosis (which is



analysed elsewhere in this series of papers), aims at identifying the characteristics of PHI<sup>4,5</sup>. This step is the prerequisite to define HA candidacy and selection<sup>6</sup>. At a later stage, some time is required to achieve HA fitting and verification<sup>6</sup>.

The hearing care professional (HCP), according to diagnostic and prescriptive audiological data, selects the appropriate HA and earmould, and defines the technical features and HA signal processing. Management of administrative aspects and family counseling are very important in this phase and require the collaboration of several professionals.

In the framework of the Italian Ministry of Health project CCM 2013 “Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children”, a multidisciplinary team of professionals undertook a strategic analysis to highlight the strengths and weaknesses of the current assets in early childhood amplification. The specific aim was the following: “to achieve an optimal HA fitting in case of significant bilateral PHI within one month after audiological diagnosis”.

## Materials and methods

A group of 24 professionals tertiary care referral centres for childhood PHI was asked to complete a survey (Table I). Asked to report at least 2 strengths, weaknesses, opportunities and threats strategic planning. Same analysis was also extended to 10 Italian HCP experienced in early childhood care who were contacted by mail.

This phase was conducted with the principles of SWOT analysis. The acronym SWOT stands for Strength (S), Weaknesses (W), Opportunities (O) and Threats (T), and corresponds to what the comments of the participants have pointed out. The responses were reviewed by the specialists responsible for. To generate recommendations from the SWOT analysis, a TOWS matrix was used to match the external threats and opportunities with internal weaknesses and strengths of the organisation or programme. The detailed description of the SWOT and TOWS matrix analysis procedure can be found elsewhere in this issue. The study and the survey was focused on this specific aim: achieve an optimal HA fitting in case of significant bilateral PHI within one month after audiological diagnosis.

## Results

In this article, we present the main results of the SWOT analysis and, based on the results, the subsequent TOWS matrix. Overall, professionals identified 78 items in the strength category, 87 items in the weaknesses category, 74 items in the opportunities category, and 86 items in the threats category, accounting for a total of 325 responses. Based on these responses, several specific themes were generated for each category (Table II).

**Table I.** Number and qualification of operators who participated in the SWOT analysis.

	N
ENT/Audiologist	10
Audiometrist	3
Speech therapist	2
Psychologist/counselor	1
Paediatrician	1
Neonatologist	1
Hearing aids specialist	1
Cochlear implant specialist	3
Parents/Associations	2
Total	24

### Strength key points analysis

The five most frequently cited strengths were (Table IIa): having a HCP working in the structure or having a close collaboration with the audiological centre (frequency 42%), systematic and standardised follow-up (22%), accurate audiological prescriptions/indications (18%), presence of a HCP trained and experienced in paediatric issues (14%) and capillarity of efficient acoustic centres (4%).

#### *Having a HCP in the structure or having a close collaboration with an audiological centres*

In this group, we gathered all the answers that refer to the possibility of including the HCP inside the team of the reference centre (III level), as an internal figure who works in the structure, or as an external figure who works in conditions of close collaboration with the team (n = 18).

This cooperation has a positive effect on the interdisciplinary approach in terms of efficiency of HA and following adjustments (n = 11); multidisciplinary meetings also strengthen the harmony with the family and the possibility to act in synergy with it (n = 2). In addition, the opportunity to have HA replacement in the structure facilitates initial assistance and counseling with families (n = 2).

#### *Systematic and standardised follow-up*

In this group, we collected all the answers that refer to an efficient follow up, with the possibility of control-verification of HA in the structure. It is very important to have the possibility to use advanced HAs with ‘data logging’, using monitoring and personalised effective counseling (n = 10).

Finally, we gathered the answers that refer to good organisation of the follow-up in medium/long term, effective in ensuring an easy access to the structure and the continuity and effectiveness of the follow-up, as well as to improve the trust relationship between family and professionals (n = 7).

**Table II.** Main key points extrapolated from the questionnaires.**Table IIa.** *Strengths.*

Strength key points	Frequency % (n)
Having a HCP in the structure, or a close collaboration with audiological centre	42% (33)
Systematic and standardised follow-up	22% (17)
Accurate audiological prescriptions/indications	18% (14)
Presence of HCP trained and experienced in paediatric issues	14% (11)
Capillarity of efficient acoustic centres	4% (3)
Total	100% (78)

**Table IIb.** *Weaknesses.*

Weakness key points	Frequency % (n)
No Italian guidelines and protocols	26% (23)
Not having a HCP in the structure or a close collaboration with audiological centre	25% (22)
Ineffective communication/lack of interdisciplinarity	14% (12)
HCP and clinicians with limited experience in early childhood care	14% (12)
Support and training to the family ineffective	10% (9)
Logistical difficulties/inadequate environments	6% (5)
High cost of HA	5% (4)
Total	100% (87)

**Table IIc.** *Opportunities.*

Opportunity key points	Frequency % (n)
Implementation of the HA assistance in the hospital	42% (31)
Continuous and specific training for HCP and clinicians	34% (25)
Guidelines, protocols and efficacy trials	22% (16)
School sensitisation	2% (2)
Total	100% (74)

**Table IId.** *Threats.*

Threats key points	Frequency % (n)
Economical aspects	27% (23)
Training and technology are not cutting-edge, efficacy trials	24% (21)
Organizational delays	15% (13)
Not having a HCP in the structure	13% (11)
Social and cultural aspects	13% (11)
Limited interdisciplinary approach	8% (7)
Total	100 (86)

Table II (a, b, c, d). Frequency of themes within each SWOT category (Total = 325).

### *Accurate audiological prescriptions/indications*

In this group all the answers that refer to an accurate audiological diagnosis and a consequent instruction and prosthetic prescription are included, as prerequisites proper selection and setting of HA (n = 14).

### *Presence of HCP trained and experienced in paediatric issues*

In this group we gathered all the answers that refer to the presence of HCP experienced in paediatric care, who is able to handle with accuracy and competency the specific features of the acoustic prosthesis, from the first year of life, and counseling to families (n = 11).

### *Capillarity of efficient acoustic centres*

In this group, considering the problems reported in the previous group, we gathered all the answers that refer to the territorial capillarity of efficient acoustic centres, which are able to ensure both rapid and efficient technical assistance, and professionalism in performing the service (n = 3).

### *Weakness key points analysis*

The seven most frequently cited weaknesses were (Table IIb): no Italian guidelines and protocols (frequency 26%), not having a HCP, or not having a close collaboration with audiological centre (25%), communication/interdisciplinary (14%), HCP ineffective and clinicians with limited experience in early childhood care (14%), ineffective support and training to the family (10%), logistical difficulties/inadequate environments (6%), HA (5%).

### *No Italian guidelines and protocols*

In this group we gathered all the answers that refer to the lack of Italian guidelines and protocols (n = 17): this shortage makes the activity of audiologists inhomogeneous with also the risk of not respecting the appropriate time for the realisation and delivery of HA (n = 2). Some answers also referred to the lack of importance that is attributed to moderate PHI, unilateral PHI, or conditions such as auditory neuropathies (n = 4). In these cases, the lack of early management can have very important implications on language and cognitive development of the child.

### *No HCP or lack of close collaboration with the audiological centre*

In this group we gathered all the answers that refer to the lack of HCP inside the audiological centres of reference or working closely with them (n = 22). This theme appears in Strengths and in Weaknesses, as it depends on both specific operational situations and administrative criteria, being subjected to changes in different areas.

The recurrence of this theme testifies, however, the importance of this type of collaboration for achieving the objective of this analysis and, therefore, the need to be subjected to appropriate regulation and discipline.

### *Communication/interdisciplinary inadequacy*

In this group we gathered all the answers that refer to difficulties of communication and collaboration between different professionals: no shared language, inhomogeneous ap-

proaches and operating procedures, difficulties in reporting plain and comprehensive information to the family (n = 12).

#### *HCP and clinicians inexperienced in paediatric HA*

In this group we gathered all the answers that refer to the lack or deficiency of audiologists trained and specialised in paediatric HA (n = 7). Also in this case, if present, this same subject appears in strengths. In the same group we included the responses that concern more specifically the lack of knowledge of the bimodal approach (HA and contralateral cochlear implant) (n = 7) and requires specific knowledge and training (n = 2).

#### *Poor training and family support*

The answers that refer to the difficult taking care of a family, especially from an emotional standpoint, when faced are included with the problem of the HA of the young patient, manage a possible refusal of the HA and, more generally, stake resources to tackle the critical time in audiological taking charge of the child (n = 5).

#### *Inadequate locations/logistical difficulties*

In this group we gathered all the answers that refer to the places where HCP welcome children and their families who are often inadequate in size and noise or unsuitable to raise the appreciation of small children (n = 4). In addition, the hearing centres often are located far away from III level clinics, which makes collaboration with other operators or the accessibility by the families difficult (n = 1).

#### *High costs of HA*

Finally, in this group we gathered all the answers that refer to costs, often high, of the HA of good quality and advanced technology. This is a very critical topic if we consider that these technical/technology features are recommended to ensure the accuracy and flexibility typically required in paediatric HA (n = 4).

#### *Opportunity key points analysis*

The four most frequently cited Opportunities were (Table IIc): activation of the HA assistance in the structure (42%), continuous and specific training of HCP and clinicians (34%), guidelines, protocols and efficacy trials (22%), school sensitisation (2%).

#### *Activation of the HA assistance in the structure*

The opportunity to fit the HA in the structure would lead to significant clinical advantages (see the previous discussion regarding the Strengths and Weaknesses) (n = 16). In this context, the opportunity is the possibility to overcome obstacles to implementation of this form of collaboration (n = 15), with institutional support (of the hospital and local authorities).

#### *Continuous and specific training of HCP and clinicians*

Maintaining regular and specific training opportunities

addressed clinicians and HCP would achieve a high level and quality of specific training dedicated to child HA, with important implications favourable the homogeneity of behaviour, information and care arrangements (n = 25). Communication between professionals and the family could have a common language and be mediated by an interdisciplinary tight-knit team.

#### *Guidelines, protocols and efficacy trials*

The possibility to create and to have guidelines and protocols diffusely and uniformly applicable on a regional or nationale scale (n = 8) could bridge the adverse effects described in the related item in Weaknesses, to ensure effective taking over that relies on the precocity and the effectiveness of the intervention (n = 8).

#### *School sensitisation*

This opportunity must be considered, in our interpretation, as an extension of the living environment and of socialisation of the child where the awareness of the needs of the young patient with PHI is crucial (n = 2). Sensitisation in these areas of school staff, social workers and family, understood in a broad sense, refers to, however, phases of the habilitation program subsequent to that identified by the objective of this analysis.

#### *Threats key points analysis*

The six most frequently cited threats were (Table II d): economic aspects (27%), training and technology is not cutting-edge, efficacy trials (24%), burocratic and organisational delays (15%), not having a HCP in the structure (13%), social and cultural aspects (13%) and limited interdisciplinary approach (8%).

#### *Economic aspects*

In this group we gathered all the answers that refer to the high cost of HA of present technology and to the limited resources available for care intervention (n = 19). A high risk is represented by an inadequate coverage by the National Health Service (NHS) for the provision of HA with adequate performance and by the difficulty to obtain the highest quality of assistance service/fitting. This aspect is exacerbated by the risk of conflict of interest, present in the figure of the HCP, who plays a dual role: the caring role of selector/adapter, and the commercial supplier of the HA. The current tariff nomenclature, dating back to 1999, does not consider the technological progress and indicates economic values, recognised today by the NHS, which are far removed from the actual value of HA suitable for the needs of the young patient and appropriate to indications (digital/conductive HA) (n = 4).

#### *Training and technology is not cutting-edge, efficacy trials*

In this category we gathered all the answers that refer to the lack of evidence of efficacy of technological and informat-

ics developments in HA (n = 8) and to the low level of specialisation in childhood HA previously described (n = 13).

*Burocratic and organisational delays*

In this group we included all the answers that refer to factors that can slow down HA programme. In particular, we point to the difficulties to quickly reach clear and definitive diagnosis in very young children (n = 4), the time required to achieve perfect fitting (n = 5) and, not least, the bureaucratic and administrative paths that the family often has to deal with (n = 4).

*Not having a HCP in the structure*

In this category we enclosed all the answers that refer to legislative and normative impediments that make difficult, if not impossible, the presence of the HCP in the structure (n = 7). The possible positive effects of this presence have been described in previous parts of this analysis.

*Social and cultural aspects*

In this category we gathered all the answers that refer to the influences of different cultures that makes it difficult to accept the audiological condition and the HA (n = 2), and communication between healthcare professionals and family, up to limiting the effectiveness of counseling, even when in the presence of a cultural mediator (n = 6).

*Limited interdisciplinary approach*

In this category we gathered all the answers that refer to the difficult communication (n = 5) and collaboration between the various structures and production/distribution companies of HA (n = 2).

**Discussion**

Based on the answers to the SWOT analysis, we processed the TOWS matrix to define possible “strategies” of intervention for the achievement of the specific objective. Strengths are combined with Opportunities (S-O strategy), Strengths with Threats (S-T strategy), Weaknesses with Opportunities (W-O strategy) and Weaknesses with Threats (W-T strategy). Through the TOWS matrix (Table III), we identified 11 strategies that, through a process of selection and considering what was discussed during SWOT analysis, we further reduced to five main strategies. These strategies are considered useful to complete the HA fitting and verification within one month from the definition of the audiometric characteristics of PHI ≥40 dB HL in the better ear.

The first strategy consists of approaching early amplification systematically through the work of a multidisciplinary team that includes all competent professionals and based on a constant and effective interaction with the family. This approach is the requisite for a fast and responsible audiological process, through diagnosis to prescription, fitting, verification and outcomes measures, until the correct management of practical aspects and control of the psychological and relational issues of the HA are achieved.

The role of the HCP becomes essential. The HCP participating in the “paediatric amplification network” should in ideal conditions belong to the audiologic centre itself or alternatively be in close collaboration as an external advisor. Interaction should always be straightforward and effective.

Prescribing and dispensing HA is a complex process in Italy. It involves coordination of a flow of information

**Table III.** TOWS matrix (see text for explanation).

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	<p><b>SO strategy</b></p> <ol style="list-style-type: none"> <li>1. Involve (with direct collaboration) HCPs competent in childhood HA by adopting guidelines enclosing protocols and systematic follow-up based on the multidisciplinary approach</li> <li>2. Regulate HCP activity in legislative and normative aspects, and in technical procedures, to achieve effectiveness and homogeneity</li> <li>3. Support and promote training and continuing education of the operators</li> </ol>	<p><b>WO strategy</b></p> <ol style="list-style-type: none"> <li>1. Defining common tracks to facilitate the access of HCP to clinics and interdisciplinary collaboration</li> <li>2. Definition of guidelines and protocols adapted and widely applicable to the Italian situation</li> <li>3. Promote opportunities for specific and shared training, to improve interdisciplinary collaboration, uniformity of training and behaviour, and the presence of a network of paediatric HCPs</li> </ol>
	Threats (T)	<p><b>ST strategy</b></p> <ol style="list-style-type: none"> <li>1. Limit constraints between technical and commercial aspects in childhood HA and help to identify specific audiological skills and certified providers.</li> <li>2. Multidisciplinary approach with the presence of HCP to reduce technical and burocratic delays and to reduce difficulties in communication with the family and those related to extraterritoriality and multiculturality</li> </ol>	<p><b>WT strategy</b></p> <ol style="list-style-type: none"> <li>1. Supporting the definition of legal and administrative paths for the certification of companies and HCPs, in accordance with guidelines and protocols developed by referral audiological centres and establishing lists of authorised HCPs</li> <li>2. Overcome organisational difficulties (secretary, connections with families and territory) caused by bureaucratic and economic limitations</li> <li>3. FAD courses or guidance - formative material with basic structure common to all the operators involved in the qualifying process (including the family) suggested at the time of audiological indication</li> </ol>



about therapeutic, technical and administrative activities done by physicians, HCPs, supplier companies and administrative staff of local health organisations, all involving the child and his family.

The application of the HA must take place only by a qualified technician (the HCT) in suitable seats equipped with full instrumentation for HA fitting and verification. The supplier and the HCT do not belong to the NHS, but are affiliated with the local authority in charge of public health (ASL). The HCP can apply the HA only with a prescription made by an ENT specialist or a Physician in Audiology and Phoniatrics. Specialty the prescription and verification test of the HA (with or without the expenditure from the regional health system) is done by the MD specialist and is regulated by a official document of the NHS named "Nomenclatore tariffario delle Protesi". The possible price difference of the HA is paid by the family only after the formal positive testing done by the prescriptive centre.

The recruitment of a HCP as an external advisor of the team may not be easy, especially in large urban centres. If the patient lives far from the hospital, which is a common condition for referral centres, connections becomes challenging. It would be useful to create a network of HCP that are formally qualified, distributed over large areas, in order to obtain effective coverage throughout the country and to guarantee an appropriate HA assistance to all children with PHI, even in locations far away from the referral audiological centre.

A second strategy, which is also related to the working methods of the audiological centre, is the optimisation of procedures and contacts with the family and with the professionals/institutions for external collaboration (family paediatrician, territorial healthcare professionals, school staff). This is a concrete need for all the phases of the habilitation programme, but especially in the initial phase. Regarding this SWOT analysis, these needs are particularly important to ensure efficacy and timeliness in HA fitting and in counseling the family. Pursuing this strategy means having the availability of economic and institutional resources to obtain appropriate instruments and a dedicated staff.

The third strategy is identified in defining and adopting standardised protocols by scientific societies and professional groups, which promote quick, easy and uniform pathways in the different phases and in different aspects (clinical, technical, burocratic/administrative) of the paediatric amplification<sup>6</sup>.

Although there are often interesting and accurate reports on various aspects of childhood hearing care by Italian authors<sup>4-7</sup>, few official documents have been published by the Italian Society of Otolaryngology, Head & Neck Facial Pathology<sup>8</sup>. Indications are, however, extremely synthetic on the topics of amplification, especially in childhood. The availability of specific and accurate guidelines, as already

issued in other countries<sup>3-6,9</sup>, would be extremely useful to all healthcare workers and their patients/clients, and also for institutions for legal and administrative implications.

The fourth strategy concerns the specific training regarding issues related to paediatric amplification, which represents a critical issue for healthcare professionals in general, but in particular for the HCP involved in HA fitting and amplification.

An adequate, certified and interdisciplinary competence in paediatric amplification is needed to potentiate skills in managing selection, fitting, counseling and outcome verification<sup>10</sup>. Training entrusted audiologic tertiary centres in hospitals and universities, i.e centres that can handle the training supply and ensure training capability, is needed. Interdisciplinary training courses should be promoted in collaboration with professional associations and HA distribution/production companies. A first positive experience in this direction has been established by the University of Padova and University of Modena e Reggio Emilia, although limited to HA technician graduates.

The participants to the SWOT analysis considered it helpful to set up a "registry" of HCPs with certified paediatric HA competency, technical skills, experience and ethical issues according to criteria established by as many as possible III level audiological centres in Italy, in collaboration with HCP associations.

In close relationship with the previous topic, the fifth strategy would be to revise and improve the regulatory issues and policies related to the management of HA, which often has an impact on the time needed to begin the (re) habilitation programme.

The process which involved the steps of prescription - budget elaboration - approval - delivery - fitting - verification should be faster. Several HA companies have the practice of giving a 'test period', which can reduce the period of time that occurs from PHI identification to the effective HA delivery to 10 to 15 days starting from the first contact with the family.

There remains, however, the need for a redefinition of the legal and administrative rules in order to optimise this process, which often varies in time for each local public health authority.

An adequate definition of the legal and administrative aspects could also help to resolve the current problem of the discrepancy between the financial support provided by the NHS and the effective economic requirements for an efficient early intervention programme that includes the complete coverage of "state of art" HA costs.

## Conclusions

UNHS programmes and improvements in audiological assessments procedures have made earlier PHI diagnosis a real fact. Restoring auditory function and implementing speech and language acquisition through the process of



amplifications should start as early and quickly as possible. As a result of SWOT analysis performed by 24 professionals involved in early paediatric amplification, five main recommendations have been developed: building a interdisciplinary network approach during all phases of the HA habilitation process; optimising procedures and mechanisms of contact with the family, adopting standardised protocols by scientific societies; having a specific interdisciplinary training on paediatric amplification issues; obtaining an adequate definition of the legal and administrative aspects. This approach is endorsed by the current international guidelines on paediatric audiology.

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# Achieving early functional auditory access in paediatric cochlear implantation

## *Adattamento precoce dell'impianto cocleare in età pediatrica*

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### SUMMARY

Cochlear implantation (CI) is a viable option for providing access to auditory stimulation in severe-to-profound hearing loss/impairment of cochlear origin. It has been demonstrated that CI is safe and effective for deaf children. Younger age at activation after CI is linked with better outcomes. It is important to study variables and issues that can interfere with an early fitting and access to sound after CI. They range from patient characteristics, family compliance and support, to technical, medical or organisational problems. A SWOT analysis and a subsequent TOWS matrix was conducted to discuss issues and propose recommendations to be considered when operating an early switch on of the CI.

KEY WORDS: Cochlear implant children • Early intervention children • Cochlear implant fitting • Auditory stimulation children

### RIASSUNTO

*L'impianto cocleare costituisce una valida opportunità per fornire l'accesso alla stimolazione uditiva nei casi di ipoacusia severa o profonda di origine cocleare. E' stato ampiamente dimostrato che l'impianto cocleare è una soluzione sicura ed efficace e che la precocità nell'attivazione è associata a risultati migliori. E' importante studiare le variabili e gli aspetti che possono interferire con un adattamento precoce e un adeguato accesso al mondo sonoro: caratteristiche del bambino, alleanza terapeutica con la famiglia, aspetti tecnici, medici e organizzativi. Obiettivo di questo lavoro è quello di proporre raccomandazioni utili per gli aspetti organizzativi-pratici relativi alle attivazioni precoci di impianto cocleare, attraverso un particolare modello di analisi SWOT e TOWS.*

PAROLE CHIAVE: *Impianto cocleare pediatrico • Attivazione precoce • Adattamento dell'impianto cocleare*

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## Introduction

Cochlear implantation (CI) is a viable option for providing access to auditory stimulation in severe-to-profound hearing loss/impairment of cochlear origin. It has been demonstrated that CI is safe and effective for deaf children<sup>1</sup>. Several observational studies have shown that early auditory intervention with a CI and prompt enrollment in a (re)habilitation and education programme enable hearing impaired children to gain good quality access to auditory stimulation, achieve age-appropriate spoken language levels and eventually provide opportunities for normal social and academic development<sup>2-9</sup>.

Younger age at activation after CI is linked with better overall outcome scores by about 0.5 SD, and significantly better developmental outcomes at 3 years of age<sup>10</sup>, whilst delaying CI from 2 to 24 months of age in case of congenital hearing impairment is associated with a reduction of global outcomes<sup>4-7,11</sup>. This framework represents a driving force for hearing

screening programmes, early diagnosis and CI intervention. In addition, CI candidacy criteria have gradually expanded to include children with complex development disabilities<sup>12-18</sup>. At present, although there is no consensus about how narrowly the critical window of time for optimal auditory development is defined, there is a growing body of evidence that supports implantation before 12 months of age<sup>2</sup> and early activation after CI<sup>19</sup>. Concerns are related to very early CI, because of the delayed maturation of auditory pathways, especially in preterm neonates, which could lead to an incorrect CI indication<sup>20</sup>. Nevertheless, some of the evidence suggests that the sensitive period may extend to about 3 years of age. It must be considered that the younger children are, the more difficult it is to test their hearing and to determine benefit from wearing a hearing aid or from CI. A decision to implant may result in irreversible loss of whatever natural hearing is still present, but delaying that decision beyond the critical window of auditory development results in less than optimal abil-

ity to develop speech and language skills<sup>2</sup>. Early CI in children enables not only the development of the verbal communications, but also improves social skills, having broader consequences on the individual's life person<sup>21</sup>. In order to achieve the most favourable access to sound with the CI, the sound processor parameters must be appropriately customised for the recipient after the switch on. This means that a number of parameters needs to be set to ensure that the electrical patterns generated by the device in response to sound offer optimal auditory speech discrimination, and thus a foundation for spoken language development. This procedure can be challenging in a typically uncooperative population such as infants and toddlers, and children with associated developmental disabilities. Families play an important role supporting and understanding the fitting procedure and subsequent specific auditory stimulation. It is important to study variables and issues that can interfere with early fitting and access to sound. They range from the characteristics of the child, family compliance and support, to technical and medical problems. The objective of this work is to discuss issues and propose recommendations to be considered when operating an early switch on of the CI using SWOT analysis. SWOT analysis was developed by the business community in early 1960s to facilitate planning strategies and nowadays is frequently used in healthcare care settings<sup>22</sup>. The acronym SWOT stands for Strength (S), Weaknesses (W), Opportunities (O) and Threats (T), and corresponds to what the comments of the participants point out. The large amount of generated information is most frequently analysed and used to develop a strategic plan named TOWS matrix. In such way, the data obtained can be used to generate specific activities to accomplish better organization goals.

## Materials and methods

A group of rehabilitation professionals involved in CI programmes was asked to complete a survey focused on improving CI early fitting. To examine issues related to achieving early access to sound after CI, the survey asked participants to report at least 2 strengths, weaknesses, opportunities, and threats for use in strategic planning. This phase was conducted with the principles of SWOT analysis. The responses obtained were reviewed by the specialists responsible for this working area. To generate recommendations from the SWOT analysis, a TOWS matrix was used to match the external threats and opportunities with internal weaknesses and strengths of the organization or program<sup>22</sup>. An exhaustive explanation of the study design was provided. The detailed description of the SWOT and TOWS matrix analysis procedure can be found elsewhere in this issue. The study and the survey was focused on this specific aim: achieving a hearing threshold within 35 dB HL within 3-6 months from CI activation for children who received a CI between two to three years of age.

**Table I.** Roles of rehabilitation professionals (n = 20) involved in the survey.

Professional role	n
Otolaryngologist/Physician in Audiology	8
Audiologist/Hearing Acoustician	2
Physician in Neonatology	1
Speech and language therapist	1
Psychologist	1
Cochlear implant technical specialist	4
Parent/Association	2
Primary Care Paediatrician	1

## Results

The rehabilitation professionals study group was composed of 20 participants with expertise in paediatric CI (Table I). All participants completed the SWOT questionnaire. The 288 open-ended answers (S = 85, W = 75, O = 60, T = 68) were reviewed by the authors and grouped in main key points (Table II).

**Table II.** Main key points extrapolated from the questionnaires.

**Table IIa.** *Strengths.*

Strength key points	n (%)
Multidisciplinary collaboration and staff expertise	31 (37%)
Good organisation	29 (34%)
Family involvement and support	18 (21%)
Surgical technology and fitting	7 (8%)
	85

**Table IIb.** *Weaknesses.*

Weakness key points	n (%)
Staff inefficiency	36 (48%)
Recipient/family issues	24 (32%)
Excessive workload and unsuitable infrastructures	15 (20%)
	75

**Table IIc.** *Opportunities.*

Opportunity key points	n (%)
Cooperation and guidelines	30 (50%)
Instrumental and methodological developments	22 (37%)
Family support	8 (13%)
	60

**Table IId.** *Threats.*

Threats key points	n (%)
Management problems/efforts for staff	28 (41%)
Training and guideline insufficiency	16 (23%)
Concerns linked to CI companies	12 (18%)
Family issues	12 (18%)
	68

**Strengths key points analysis**

The four most frequently cited strengths were family involvement and support (41%), team work and staff expertise (23%), issues linked to CI companies (18%) and family issues (18%) (Table IIa). These themes are analysed in detail as follows:

*Family involvement and support*

This theme includes family counselling pre- and post-CI surgery, which is technical (CI operating principles, surgery steps, CI accessories), informative (i.e. regarding all aspects of the hearing problems, different possible communication modes, normal and abnormal child development) or linked with the support needs of the family (n = 8). This theme includes also issues regarding family-clinic alliance or sustain offered to the family by support groups and associations (n = 5). A family centred intervention is required to achieve better outcomes in CI recipients. The first month following CI is crucial to be helpful to the family, and given support can be boosted by the collaboration with regional associations of families of deaf children (n = 5).

*Teamwork and staff expertise*

This theme includes the multidisciplinary team collaboration with companies' CI clinical specialists (n = 17), whose support should be directed to enable clinicians to be independent in CI fitting (n = 4). Other issues concern continuing education and shared training opportunities for all professionals involved (n = 10).

*Good organisation*

This theme includes answers related to a good organisation regarding logistics and timeline (suitable and comfortable place, determined time for fitting, telephone line reserved for this purposes) (n = 7). Good organisation of pre-surgical work-up allows accurate audiologic, logopedical, cognitive evaluations before CI (n = 10), facilitates early activations (n = 6) and allows to start specific rehabilitation together with the fitting of CI (n = 6).

*Surgical technology and fitting*

This theme includes the answers related to the best possible surgical equipment (n = 7), which should be regularly updated and verified; the introduction of innovative materials is advisable.

**Weakness key points analysis**

The three most frequently cited weaknesses were staff inefficiency (48%), recipient/family issues (32%) and excessive workload and unsuitable infrastructures (20%) (Table IIb). These themes are analysed in detail as follows:

*Staff inefficiency*

Some answers were related to ineffective interdisciplinary collaboration between clinics and cochlear implant com-

panies (i.e. poor support in case of failure or damage of the CI, challenging fitting) (n = 20), to the lack of education and training for all professional profiles (physicians, audiometrists, speech-language therapists, paediatricians) (n = 7), to the lack of guidelines and insufficient tools for fitting of the CI (i.e. modality of masking of good ear in CI for single sided deafness, new electrophysiological instruments capabilities) (n = 6), or to inadequate family counselling (n = 3).

*Recipient/family issues*

This theme includes difficulties related to the management of families whose place of residence is distant from the audiology referral centre (n = 16). The answers focused on the difficulties to build a systematic communication network with health services from the patient's hometown, and on the management and organisation of controls necessitating more than one day stay. The interaction with users belonging to different cultures is even more difficult, where cultural and linguistic barriers are a serious obstacle for accepting diagnosis and receiving CI or hearing aids. Other issues concerned the difficulties related to early age management and/or presence of associated disabilities (n = 8).

*Excessive workload and unsuitable infrastructures*

In this category the answers regarding excessive workload of small groups and unsuitable infrastructures (scattered locations, organisation of the working places, facilities for children and families) (n = 15).

**Opportunities key points analysis**

The three most frequently cited opportunities were cooperation and guidelines (50%), instrumental and methodological developments (37%) and family support (13%) (Table IIc). These themes are analysed in detail as follows:

*Cooperation and guidelines*

This theme includes the answers concerning the opportunity to increase guidelines, training and new interdisciplinary models (n = 23), i.e. training and education for clinicians and territorial rehabilitation professionals, regional guidelines for early rehabilitation.

Other issues concerned the cooperation between clinical and technical groups (CI companies, hearing aids specialists) (n = 7), i.e. shared education and training, regulation of in-hospital activity of company hearing aids.

*Instrumental and methodological developments*

This theme includes the answers concerning new methods, tools and techniques for rehabilitation, monitoring and fitting (n = 22). The answers focused on improving technological systems as data logging, fitting techniques, tools to optimise communication between the CI centre and the family, databases and tools for rehabilitation.

*Family support*

This theme includes opportunities to strengthen the counselling that is systemised and well inserted in the diagnostic path, CI selection and rehabilitative process, either for information or support (n = 8).

*Threats key points analysis*

The four most frequently cited threats were training and guideline insufficiency (41%), family issues (23%), concerns linked to CI companies (18%), management problems/efforts for staff (18%) (Table II). These themes are analysed in detail as follows:

*Training and guideline insufficiency*

This theme includes the answers concerning poor or expensive professional education/training and poor scientific evidence-based research (guidelines) (n = 12) as well as scarce knowledge of bimodal and bilateral fitting management (n = 4).

*Family issues*

This category includes the answers concerning family efforts when dealing with extraterritorial recipients and linguistic/cultural diversity (n = 12). The answers focused on the difficulties in building a systematic communication network with health services from the patient’s hometown, and on the management and organisation of controls necessitating more than one day stay. The interaction with users from different cultures is even more difficult, where cultural and linguistic barriers are a serious obsta-

cle for understanding/accepting clinical information and CI or hearing aids.

*Concerns linked to CI companies*

This theme includes the answers concerning commercial aspects related to CI companies and conflicts of interest (n = 10), i.e. different fitting strategies between CI centres and CI companies, commercial constrains. Other answers were related to specific technical issues (n = 2).

*Management problems/staff efforts*

This theme includes the answers concerning insufficient funding aimed at audiology clinics with subsequent reduced staff, long waiting lists and scarcity of funds for research projects (n = 16). Other issues were related to complex and prolonged family management for clinicians and linguistic/cultural barriers (n = 6), and to medical assessment of complications (n = 6)

**Discussion**

Starting from the SWOT analysis data, a TOWS matrix was created, which compares Strengths-Opportunities, Weaknesses-Threats and Weaknesses-Opportunities on the basis of the multidisciplinary discussion. These recommendations can represent food for thought for tertiary care audiology centres, to optimise resources and generate positive changes. Analysing and discussing the data obtained from this research, 9 recommendations were obtained (Table III). The 9 recommendations have been

**Table III.** TOWS matrix (see text for explanation).

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	<p><b>SO strategy</b></p> <ol style="list-style-type: none"> <li>Fast achievement of technological and methodological advances that encourage, facilitate and accelerate organised teamwork and family alliance in the rehabilitation process (as remote control for NRT, data logging, material for parents/ling six sounds test).</li> <li>Strengthen the family counselling by outlining the surgical procedure and the following steps immediately after selecting the implant, by establishing a “therapeutic agreement” and using written and illustrated material/video.</li> <li>Review the guidelines and evidence-based results that, as part of a good organisation, can speed up the first phases of CI fitting (e.g. early activation of the speech processor, validity of the electrophysiological tests, neural adaptation course).</li> </ol>	<p><b>WO strategy</b></p> <ol style="list-style-type: none"> <li>Fast implementation of the technological improvements that enable distant follow-up reduce the workload for the CI centre (tele-sharing of data between the professionals using, tele-fitting).</li> <li>Entire team shared education by means of new interdisciplinary models, which should include most technical aspects of CI fitting even for speech therapists, and early intervention modalities for CI technicians, and should be organised</li> </ol>
	Threats (T)	<p><b>ST strategy</b></p> <ol style="list-style-type: none"> <li>Multidisciplinary team, constantly updated and shared education (e.g. for achieving clear collaboration with the companies, effectiveness in short term and mild impact decisions, e.g. managing technical assistance for failures, administrative issues, unexpected reactions of the child)</li> <li>Family involvement with effective connections to the territorial audiology services, in order to minimize cultural and extra-territoriality issues</li> </ol>	<p><b>WT strategy</b></p> <ol style="list-style-type: none"> <li>Difficult cases should not be managed by incompetent centres (e.g. complex syndromes, severe disabilities, logistic issues).</li> <li>Reduce contradictory, not coherent, or obscure indications to the families and communications among territory, hospital, companies.</li> </ol>



summarised into 3 main fields of action to speed up the first phases of CI fitting and achieving and early and effective auditory stimulation:

- to strengthen family counselling, achieving high levels of alliance and therapeutic agreement along the pre- and post-surgical rehabilitation process;
- to implement technological and methodological advances directed at improving outcomes and teamwork, while reducing the workload;
- to establish a multidisciplinary approach and a cooperation platform among professionals, regulated by up-to-date guidelines, latest evidence-based principles and shared information.

CI is not yet a standardised procedure<sup>23</sup>. Moreover, indications to paediatric CI and technological advancements are constantly updated, causing potential differences of care and misunderstandings among professionals and families involved in the CI programme<sup>23</sup>. Several pre-operative variables have been identified in association with successful activation and early achievement of an effective auditory stimulation. Even if traditional candidacy to paediatric CI is actually based on a few basic parameters, i.e. severe-to-profound deafness with poor aided performance, outcomes are largely affected by patient-related factors and possibly by surgical factors. Moreover, some candidacy criteria are sometimes bypassed, such as in skipping the hearing aid trial case of progressive hearing loss, or in the case of delayed diagnosis auditory deprivation. Presurgical patient-related factors are previous effective auditory experience, previous trial with hearing aids, proactive family involvement and support, absence of concurrent disabilities, and conclusive audiologic evaluation. Surgery may possibly be involved in improving early outcomes by using minimally invasive approaches that are associated with a smaller surgical injury/wound and allow less inflammation/tissue swelling, better telemetry results and very early activation (up to 24 hours after surgery). In our opinion, the therapeutic alliance with the parents of the deaf child can lead to early achievement of best fitting. Considering that the introduction of some new technologies is aimed at increasing the collaboration between families and CI centres, e.g. in the case of remote control telemetry, data logging capabilities, information sheets for parents, tele-fitting, distance learning, distance mentoring, education about these advancements and their implementation in the daily clinical practice is encouraged as both a strength and opportunity to achieve the specific goal of early optimal auditory stimulation. The development, review and constant update and sharing of guidelines covering all the aspects of early rehabilitation after CI is needed. There are new and controversial aspects related to early CI in congenital deafness, early activation after CI in children<sup>19</sup>, reliability of electrophysiological tests in view of the auditory maturation process, especially in children affected by severe adjunctive dis-

abilities<sup>12 20</sup>. There is a lack of international consensus also on how to apply bilateral, bimodal or electroacoustic strategies and on how to select patients for those indications. It may be difficult to interpret with the authority the actual impact of the different technologies that are available on the market. Caution is deemed in proposing new technologies to be applied on children before extensive research has been carried out<sup>12 18 23</sup>. Good and clear connections among patients, patient associations, territorial audiology services, private hearing aid centres, technical specialists of cochlear implants and tertiary referral centres are of utmost importance<sup>24</sup>. Moral and ethical issues are still associated with biomedical engineering technologies, and may be modulated by personal background and cultural heritage. Rehabilitation methodologies of the deaf children may also raise discussion with parents. The therapeutic alliance with the family requires moral and ethical issues to be made plain<sup>25</sup>.

## Conclusions

To achieve early access to functional auditory stimulation after paediatric CI, recommendations have been developed directed to professionals involved in the (re)habilitation process. Establishing a cooperative platform among professionals, overcoming organisational issues, strengthening family counselling and sharing continuing education of high quality are mandatory. New interdisciplinary models are needed shared within all surgery and rehabilitation professionals. Interdisciplinary training should include updated technical and methodological aspects of CI fitting and early auditory stimulation.

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# Early care in children with permanent hearing impairment

## *Presa in carico precoce del bambino ipoacusico*

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### SUMMARY

The implementation of regional protocols for newborn hearing screening and early audiologic diagnosis represent the first step of the entire diagnostic, rehabilitative and prosthetic programme for children with permanent hearing impairment. The maximum benefit of early diagnosis can indeed be obtained only by prompt rehabilitation aimed at fostering the child's communicative, linguistic and cognitive development. Within the framework of the CMM 2013 project of the Ministry of Health entitled "Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children", the problems concerning the promotion of the global development of children with PHI through an early rehabilitation project based on shared knowledge and scientific evidence. In this project, our specific aim was to define the features and modes of access to a precise and specialised rehabilitation project for the small hearing-impaired child within three months from audiologic diagnosis. Three main recommendations relative to assessment and rehabilitation aspects of early care emerged from the study.

**KEY WORDS:** Early care • Childhood permanent hearing impairment • Auditory rehabilitation • SWOT analysis

### RIASSUNTO

*La messa a punto di protocolli regionali di screening audiologico neonatale e la diagnosi audiologica precoce rappresentano il primo passo dell'intero percorso diagnostico, protesico e riabilitativo a cui deve sottoporsi un bambino ipoacusico. Il massimo beneficio di una diagnosi precoce può essere ottenuto solo con una presa in carico riabilitativa tempestiva finalizzata a promuovere lo sviluppo comunicativo-linguistico e cognitivo del bambino. Nell'ambito del progetto del Ministero della Salute CCM 2013 "Programma regionale di identificazione, intervento e presa in carico precoce per la prevenzione dei disturbi comunicativi nei bambini con deficit uditivo" è stata affrontata l'attuale modalità di presa in carico precoce del bambino ipoacusico in Italia e la promozione del suo sviluppo globale basate su un progetto riabilitativo fondato su evidenze scientifiche. All'interno del progetto il nostro obiettivo specifico è stato quello di definire le caratteristiche e le modalità di accesso ad un progetto riabilitativo specifico e specializzato per il bambino ipoacusico piccolo entro 3 mesi dalla diagnosi audiologica. Dall'analisi effettuata sono emerse tre principali raccomandazioni relative agli aspetti valutativi e riabilitativi della presa in carico precoce.*

**PAROLE CHIAVE:** *Presa in carico precoce • Ipoacusia infantile • Riabilitazione audiologica • Analisi SWOT*

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## Introduction

The implementation of regional protocols for newborn hearing screening and early audiologic diagnosis represent the first step of the entire diagnostic, rehabilitative and prosthetic programme for the child with permanent hearing impairment (PHI). The maximum benefit of early diagnosis can be obtained only by prompt rehabilitation care aimed at fostering the child's communicative, linguistic and cognitive development.

According to the guidelines laid down by the Joint Committee on Infant Hearing of 2007<sup>1</sup> and confirmed in the recent Supplement of 2013<sup>2</sup>, diagnosis of PHI and the ac-

tivation of an early rehabilitation prosthetic intervention must take place within the first 6 months of life. Prompt intervention is aimed at favouring functional substrate necessary to verbal communication development and at promoting the development of the basic perceptive abilities<sup>3</sup>. A direct relation exists between early care (diagnosis and intervention) and the progress of the disability. The first months of life are decisive for developing the fundamental processes of the child's growth, especially for those children with a sensorial congenital deficit. The specific environmental inputs (sensorial, linguistic, social, emotional) for the development of the various functions (cognitive, motor, linguistic, perceptive, etc.) stimulate

the child's development, especially when there is greater plasticity. Understimulation by the peripheral nervous system may impoverish the cortical areas dedicated to a specific function, resulting in a colonisation of these areas by neuronal tissue devoted to different competences. It has been shown that these effects are strictly correlated both to the duration of sensory deprivation and to the biological age of the subject. In case of congenital neurosensory hearing loss, the temporal areas designed to process auditory stimulation may undergo considerable manipulation due to inappropriate stimulation, with important consequences for both the perceptive and communicative-linguistic development of the child<sup>4</sup>.

In the light of these considerations, it is evident that a diagnostic-rehabilitative-prosthetic programme can produce the greatest benefits only when it is performed with extreme precocity. In parallel with prosthetic treatment, it is essential to start an early rehabilitation programme aimed at developing and enhancing the perceptive and communication-linguistic abilities of the impaired child. "Rehabilitation is a problem-solving process and an educational process, during which a person reaches the best quality of life at a physical, functional, social and emotional level". (Guidelines of the Ministry of Health for Rehabilitation Activities, 1998). The features of rehabilitation vary on the basis of the patient's functional profile, and therefore early, multidisciplinary and global care is required.

Global intervention consists in getting involved not only the child but also the family, starting from the very first phases. Many authors have confirmed that the quantity and quality of maternal stimulations influence considerably the linguistic abilities reached by small children with cochlear implants<sup>5-9</sup>. Tobey et al. (2012) have recently demonstrated that hearing impaired children for whom care started immediately (before 12 months of age) and whose parents integrally participate in the rehabilitation process at 5 years, reach better linguistic performance than those involved later<sup>10</sup>. When the child is taken into rehabilitative care, the family must be appropriately informed and trained with regards to the different therapeutic proposals and possible objectives that can be attained. After defining the features of the intervention, the team members will need to share the specific treatment programme with the family using clear and transparent communication.

One of the main objectives of early speech therapy treatment addressed to hearing impaired children is to stimulate the development of their perceptive abilities. Within the rehabilitation project the therapist must plan and realise customised perceptive training targeted to the enhancement of auditory attention and to the development of complex perceptive abilities<sup>11</sup>. Within the rehabilitation project, information counseling will allow the therapist to inform the parents on the child's difficulties caused by sensory deficits; the activity will also foster the

emergence of types of behaviour that can help the child enhance auditory attention and achieve increasingly complex perceptive abilities. Another important objective of rehabilitation is to favour communicative-linguistic development. The communication aims will be different according to the age of the child.

Early care is therefore essential for the good success of an audiologic and rehabilitation protocol whose aim is to achieve optimal global development. From the very early phases of the diagnostic program the child faces different specialists who coordinate their efforts to achieve common objectives. The multidisciplinary team rotates around the needs of the child and the family; therefore, the professionals of the team can change according to the specific requirements (e.g. patients with multiple disabilities). The multidisciplinary team is generally formed of physicians (neonatologists, otolaryngologists, audiologists, family paediatricians, neuropsychiatrists), technicians and therapists (audiometrists, hearing aids specialist, psychologists, speech therapists), school operators (curricular teacher, assistant teacher, communication assistant) and social workers. In order to guarantee optimal care, all team members need to possess a basic background of knowledge concerning physiological and pathological development<sup>12</sup>. The implementation of guidelines could represent a valid solution to standardise this knowledge and to structure a control system ensuring quality of treatment to patients.

To date, numerous studies and systematic reviews are available in the literature concerning the perceptive and communicative-linguistic outcomes in hearing-impaired children<sup>4</sup>. These allowed to outline the probable evolutionary lines, but unfortunately only a few systematic reviews exist on the treatment approaches and their efficacy. One of the general objectives of the project of the Italian Ministry of Health is to favour the global development of children with hearing loss through an early rehabilitation project and the activation of assessment and rehabilitation protocols based on scientific evidence and shared knowledge. In this respect, a preliminary strategic analysis has been established. To investigate positive and negative issues in early rehabilitation care for PHI children, the study was carried out by a multidisciplinary group and specifically aimed at defining the features and modes of access to a tailored and specialised rehabilitation project for the small hearing-impaired child within three months from audiologic diagnosis.

## Materials and methods

In order to facilitate the collection of information for strategic analysis of early care, a questionnaire was developed to assess the positive and negative aspects of the protocols and programmes of diagnosis and early treatment of pre-lingual child hearing impairment currently available at our Unit. The questionnaire was then distributed among the



families whose children are being treated at the Operative Unit of Otorhinolaryngology, Audiology and Phoniatrics, University of Pisa, and a group of operators belonging to or collaborating with our Unit (otolaryngologist, audiologist, speech therapists, audiometrist, hearing aid specialist, neuropsychiatrist, paediatrician). The families and operators were informed on the objectives and modes of the research, and gave their consent to participate in the project.

Twenty families of children with different types of permanent impaired hearing were involved in the study, and in particular 13 with profound bilateral sensorineural PHI, 7 with severe bilateral sensorineural PHI, along with 12 healthcare workers (3 otolaryngologists, 3 audiometrists, 3 speech therapists, 1 paediatrician, 1 neuropsychiatrist and 1 hearing aids specialist).

The questionnaire was structured in two specular versions: one for the operators and the other for the families. Both versions included 31 multiple-choice questions concerning multidisciplinary rehabilitation care after audiologic diagnosis. More precisely, the questions concerned the management of the child by the several involved professionals (audiologist, neuropsychiatrist/psychologist, speech therapists, and other therapists belonging to the team). In the final part of the questionnaire, parents and operators were also asked to list what they considered as the strong and weak points of the programme.

The questionnaire examines the following topics in detail: specialist assessment (audiologic, logopedic, neuropsychiatric/neuropsychological); planning of follow-ups and modes of communication concerning clinical test outcomes and observations to the family (interviews and/or written medical reports); subjective perception of the parent in relation to the level of involvement within the rehabilitation project: times of inclusion, frequency and modes of speech therapy treatment (cyclical/continuous therapies, participation/or not of the parent during the session); structures (hospital/territory, healthcare centres, public and private hospital systems); involvement of other professional figures in the rehabilitation project; level of school assistance, parents' enrolment in associations and sharing of opinions among families with impaired-hearing children; qualitative assessment on the general organisation of the service (waiting times, respect of privacy, access to ambiances).

The data were useful to the working groups to form items that drove SWOT analysis and the successive TOWS matrix. For a review of the SWOT methodology, see the work by White and Blaiser (2011)<sup>10,11</sup> or, more specifically, the introductory article of this volume.

## Results

This article concerns the topics related to SWOT analysis, the successive study performed by the working group that examined the questionnaire and the final TOWS analysis based on the results obtained by SWOT analysis.

**Table I.** Main key-points extrapolated from the questionnaires

**Table Ia.** *Strengths.*

Strength key points	Frequency (%) n = 40
Early rehabilitation prosthetic diagnostic intervention	20 (50%)
Involvement of the family in the rehabilitation treatment project	10 (25%)
Multidisciplinary collaboration	9 (22.5%)
Other	1 (2.5%)

**Table Ib.** *Weaknesses.*

Weakness key points	Frequency (%) n = 48
Absence of protocols of speech therapy rehabilitation	15 (31.5%)
Difficult communication network between third-level centre and territory	13 (27.08%)
Lack of standardisation in early rehabilitation care	11 (22.91%)
Absence of assessment and follow-up protocols	6 (12.5%)
Other	3 (6.25%)

**Table Ic.** *Opportunity.*

Opportunity key points	Frequency (%) n = 36
Implementation of shared assessment and rehabilitation protocols	19 (52.7%)
Specific training on early care of the child with PHI	11 (30.55%)
Activation of an efficient communication network among the professionals involved in early care of the hearing impaired child	6 (16.66%)

**Table Id.** *Threats.*

Threats key points	Frequency (%) n = 40
Variability in the assessment and rehabilitation process	17 (42.5%)
Resources	13 (32.5%)
Inefficient communication among operators	5 (12.5%)
Other	5 (12.5%)

*Table I (a b c d) The table shows the frequency of the topics emerged in the categories Strength, Weakness, Opportunity and Threat. (n=164)*

From the working group a total of 40 replies were obtained for category S, 48 for category W, 36 for category O and 40 for category T, for a total of 164 replies. These data were then grouped according to type and area of reference. The topics obtained are listed in Table I.

### *Strength key points analysis*

From the overall SWOT analysis, 3 principal topics emerged, which represent the Strengths characterising the area of early care: implementation of early rehabilitation prosthetic intervention (50%), involvement of families in therapeutic rehabilitation (25%) and presence of multidisciplinary collaboration (22.5%) (Table Ia).

The above-mentioned strengths can be analysed in further detail:

*Implementation of early prosthetic rehabilitation intervention*

This category includes all the replies concerning activation of early intervention including diagnosis, first prosthesis and rehabilitation care. The possibility of starting rehabilitation care at the third-level audiological centres was seen as a strength to favour early intervention.

*Involvement of families in the rehabilitation project*

This category includes all the replies concerning the need for family involvement in the therapeutic and rehabilitation project for the child. Transparent sharing of the rehabilitation objectives established by the multidisciplinary group can help the family understand better the methods that will be used, thus fostering the process of generalisation in everyday life. In order to increase the competence and awareness of the parents with regards to the strengths and weaknesses of their child, it is generally better if the caregiver participates in speech therapy sessions (unless contraindicated for any particular reason).

*Efficient multidisciplinary collaboration*

This category includes all the replies concerning care of the child by the multidisciplinary team. All the members of the team should have specific training in psycho-physical and communicative-linguistic development of the hearing-impaired child. For the multidisciplinary care to be optimal, there needs to be an active collaboration among all the professional figures involved. The possibility of monitoring the development of the child in its entirety by periodical follow-ups allows to determine if the child as a whole is in line with the normal developmental profile and to intervene promptly in case the child is not.

**Weakness key points analysis**

From the analysis of the overall SWOT, 4 main topics emerged, which represent the weaknesses characterising the area of early care: absence of shared rehabilitation protocols (31.5%), inefficient communication between the implantation centre and the territory (27.8%), lack of standardisation in rehabilitation care (22.91%), absence of shared assessment and follow-up protocols (12.5%) and other (6.25%) (Table Ib). All the weaknesses mentioned above can be analysed in further detail:

*Absence of shared speech therapy rehabilitation protocols*

This category includes all the replies concerning the lack of shared speech therapy rehabilitation protocols. No standardised methods were used for speech therapy rehabilitation adopted within the same type of approach (e.g. oralist approach), nor were any guidelines or official recommendations that could provide uniformity to the vari-

ous interventions. The presence of different methods may be associated with the lack of shared rehabilitation objectives (e.g. different aims between the audiological centre and the territory).

*Difficult communication network between third-level centre and territory*

This category includes all the replies concerning the difficulties in training and maintaining efficient communication networks between the third-level audiological centre and the rehabilitation structure taking the child into care (territory, structure operating within the national health-care service/private system). It emerges that communication is often fragmentary, inconstant and unidirectional, which makes it incompatible with the overall programme.

*Lack of standardisation in early rehabilitative care*

This category includes all the replies concerning the lack of standardisation in early rehabilitative care. No unanimous consensus exists on the categories of patients to be included in a programme of early speech therapy rehabilitation. The weaknesses reported are referred to the scarce lack of systematic protocols when caring for children with mild and moderate PHI and monolateral PHI. Another element included in this category of replies regards the fact that the structures intended for very early care are not being clearly identified (third-level centres? Territory?).

*Absence of shared assessment and follow-up protocols*

This category includes all the replies concerning the lack of shared assessment and follow-up protocols among the audiological centres, territorial structures, between the audiological and different rehabilitation centres (e.g. patients with multiple disabilities who need various therapies). The lack of standardisation concerns several aspects: the areas to investigate during assessment (cognitive, emotional-affective, motor, communicative-linguistic, auditory and perceptive), the assessment tools to be used (variability of test batteries) and follow-up times.

**Opportunities key points analysis**

From the analysis of the overall SWOT table, three main topics emerged, which represent the opportunities characterising the area of early care: implementation of shared assessment and rehabilitation protocols (52.7%), specific training on early care of the child with PHI (30.55%), activation of a communication network among professionals (16.66%) (Table Ic). These Opportunities can be analysed in further detail:

*Implementation of shared assessment and rehabilitation protocols*

This category includes all the topics offering a possible solution to the extreme lack of uniformity of assessment and rehabilitation protocols of the child with PHI. The

implementation of assessment protocols shared among various audiologic centres and territorial structures that have taken the child into care could diminish considerably the current variability, with appropriate indications at an international level. To make standardised rehabilitation intervention possible it is necessary to be able to refer to guidelines resulting from a common consensus of professionals, and based on solid theoretical and scientific grounds.

#### *Specific training on early taking into care of the child with impaired hearing*

This category includes all the replies offering opportunities to increase training for healthcare operators. In particular, operators involved in early care of the hearing-impaired child should possess basic knowledge about specific physiological and pathological development. The organisation of compulsory training courses and consequent achievement of certificates/qualifications could guarantee the adequacy of competence of the operators involved. In order to encourage all the members of the team, it would be advisable to involve school operators in the training process as well as all those involved in the child's everyday life.

#### *Activation of an efficient communication network of professionals involved in child care*

This category includes all the topics that offer a possible solution to the problems associated with partial and inefficient communication between a third-level audiologic centre and territory network. The creation of a shared database and telematic systems that can be accessed by all professionals participating in the care programme (or some representatives located in the different structures) may facilitate the exchange of information among the team members, increasing the possibility of controlling the child's overall development. Within the multidisciplinary communication network, the family paediatrician represents an important resource, owing to the constant contact with the child's family.

#### **Threats key points analysis**

From the overall SWOT analysis, 3 principal topics emerged representing the threats characterising the area of early rehabilitative care: variability in the process of assessment and rehabilitation (42.5%), insufficient resources (32.5%), difficulty of communication among operators (12.%) and other (12.5%) (Table Id). The above-mentioned Weaknesses can be analysed in further detail:

#### *Variability in the process of assessment and rehabilitation*

This category includes the responses relative to the lack of shared assessment protocols specifying the developmental areas to be investigated, follow-up times and assessment tools to be employed. The wide variety of tests avail-

able on the market represent a risk for standardisation of the evaluation process.

The same variability can be found in the different rehabilitation approaches that are currently used. Owing to the absence of solid theoretical and scientific grounds, the customisation process adopted by therapists for rehabilitation of the single patient runs the risk of not focusing on general objectives that can be shared by all the colleagues belonging to the same specialisation (e.g. different logopaedic aims between the third-level centre and the territory).

The risks correlated to the lack of standardisation in the processes of evaluation and rehabilitation are increased in the case of deafness-associated disabilities. In multi-handicapped patients, the evaluation process presents even greater problems, probably caused by the difficulties of interpretation of the results obtained with structured material.

#### *Resources*

This category includes the replies relative to the lack of resources. The lack of resources destined to rehabilitative care induce a chain reaction: the lack of personnel affects the waiting times, with the risk of compromising the "precoity of the intervention".

The risk associated with the lack of resources was also studied in relation to the financial resources of the family. Family units belonging to poorer and more destitute social layers may have difficulty in ensuring complete adhesion to the follow-up calendar or rehabilitation project.

#### *Difficulty of communication among operators*

This category includes the responses relative to the difficulties in communication among the different team members who have taken the child into care. The distribution of the interventions in various centres (e.g. third-level audiologic centre/territory) represents a risk for complete and constant exchange of information. Communication exchanges often risk to be unidirectional, so that it is impossible to monitor the developmental growth of the child in optimal manner. The difficult communication among the healthcare operators is linked to communication involving professionals that belong to other fields, e.g. school operators.

#### *Other*

This category includes the replies relative to general management problems (medical reports legislation, respect of privacy) and those relative to extraterritorial and multicultural risks. Patients living geographically distant from the audiologic centre of reference might have greater difficulties in structuring a systematic communication network between the audiologic centre and the local rehabilitation centre. Furthermore, the distance from the audiologic centre implies general organisational difficulties concern-

ing various follow-up visits and fosters incomplete adhesion to the programme.

Patients belonging to different cultures are even more complex. In these cases, communication with the team may encounter further problems of a cultural and linguistic type that can make it difficult for the program to be fully efficient.

### Discussion

The TOWS matrix was created on the basis of the data of the SWOT analysis. A number of specific recommendations were obtained from the matrix to optimise the process of early (within six months from detection) care of the child. The recommendations can constitute an excellent cause for reflection for third-level audiologic centres, and provide suggestions to optimise resources and produce positive changes. A total of 14 recommendations were obtained from the study and discussion of the current research (Table II).

From the strategic analysis performed, 3 principal themes emerged, representing the greatest Strengths for rehabilitative care, for which external threats are to be minimised and the opportunities implemented:

- implementation of guidelines providing shared indications for assessment and rehabilitative care, also with regards to timing;

- early care by the multidisciplinary team with shared training and creation of a good communication network between the third-level centre and territory;
- involvement of families in the rehabilitation project, starting from the early stages.

In terms of early care, the first recommendation is related to the need to define protocols of well-structured and shared assessment and rehabilitation. Assessment and rehabilitation represent crucial moments in early care, and one of the greatest problems is represented by the different approaches and scarce systematic approach of the procedures.

The definition of a reference point that can guide operators in both the assessment and rehabilitation phases would provide greater consistency of intervention, enabling all children with PHI to have access to the same quality of treatment. Concerning the assessment phase, it will be essential to define which areas of development will have to be evaluated and followed-up (e.g. neuropsychiatrist/neuropsychological assessment, logopaedic assessment, audiologic assessment, etc.) and to indicate follow-up times. It would also be useful to specify the structured tests of reference. The use of the same tests (therefore of a common language) could favour discussion and exchanges of opinion among operators, making it easier to collect data. A systematic collection of data could form a solid base for future research concentrated on the development of the

Table II. TOWS matrix (see text for explanation).

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	<p><b>OS strategy</b></p> <ol style="list-style-type: none"> <li>1. Implementation of guidelines providing shared indications relative to the assessment and rehabilitation aspects</li> <li>2. Early taking into care by a multidisciplinary team with specific training for early care of the very small child with PHI. Creation of a good network with the territory and in general with all the centres destined to rehabilitation of the child.</li> <li>3. Involvement of families in the rehabilitation project at the very early phases of intervention</li> </ol>	<p><b>WO Strategy</b></p> <ol style="list-style-type: none"> <li>1. Official definition by the institutions on the structures destined to early rehabilitation. Definition of the users who need immediate access to speech therapy rehabilitation and of users whose difficulties were only detected during follow-up</li> <li>2. Definition of official assessment protocols (areas of development to investigate, timing of follow-up for each area, assessment tools that can be employed)</li> <li>3. Development of specific guidelines for early rehabilitation care of the child with PHI (theoretically and scientifically based recommendations)</li> <li>4. Implementation of shared databases for systematic collection of the data achieved during the various stages of assessment for both clinical and research evaluations.</li> <li>5. Organisation of compulsory training events to standardise the knowledge of team operators with regards to early care</li> </ol>
	Threats (T)	<p><b>ST strategy</b></p> <ol style="list-style-type: none"> <li>1. Implementation of shared guidelines for early care (assessment and rehabilitation) allows to standardise care intervention by providing the same learning opportunities to patients from different socio-assistance contexts.</li> <li>2. Availability of a multidisciplinary team with a good communication network allows to take the patient into care at a global level. Strengthening the communication network with the territory minimises extraterritorial effects.</li> <li>3. Involvement of the families in the rehabilitation project increases their participation in the project itself.</li> </ol>	<p><b>WT strategy</b></p> <ol style="list-style-type: none"> <li>1. Sensitising the healthcare institutions and organisations for the allocation of resources destined to early and overall rehabilitation care of the child with PHI.</li> <li>2. Sensitising the healthcare institutions for allocation of funds destined to the implementation of systems of communication that can facilitate the collection of clinical data and the exchange of information (e.g. digital databases)</li> <li>3. Promoting the organisation of compulsory training courses for multidisciplinary team members.</li> </ol>



hearing-impaired child. The implementation of ad hoc databases in which the developmental outcomes have been recorded during assessment and rehabilitation could also offer numerous advantages. Access to the database by the professionals involved in early care (audiologist, neuropsychiatrist, family paediatrician) would allow monitoring the development of the child, in order to detect any particular follow-up gaps.

When faced with the variety of rehabilitation approaches in the field of early care, we cannot but refer to evidence-based medicine (EBM). EBM constitutes an approach to clinical practice in which clinical decisions result from integration of clinical practice and the meticulous, clear and sensible employment of the best scientific experience available, and mediated by patient preferences<sup>14</sup>.

However, such an approach has long been widely diffused in the medical, but not in the rehabilitation field. There are, in fact, many problems to be faced for the application of these principles to rehabilitation. For example, in order to check the efficiency of a specific therapy, it is necessary to recruit one or more control groups that will not be submitted to any type of intervention. Despite the methodological and procedural difficulties in applying the EBM principles to the rehabilitation process, it is important to promote a culture in which the efficiency of a therapy is evaluated by experimentation based on statistical principles: in fact, the therapist's individual experience alone has limited value in the therapeutic choice<sup>15</sup>.

Early care must be as uniform as possible, with guidelines resulting from common consensus and based on solid theoretical and scientific grounds. A positive experience of this type is represented by the Italian Speech Therapists Federation (FLI), which since 2003 has been involved in setting up specific groups of interest aimed at identifying guidelines and recommendations for common models of behaviour by healthcare professionals. It is hoped that common guidelines will also be established for early care of the child with impaired hearing.

A systematic care programme should regard not only the methods of treatment, but also more general management/organisational aspects. In this respect, an important recommendation is the need to define the types of patients to be included in the programme of early care, instead of including patients to rehabilitate only after communicative-linguistic deficits have been detected during follow-up. It is fundamental that all impaired-hearing children requiring logopaedic treatment are included in well-structured rehabilitation programmes specifying times, frequency of treatment and general principles (objectives and methods). The most debatable category, with regard to early care, is represented by children with mild-moderate bilateral hearing loss and children with mono-lateral deafness.

The process is complex even for two other types of patients: children with PHI belonging to a multicultural/

multilingual context and children presenting with PHI associated disabilities. For bilingual children, it will be necessary to consider their multicultural/multilingual context with regard to both the process of assessment (use of standardised tests in their own language associated with semi-structured observations) and the program of rehabilitation. Multi-handicapped children also require complex and global care that takes into account all their areas of development, with particular attention to those more greatly influenced by PHI-associated deficits.

One of the recommendations linked to the organisational aspects is to define at an institutional level the times required for early care; on the basis of the different health-care structures available in the national territory, it will also be necessary to officially define the structures responsible for care. Since the times of access to rehabilitation do not always correspond to the waiting lists of the territory, it will be important to find alternative solutions for effective care (i.e. within 6 months of life). The external threats related to the first recommendation are basically constituted of the lack of both financial and human resources. The creation and diffusion of a database present several problems associated with implementation costs, personnel assigned to its compilation and preservation of privacy for the users. Considering rehabilitation aspects, the greatest drawbacks derive from the waiting lists of the territorial structures that are not always consistent with the needs of early intervention and are probably linked to insufficient availability of personnel and resources.

The second recommendation concerns the need for early care that is multidisciplinary, integrated and global. The rehabilitation project requires therapeutic polyvalence and a series of competences that vary according to the child's disabilities and developmental stage. Early global care, with integrated and coordinated treatment, is based on different synergies and on the collaboration of all the multidisciplinary team members, even when they belong to services located on different sites (e.g. third-level centre or rehabilitation centre). In order to include the child in a global rehabilitation project, the various professionals need to connect through a solid and efficient communication centre that is able to fully guarantee the multidisciplinary care.

An important aspect of the second recommendation consists in training the members of the multidisciplinary team. Taking a very small (6-9 months) impaired-hearing child into care implies specific training both in terms of developmental features and best communicative and perceptive modes that can stimulate the child. These aspects must be considered during the training process of the operators involved in the project, and an opportunity in this respect is offered by the participation to specific training courses. The need for specific training increases in the case of a medically complex child should also be considered. An external risk might be represented by the insuffi-

cient competence of some operators and the impossibility to check whether the competences of the rehabilitator are actually suitable to the role.

Multidisciplinary care is based on a constant exchange of information among team members. Even in this case, the exploitation of a shared database and telematic systems could be useful. Constant updating of the data available in the database would allow all those who have taken the child into care to check whether the child's growth is in line with the normal developmental stages or whether it presents any peculiarities that are worth investigating. In the absence of a shared database, periodical reports written by all the professionals involved in follow-up and rehabilitation could facilitate the exchange of information among operators, with the inconvenience of the parents having to act as mediators, and burdened with a duty that falls outside their function. An important resource could be represented by the organisation of logopaedic networks over the entire territory. A network of this type, although not yet formalised, has already proven efficient and has for some years now been active in our implantation centre. In the absence of a database, the availability of answering services/direct numbers/e-mail reference addresses for both the audiologic and territorial centres could foster the exchange of information. Even in this case, the major external risk is the impossibility to use the resources that can be assigned to the personnel dedicated to these activities. The third recommendation concerns the need to involve the parents in the rehabilitation project. By exerting the right of "informed choice", the family must be adequately informed and trained on the various therapeutic proposals and possible rehabilitation objectives to be pursued. This recommendation agrees with the guidelines of the JCIH <sup>2</sup>, which underline the importance of the parents' role within the framework of early intervention. According to numerous authors, the child and his/her family must be involved in an intervention that can improve their quality of life, thus fostering the development of auditory and communication abilities <sup>16 17</sup>. The role of parents considerably affects the success of rehabilitation.<sup>18-19</sup> The quality and quantity of maternal stimulation influence the linguistic abilities reached by small children with cochlear implants: for this reason, the parent should know how to relate with the child since the very first years of life, by assuming the role of scaffolder in development <sup>5-9</sup>. An external opportunity favouring the involvement of the caregivers in the rehabilitation project is represented by the possibility to participate in the logopaedic sessions so as to observe directly the perceptive and communicative strategies used by the speech therapist to interact with the child. During sessions, the activities are aimed at achieving communication objectives (enhance non-verbal communication prerequisites; foster all components of verbal communication devel-

opment; stimulate auditory attention by pursuing the attainment of increasingly complex perceptive abilities). Personal participation in the rehabilitation sessions and observation of the various specific activities will make the parent more conscious of the strengths and weaknesses, both perceptive and communicative, of the child.

The external risks for this last recommendation concern the difficulties in using clear and exhaustive communication with families. The professionals involved in the rehabilitation process should be sure that the families are fully aware of the rehabilitation objectives and of the methods that will be used for their attainment. The language employed with families will need to be customised to their socio-linguistic features (e.g. foreign parents with scarce competence in Italian), and specialists should be certain that the contents of the message have been clearly understood. In order to facilitate the entire process, it may be useful to give the family periodic medical reports, clarifying the steps of care (short-medium and long-term objectives). According to our clinical experience, in agreement with the recommendations provided by JCIH <sup>1 2</sup>, we have observed that for parents of newly diagnosed children the possibility of exchanging ideas with other parents represents an important resource. The activation of a "help-desk" in which professionals and volunteer parents can offer their support to the families represents an important external opportunity to help families in the taking into care process. In our Unit, this activity of family support is carried out by structured medical and technical staff and avails itself of the collaboration of volunteer members of the Association ASIC (Association for Deafness and Cochlear Implants). ASIC is a non-profit volunteer association formed by the parents of hearing-impaired children and by adults with impaired hearing, with the scientific support of audiologic specialists.

## Conclusions

In the working area for early care, three main recommendations were identified that are useful for the planning of a centre for paediatric PHI: implementation of guidelines providing shared indications relative to the assessment and rehabilitation aspects of early care; early taking into care by a multidisciplinary team sharing the same type of appropriate training, and successive realisation of a good communication network between third-level centre and territory; involvement of the families in the rehabilitation project from its very early stages. For the third-level audiologic centres, the recommendations emerging from this process can be valid recommendations to optimise resources and produce positive changes.

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# Follow-up of permanent hearing impairment in childhood

## *Il follow up del bambino con ipoacusia permanente*

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### SUMMARY

Programmes for early childhood hearing impairment identification allows to quickly start the appropriate hearing aid fitting and rehabilitation process; nevertheless, a large number of patients do not join the treatment program. The goal of this article is to present the results of a strategic review of the strengths, weaknesses, opportunities and threats connected with the audiologic/prosthetic/language follow-up process of children with bilateral permanent hearing impairment. Involving small children, the follow-up includes the involvement of specialised professionals of a multidisciplinary team and a complex and prolonged multi-faced management. Within the framework of the Italian Ministry of Health project CCM 2013 "Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children", the purpose of this analysis was to propose recommendations that can harmonise criteria for outcome evaluation and provide guidance on the most appropriate assessment methods to be used in the follow-up course of children with permanent hearing impairment.

**KEY WORDS:** Childhood hearing loss • Follow-up • Lost to follow-up • Outcome evaluation protocols • SWOT analysis

### RIASSUNTO

*I programmi di identificazione precoce delle ipoacusie infantili permette di intraprendere rapidamente l'iter riabilitativo e protesico appropriato; nonostante ciò appare ancora elevato il numero di pazienti che non aderiscono al programma terapeutico. L'obiettivo di questo articolo è presentare i risultati di un'analisi strategica che prende in considerazione i punti di forza, i punti di debolezza, le opportunità e i rischi del processo di follow up audiologico/protesico/linguistico di bambini affetti da ipoacusia bilaterale permanente. Il follow up in questione, coinvolgendo bambini piccoli, implica il coinvolgimento di professionisti specializzati e inseriti in un team multidisciplinare e una gestione plurisettoriale complessa e prolungata. Nell'ambito del progetto finanziato dal Ministero della Salute Italiano CCM 2013 denominato "Programma regionale di identificazione, intervento e presa in carico precoci per la prevenzione dei disturbi comunicativi nei bambini con deficit uditivo" lo scopo di quest'analisi è stata quella di offrire delle raccomandazioni per armonizzare i criteri di valutazione dei risultati terapeutici e trarre spunto da questi per successivamente fornire delle linee guida riguardanti le metodiche più adeguate nella valutazione del bambino con ipoacusia permanente.*

**PAROLE CHIAVE:** Ipoacusia infantile • Follow up • Persi al follow up • Protocolli di valutazione di beneficio • Analisi SWOT

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## Introduction

Early identification of infant permanent hearing impairment (PHI) is one of the primary actions to prevent the occurrence of changes in cortical and subcortical structures caused by the absence of sensory input; these changes will be much more severe and long lasting if the sensory deprivation started early in life and is of longer duration<sup>1</sup>. If the PHI is congenital, it is necessary to provide proper amplification preferably within six months of life to avoid reorganisation of neural networks involved in acoustic processing and eventually offer the opportunity to normally develop auditory perception and verbal comprehension<sup>2,3</sup>. In case of late diagnosis, it will be mainly neces-

sary to correct the PHI and quickly start a rehabilitation program that seeks to compensate for the lack of acoustic inputs. In event of post-verbal PHI, the threshold correction will be followed by careful assessment of the effects caused by the lack of input to plan the most appropriate treatment<sup>4</sup>.

The treatment will be based on an effective cooperation between the multidisciplinary team, family and paediatrician. All are in some way involved in monitoring the outcomes of the treatment program and nurture the relationship with the family.

To determine the benefit of prosthetic intervention/rehabilitation, the tertiary centre team will need to periodically evaluate the young patient in order to assess the aided



auditory response, cognitive and attention development, auditory processing skills and language development<sup>5</sup>.

The follow-up evaluation gives a measure of the rehabilitative treatment efficacy and allows to modulate it according to the needs of the young patient. At present time Italian centres do not share a reference model of follow-up methodology and tools for PHI children.

Within the framework of the Italian Ministry of Health project CCM 2013 “Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children”, it was decided to consider the problems relative to the harmonisation of criteria for outcome evaluation. The specific aim is to implement a follow-up protocol that supports effective feedback within tertiary centres and primary care.

## Materials and methods

A group of professionals working in tertiary care referral centres for childhood PHI was asked to complete a survey having as its object the follow up of children with PHI. The survey asked to participants to report at least 2 strengths, weaknesses, opportunities and threats for use in strategic planning. This phase was conducted using the principles of a SWOT analysis. The acronym SWOT stands for Strength (S), Weaknesses (W), Opportunities (O) and Threats (T), and corresponds to what the comments of the participants have pointed out. The responses obtained were reviewed by the specialists responsible for this area. To generate recommendations from SWOT analysis, a TOWS matrix was used to match the external threats and opportunities with internal weaknesses and strengths of the organisation or programme<sup>6</sup>. The detailed description of the SWOT and TOWS matrix analysis procedure can be found elsewhere in this issue. The study and the survey was focused on this specific aim: schedule a follow-up protocol that supports an effective feedback within tertiary centres and primary care.

## Results

The study group included 21 professionals. All participants completed the SWOT questionnaire.

The 150 open-ended answers (S = 38, W = 45, O = 38, T = 29) were reviewed by the authors and grouped in main key points (Table I).

### Strength key points analysis

1. The professionals highlighted the presence of a multidisciplinary working group. A dedicated competent/experienced staff (41%), underlining the specific training of all specialists in the field, is needed.
2. Follow-up with standard tests (28%) is considered more competent and reliable feedback of follow-up

**Table I.** Main key points extrapolated from questionnaires.

**Table Ia.** *Strengths.*

Strengths key points	
Multidisciplinary working group	17 (41%)
Follow-up with tests	12 (28%)
Immediate booking appointments	7 (17%)
Accessibility of the centre	5 (12%)

**Table Ib.** *Weaknesses.*

Weakness key points	
Limited personnel	16 (33%)
Weak feedback with paediatricians, speech therapists	14 (28%)
Missed appointments	7 (15%)
Absence of shared protocols	6 (13%)
Multiculturalism and family circumstances	3 (6%)
Miscellaneous	2 (5%)

**Table Ic.** *Opportunities.*

Opportunity key points	
Dedicated secretary	17 (42%)
Paediatric centre	14 (35%)
Follow-up protocols	6 (15%)
Book appointments in advance	2 (4%)
Miscellaneous	2 (4%)

**Table Id.** *Threats.*

Threats key points	
Lack of funding	15 (46%)
Multiculturalism	8 (25%)
Lack of cooperation between specialists	7 (22%)
Miscellaneous	2 (7%)

language when based on the use of standardised tests and accepted nationally and internationally.

3. Immediate booking of appointments and control visits directly by staff (17%), which gives the possibility to scan appointments efficiently and without waiting lists.
4. The hearing impaired child will undergo several medical examinations, therefore, in order to not discourage patients it is appropriate that the reference centre is reachable without great difficulty (12%).

### Weakness key points analysis

1. Limited personnel (33%) related to lack of founding or hiring freezes, with loss of pertinent information.
2. Weak feedback with paediatricians, speech therapists (28%), with loss of effectiveness of the team of the reference centre and difficulties in communicating the results and therapeutic programmes.
3. Missed appointments (15%), are an expression of an unorganised service without a dedicated secretary.

4. Absence of shared protocols (13%) causes poor assessments of information on language development and enables collaboration between specialists.
5. Multiculturalism and family circumstances (6%), in which we also include situations of cultural differences that prevent the family to fully understand the therapeutic program.
6. Other answers were uncategorised (n = 2).

**Opportunities key points analysis**

1. Dedicated secretariary (42%) to manage appointments regularly and enable monitoring them.
2. Paediatric centre (35%) that allows managaing shared programmes with paediatricians and rehabilitation centre within dedicated environments.
3. Follow-up protocols (15%) made of standardised tests that have a rapid and easy execution and low time of administration.
4. Establish appointments in advance (4%) before the patient leaves the centre so as not to create work overload and better manage the timing of follow-up.
5. Other answers were uncategorised (n = 2).

**Threats key points analysis**

1. Lack of funding (31%), resulting in inadequate staff, long waiting lists and time constraints, lack of secretaries and dedicated spaces.
2. Multiculturalism (25%), in which reference is made to the difficulties of managing users geographically distant from the centre audiologic reference and all the family circumstances.
3. Lack of cooperation between the specialists (22%), with sometimes conflicting information, failure of reporting and monitoring, and absence of compliance of the family.
4. Other answers were uncategorised (n = 2).

**Discussion**

The Joint Committee on Infant Hearing<sup>7</sup> stresses the need to increase awareness and knowledge of healthcare personnel about issues related to PHI, coordinate efforts to follow-up allowing for benefit from family collaboration, reduce inequalities in healthcare delivery and ensure that the recommended services are received and reported<sup>7,8</sup>. It is difficult, for this specific clinical area, to divide the external issues from the internal ones because there are variables related both to the compliance of the family and to the territorial professionals (paediatrician, speech therapist) that may affect the work of the referral center. For this reason, it is necessary for the paediatrician and the family to be constantly informed about the treatment plan. Specific educational and training meetings or sessions organised by tertiary centre specialists should be sought. Starting from the SWOT analysis data, a TOWS matrix was created, which compares Strengths-Opportunities, Weaknesses-Threats and Weaknesses-Opportunities. Analysing the data obtained from this research, 8 recommendations were obtained (Table II). Finally, three main themes were recognised, which can contribute to accurate, effective and shared audiologic/prosthetic/language follow-up in children with permanent hearing loss:

- establish the steps of follow-up, defining timing, type and duration of the assessment to be made;
- focus on training of all professionals who are part of the multidisciplinary team, which should also include planning themes such as managing appointments, reporting on databases, etc.;
- build a network with professionals working in the territory with whom to share the follow-up process of the child so that they can be active and aware in the therapeutic programme. This is a particular concern for patients who do not follow the correct follow-up programmes.

**Table II.** TOWS matrix (see text for explanation).

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	<p><b>SO strategy</b></p> <ol style="list-style-type: none"> <li>1. Use standardised tests to make quick and effective follow-up in relation to age and prosthetic trim.</li> <li>2. Competent and motivated multidisciplinary team with specific knowledge of the diagnostic and therapeutic that requires hearing loss.</li> </ol>	<p><b>WO strategy</b></p> <ol style="list-style-type: none"> <li>1. Improve feedback between the referral centre, family paediatricians and local rehabilitative staff by training all professionals and secretarial staff.</li> <li>2. Book the next appointment before leaving, clarifying duration and assessments to be done so that the families can organise themselves better. If a paediatric center optimises all evaluations (also other departments) it can facilitate families who liver far away.</li> </ol>
	Threats (T)	<p><b>ST strategy</b></p> <ol style="list-style-type: none"> <li>1. Give comprehensive and complete information to the family and to the operators of the territory about the goals to be achieved.</li> <li>2. Ensure that the paediatrician and families are an integral part of the multidisciplinary team, establishing regular meetings with them to make the family aware of the importance of regular visits.</li> </ol>	<p><b>WT strategy</b></p> <ol style="list-style-type: none"> <li>1. Improve follow-up rates for families at risk of being lost to follow-up by strengthening the therapeutic alliance with the professionals who deal with family support.</li> <li>2. Build a network with specialists working within the territory; increase awareness to so that healthcare institutions and organizations can have increased funding for the team, its projects and continuing education.</li> </ol>

The first recommendation emphasised the need for valid and standardised protocols that can make the evaluation of young patients effective and quick. Correct assessment of language and cognitive development are essential to establish an effective rehabilitation programme, and thus the need to determine which method will allow following as many patients as possible<sup>9</sup>. Speech therapy and follow-up tools require an operative model of reference, updated to the evolution of knowledge and, ensure standard uniform procedures that allow follow up checks to be unambiguous and comparable in data. Most of the tests that are internationally used are in English or standardised in foreign samples, making it difficult to have international shared protocols. The beginning of a national uniformity is foreseen by the authors in the framework of the CCM project shared by the five regions involved.

Clarity regarding the child's rehabilitation programme will facilitate the understanding of the family and make the rehabilitators and paediatrician aware of the rehabilitation project. The second recommendation is that the multi-disciplinary management of the patient should be referred to specialists who are properly trained and aware that the rehabilitation programme is based on the communication between the team members, paediatrician and the family. In fact, a motivated and competent team will be able to encourage the family in a long and demanding follow-up process.

In the management of so many professionals, we need to rely on nurses and administrative employees who are properly trained to manage appointments, to limit the lost to follow-up, and guide families; for this reason, it is necessary to plan training sessions for administrative staff and nurses. In fact, there is still a high percentage of patients lost to follow-up that in part depends on waiting lists, family organisation, and lack of dedicated secretarial staff. The chance to determine the next appointment before leaving seems an opportunity to limit the loss of patients. Equally important will be an updated database with the data of the patient and the telephone numbers of family and paediatrician for better tracking of patients and to improve follow-up rates in families with demographics that place them at risk of being lost to follow-up.

The third recommendation emphasises the importance of a constant exchange of information that allows observing the evolutionary stages of the patient with permanent hearing loss compared to a hearing child, and providing for the creation of a collaborative network between

speech therapists, referral centre, paediatrician and family in order to avoid loss to follow-up. Furthermore, the training of speech therapists and paediatricians in the territory enables collaboration in order to accelerate the execution of tests and improve the clarity of information provided to families.

## Conclusions

Three main recommendations were recognised to have a correct and shared audiologic/prosthetic/language follow-up in children with permanent hearing loss, i.e. establish the steps of follow-up, and define the timing, type and duration of the assessment to be made; focus on training of all professionals who are part of the multidisciplinary team and managing appointments; build a network with specialists working within the territory and following the child so that they can make follow-up faster.

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# Empowering the family during the first months after identification of permanent hearing impairment in children

## *Rendere competente la famiglia nei primi mesi successivi all'identificazione di una ipoacusia del figlio*

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### SUMMARY

The latest international guidelines highlight the importance of involving the family in the diagnostic and rehabilitation process of children affected by permanent hearing impairment. This emphasises how meaningful this approach is for the development of the deaf child. So far, there is very little evidence about this approach in Italy, and there are still some barriers to its practical management. The aim of this paper is to report the results of a strategic analysis, which identifies the strengths, weaknesses, opportunities and threats of the family empowerment process during early auditory diagnosis and rehabilitation. The audiology programme should have the goal to offer information and support to families in order to achieve a conscious decision about the use and type of auditory prosthesis and rehabilitation choice within three months after audiological diagnosis. Within the framework of the Ministry of Health project CCM 2013 "Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children", a group of professionals identified three main recommendations that can be useful to foster the natural communicative development of the child by strengthening the therapeutic alliance and empowerment of the family. The recommendations obtained with this analysis can help to develop new Italian guidelines with the aim to foster natural communicative development of the child by strengthening the therapeutic alliance and empowerment of the family.

KEY WORDS: Childhood hearing loss • Early audiological intervention • Interdisciplinary collaboration • Parental empowerment • SWOT analysis

### RIASSUNTO

*Nelle più recenti linee guida internazionali sull'intervento precoce in audiologia pediatrica emerge l'importanza del coinvolgimento della famiglia nel percorso diagnostico-riabilitativo del bambino con deficit uditivo permanente. Questa modalità di approccio costituisce una ricchezza per lo sviluppo dei bambini con deficit uditivo. Vi sono ad oggi poche evidenze del panorama italiano rispetto a questo ambito e rimangono aperte perplessità e difficoltà di gestione pratica. L'obiettivo di questo articolo è presentare i risultati di un'analisi strategica che prende in considerazione i punti di forza, i punti di debolezza, le opportunità e i rischi di una presa in carico precoce che renda competente la famiglia. Le iniziali fasi della presa in carico devono fornire alle famiglie di bambini con recente diagnosi di ipoacusia permanente le informazioni e/o il sostegno necessario al fine di indurle a compiere la scelta del dispositivo protesico uditivo più idoneo, entro tre mesi dalla diagnosi audiologica. Nell'ambito del progetto del Ministero della Salute CCM 2013 "Programma regionale di identificazione, intervento e presa in carico precoci per la prevenzione dei disturbi comunicativi nei bambini con deficit uditivo" un gruppo di esperti ha identificato tre principali raccomandazioni utili per migliorare lo sviluppo comunicativo del bambino attraverso il coinvolgimento della famiglia e il rafforzamento dell'alleanza terapeutica. Queste considerazioni costituiranno il punto di partenza per riflessioni e analisi più dettagliate che potranno dare luce a linee guida e indicazioni specifiche su come buone prassi di presa in carico di bambino con deficit uditivo e famiglia possano inserirsi e concretizzarsi nel reale panorama italiano.*

PAROLE CHIAVE: *Ipoacusia infantile • Intervento audiologico precoce • Collaborazione interdisciplinare • Empowerment familiare • Analisi SWOT*

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### Introduction

The implementation of the universal newborn hearing screening (UNHS) has allowed for early identification and treatment of permanent hearing impairment (PHI). In the first months after diagnosis, the family of a deaf child

is involved by the audiological team of professionals in making relevant and awkward health choices, i.e. the application of hearing aids or cochlear implantation. Several issues are related with management and emotional issues noticed by professionals and caregivers in the first 3 months after identification of the PHI. Among these are



emotional issues of parents/caregivers after diagnosis; issues related to the communication of diagnosis or related to multiple consultations among referral centres; the role of the rehabilitation professionals or how to communicate with parents/caregivers.

According to the current guidelines of the Joint Committee on Infant Hearing (JCIH), it is essential to coach parents to have a conscious and active role in the auditory, speech and language rehabilitation of the hearing impaired child<sup>1-6</sup>. Empowerment practices are effective in supporting the families of children<sup>7-10</sup>. Moreover, the self-perception of parents to efficiently take part in the rehabilitation programme can improve language outcomes<sup>2-5</sup>. High levels of family support can dramatically improve the language development of the impaired child. In this family-centred perspective, the teamwork of a multidisciplinary group of professionals with skills in developmental neuropsychology and family mentoring is of utmost importance. Even if several paediatric audiology services are embracing this model, a systematic approach to the family-centred rehabilitation of the deaf child is not widespread. In the framework of the Italian Ministry of Health project CCM 2013 “Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children”, a multidisciplinary team of professionals carried out a strategic analysis with the specific aim to provide a preliminary set of recommendations to coordinate professional activities that involve and empower families in the first three months after PHI identification in children.

## Materials and methods

In the initial phase, positive and negative considerations of current rehabilitation programs were explored with an open-ended questionnaire administered to parents and territorial rehabilitation professionals. Questionnaires were administered prospectively during 10 days in the third level centres of Audiology at Trieste, Pisa and Rome. Inclusion criteria for parents were: a) children affected by non-syndromic PHI, either congenital or acquired, whatever the type and severity; b) Italian native language, to avoid language barrier bias. The results of the questionnaires were discussed by a group of professionals working in tertiary care referral centres for childhood PHI. Professionals reported at least 2 strengths, weaknesses, opportunities, and threats for use in strategic planning. This phase was carried out using the principles of SWOT analysis. The acronym SWOT stands for Strength (S), Weaknesses (W), Opportunities (O) and Threats (T), and corresponds to what the comments of the participants have pointed out. The responses obtained were reviewed by the specialists responsible for this area. To generate recommendations from the

SWOT analysis, a TOWS matrix was used to match the external threats and opportunities with internal weaknesses and strengths of the organization or programme<sup>11-12</sup>. The detailed description of the SWOT and TOWS matrix analysis procedure can be found elsewhere in this issue. The study and the survey was focused on this specific aim: coordinate professional activities that involve and empower families in the first three months after PHI identification in children.

## Results

Twenty-five consecutive families of children affected by PHI were enrolled. All patients had been referred to the tertiary care centre after having completed the PHI identification work-up. On the basis of inclusion criteria, 2 families were excluded, because of foreign mother language (n = 1), or because of syndromic habitus (n = 1). The severity of PHI in the study population is reported in Table I. The rehabilitation professionals study group was composed of 25 participants (Table II). The 231 open-ended answers (S = 66, W = 62, O = 53, T = 50) were reviewed by the authors and grouped in main key points (Table III).

### Strength key points analysis

#### Multidisciplinary working group

In the experts' opinion, the strength of a supportive working group is related to the multidisciplinary competences of its members (n = 9). Among them, the presence of a psychologist and/or a counsellor is requested (n = 9). Specific skills (e.g. paediatric audiology, children care, family mentoring) are encouraged (n = 7), along with effective communication strategies (n = 6).

**Table I.** Severity of PHI in the study population.

Severity of PHI	N
Bilateral severe-to-profound	12
mild-to-moderate	8
Unilateral severe-to-profound	3

**Table II.** Roles of rehabilitation professionals (n = 25) involved in the survey.

Professional role	N
Otolaryngologist/Physician in Audiology	5
Audiologist	
clinical audiometry duties	8
hearing aids/cochlear implant fitting	1
Speech and language therapist	6
Cochlear implant technical specialist	2
Psychologist	1
Primary care paediatrician	2

**Table III.** Main key points extrapolated from questionnaires.**Table IIIa.** *Strengths.*

Strength key points	N (%)
Multidisciplinary working group	31 (47.5)
Efficient family involvement	16 (23.5)
Strong connection with external networks of care	8 (12)
Tertiary care proficiency and accessibility	5 (8)
Other	6 (9)

**Table IIIb.** *Weaknesses.*

Weakness key points	n (%)
Inadequate funding opportunities	21 (33)
Inefficient working group	18 (30)
Weak connection with external networks of care	12 (19)
Lack of multidisciplinary continuing education	11 (1)

**Table IIIc.** *Opportunities.*

Opportunity key points	n (%)
Empowered connection with external networks of care (e.g. web-based technologies)	21 (39)
Strengthen counseling for the caregivers	18 (34)
Multidisciplinary continuing education opportunities	11 (21)
Other	3 (6)

**Table III d.** *Threats.*

Threats key points	n (%)
Conflicts inside the working group	16 (32)
Increasing multiculturalism	14 (28)
Inadequate funding opportunities	12 (24)
Non-homogeneous competences among professionals with similar roles	6 (12)
Other	2 (4)

### *Efficient family involvement in the rehabilitation programme*

In order to engage the family in the diagnostic and rehabilitation process, valid counseling (n = 7), the enrolment of the whole family in an active care process (n = 5) and the coordination of meetings involving groups of families (n = 4) were deemed to be of utmost importance. A professional can either lead family meetings, or can be self-managed by families.

### *Strong connection with networks of care*

This field focuses on the development of strong connections among caregivers in order to improve the support to families in every step of the diagnostic and rehabilitation process, i.e. logistics, psychological support, opportunity to share experiences. Efficient collaboration with deaf associations (n = 5) and networking among hospitals, schools and family doctors (n = 3) are included.

### *Tertiary care proficiency and accessibility*

This category includes the answers that consider good organisation of services, with adequate facilities for specific kinds of care (n = 3), i.e. medical visits and counseling appointments, short waiting lists, dedicated administrative staff (n = 2) that endorse easy connections with caregivers and make appointments efficiently.

There were 6 unspecified strength key points suggested by the respondents.

### *Weakness key points analysis*

#### *Inadequate funding opportunities*

Inadequate funding can have an impact on most of aspects of family support. Long waiting lists and crowded clinics with short time-per-visit (n = 8), poor facilities for adequate counseling (n = 5), reduced staff (n = 4) can be consequences of inadequate resources. Dedicated administrative offices can also be unavailable due to funding restrictions (n = 4).

#### *Inefficient working group*

This group includes issues about the efficiency of the working group. Absence of a counsellor/psychologist with competence in the field of audiology and absence of a supportive team were considered of great importance (n = 11). The working group can be affected by organisational issues (n = 7), i.e. ambiguous competence assignment, uneven sharing of information and lack of working meetings, leading to incoherent information given to families.

#### *Weak connection with external networks of care*

A strong and efficient network can be compromised by inefficient physical connections between the tertiary referral centre and the other caregivers, schools or families (n = 8). Connections are even weaker with families living far from the audiological referral centre (n = 4).

#### *Lack of multidisciplinary continuing education*

Continuing education with a multidisciplinary approach can be a big issue in the field of audiological rehabilitation, with particular reference to efficient communication (among caregivers with different competences and between caregivers and families), and competent care of very young children (n = 11).

### *Opportunities key points analysis*

#### *Empowered connection with external networks of care (e.g. web-based technologies)*

Empowerment of connection with external networks of care was reported to be a great opportunity, i.e. through web-based technologies, videoconferences, shared data-

bases, distance mentoring and distance learning (n = 17). Collaboration with associations that offer support to families of deaf children, including logistic management, can be improved (n = 4).

#### *Strengthen counseling for caregivers*

This category includes opportunities to strengthen counseling that is systematic and well integrated in the diagnostic and rehabilitative process, for either information or support. Moreover, it is important to sustain and increase the involvement of families in the recovery path, and to organise mutual-help groups (n = 10). The provision of reliable informative material, such as pamphlets and social network sites, with a family-oriented language and readily accessible, can make them more competent and prepared regarding the needs during the first months after diagnosis of PHI in their child (n = 8).

#### *Shared formation for operators.*

In this category the answers regarding education for operators was included, especially shared formation for healthcare professionals who deal with paediatric PHI, with sessions combining formation and discussion dedicated to single groups, and advanced courses in counseling techniques (n = 11).

Other answers were uncategorised (n = 3).

#### ***Threats key points analysis***

##### *Conflicts inside the working group*

In this category the themes concerning a group without a counsellor/psychologist, or where the members didn't provide the correct degree of importance to family's support were included (n = 11). In view of the increasing reliance on family support, the absence of a counsellor becomes very problematic. Other issues undermining the group's efficiency arose from poor integration and communication among caregivers, and from disengagement of the family paediatrician (n = 5).

##### *Extraterritoriality and multiculturalism*

Difficulties related to management of families whose hometown is far from the audiology referral centre were reported. The answers focused on the difficulties to build a systematic communication network with healthcare services from the patient's hometown, and on management and organisation of control visits necessitating more than one day stay (n = 8). The interaction with users from different cultures was considered even more difficult, where cultural and linguistic barriers are a serious obstacle for family counseling (n = 6).

##### *Lack of funds*

This category includes answers concerning the lack of funds and projects aimed at audiology and counseling,

with subsequent reduced staff, long waiting lists and scarcity of funds for research projects (n = 12).

#### *Differences in formation for healthcare operators*

This category contains the answers regarding the lack of shared formation and continuing education, for all the operators involved in paediatric audiology, particularly for counsellors and psychologists (n = 3). Many information sources for both operators and parents lack reliability and can cause confusion and false beliefs (n = 3).

Other answers in this area were unspecified (n = 2).

## **Discussion**

Starting from the SWOT analysis data, a TOWS matrix was created, which compares Strengths-Opportunities, Weaknesses-Threats, Weaknesses-Opportunities. Analysing and discussing the data obtained from this research, 10 recommendations were obtained (Table IV). These recommendations can represent basis for tertiary care audiology centres to optimise resources and generate positive changes. Finally, three main themes or main recommendation were recognised that contribute to good family support during the first months after PHI diagnosis. These themes are:

- presence of a multidisciplinary team with adequate shared education and training;
- active involvement of families, with adequate informative material;
- building a good interchange net between the tertiary care referral centre and the territory.

American Guidelines for paediatric audiology give great importance to the professional qualifications needed to ensure timely action centred on the family, from birth to three years of age. The formation and continuing education of professionals are also deemed important to ensure a competent working group<sup>56</sup>. The first recommendation is then to ensure the presence of all healthcare professionals, which are important for a timely diagnosis and treatment of the child with PHI, such as the audiologist, oto(rhinolaryngo)logist, speech and language pathologist, counsellor-psychologist expert in PHI and technical specialist (for hearing aids and cochlear implants).

Shared formation and continuing education meetings must be implemented to allow for exchange opinions and integration of knowledge coming from different approaches to the same condition. A team where part of the specific formation is shared permits to favour teamwork and better define roles. This operative method allows giving parents information that is coherent and clear, to grant them a complete understanding of their child's condition, easing trust in the referral centre and reducing the need for consulting other opinions. Allowing the

**Table IV.** TOWS matrix (see text for explanation).

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	<b>SO strategy</b> 1. To create an efficient and multidisciplinary team with adequate shared formation, inserted in a well-organised service 2. To involve families through systematic counselling and providing adequate informative material 3. Building a network with the territory, with better links with the territory and deaf patient associations	<b>WO strategy</b> 1. Implementing the family counselling to foster a therapeutic alliance that could also form a bridge between tertiary care centre and territory 2. Organising advanced formation and continuing education events where the whole team can take part, so that the family would perceive equity, up to date information and continuity of the cure.
	Threats (T)	<b>ST strategy</b> 1. Having an effective multidisciplinary team, with formative objectives that are clear and to be pursued as a group, where each member has a correct and defined role 2. To involve families and create a network within the territory to minimise problems related to extraterritoriality and multiculturalism 3. Having efficient organisation of the services allows optimising the available funds	<b>WT strategy</b> 1. Reinforcing interactions with national healthcare institutions and structures that support the families, especially with extraterritoriality and different cultures 2. To sensitise healthcare institutions and organisations to assign funds to the team, its projects and continuing education.

team to work in a well-organised structure, with a dedicated administrative staff and adequate personnel, grants the ability to optimise case management. Lack of funds or absence of specific formation courses for the entire team is a major threat for this purpose. It is desirable to create awareness programmes aimed at institutions and healthcare organisations to prompt them to invest in timely and multidisciplinary approach to the child’s condition, to ensure that the team is efficient and constantly up to date <sup>2 5 6 13-15</sup>.

The second recommendation is the need to incorporate, especially in the diagnostic phase, counselling for the family to ensure an action of identification, intervention and caretaking of the hearing impaired child centred on the family. The family should be accompanied, supported and informed to be able to make the best choices for their child, in a family-and-child centred manner <sup>15-17</sup>.

Counselling is regarded internationally as a process that, through dialogue and interaction, provides support, guidance and supervision in the diagnosis-rehabilitation route. The fundamental characteristic is that the counselling is focused, in terms of time and work-space, to the current medical condition.

In audiological counselling, the two main aspects are:

- a) support counselling, which is necessary to empower, develop correct coping strategies, overcome critical passages tied to the current medical condition, maximise resources, expectations and issues, explore the impact that PHI has on daily living and develop empathic reactions to emotional stress <sup>15-18</sup>;
- b) informative counselling, which is dedicated to all the information to be provided to the patient and his/her family. All healthcare workers are involved in this step, especially those who have, as a fundamental part of their work, a role in communication of information. Among these professionals: the medical audiologist/

otorhinolaryngologist (to communicate diagnosis, follow-up the patient, coordinate the entire process, etc.), technical audiologist (for explaining to parents the operations and characteristics of the different tests, depending on the age), technical specialists (to give information regarding technical features and maintenance of the hearing aid devices) and speech and language therapist (who explains to parents the hearing and speech development status, the purpose and methods of rehabilitation, etc.) <sup>15 17 18</sup>.

Recent studies have demonstrated that it is necessary to make the parents of the deaf child active components in the rehabilitation process, supporting them and helping them understand that their role is crucial in the success of rehabilitation <sup>15 16</sup>. Evidence on the efficacy of empowerment practices that can support the hearing impaired children’s families have been shown in several clinical investigations that show how the feeling of self-efficacy in parents during cure and management of the child’s hearing impairment can have a positive effect on the child’s language development <sup>15 17 21-24</sup>.

The recommendations identified herein are sustained by the indications of JCIH that stress the importance of ensuring that families receive complete and accurate information about the child’s development, play an active role in screening and precocious treatment, and, more broadly, that family and child are involved in treatment that promotes the family’s quality of life, favouring the development of hearing and communicative skills <sup>2 5 6 15 17</sup>.

Parents who are competent in managing the child’s PHI and in the therapeutic process aids in minimising extraterritoriality and multiculturalism problems. Good family counselling is establishing a line of direct communication between families and tertiary care referral centres, and building, if necessary, an indirect line of communication with the territory and with different cultures.



In research on the perceived problems of integration of the counselling in the busy activity of an audiology service, English reported that the staff perceives that it is easy to implement counselling activity, without negative consequences on time schedules<sup>25</sup>.

Many informative pamphlets and brochures exist on paediatric PHI, but sometimes, if given to an unaware parent, they may give rise to confusion (also considering that they may not be in line with current services and practices). It is necessary to have informative material originating from reliable and traceable sources, which can give a valid and exhaustive vision of the problem, from all viewpoints, which is coherent and tailored on the organisation the family will rely on<sup>18</sup>.

The third recommendation is to ease the exchange of information among the tertiary care referral centre and territorial centres, using new communication technologies such as videoconferences, distance mentoring, shared databases and informative internet sites with the option to selectively access specific projects, with easy access to early diagnosis and rehabilitation programmes. Another critical facet to obtain a good network of care is the synergic collaboration with deaf associations. To this endpoint, the American guidelines recommend to develop a mechanism that ensures to the family the access to all the resources and informations available, in an accurate, global and impartial way (manuals, websites, associations/national organisations), from the birth to the start of an early treatment programme<sup>5,6</sup>.

The conclusion is that, to focus on the three main recommendations, it is necessary to have a service with an efficient organisation, a dedicated administrative office, adequate personnel (either staff or skills), this also provides the chance to optimise available funds and invest them to achieve better results, instead of establishing only a minimum standard of quality.

## Conclusions

In the field of family support up to three months after identification of paediatric PHI, three main recommendations have been developed, i.e. the presence of a multidisciplinary team with a common basis of knowledge, active involvement of families with adequate information support and strong connections between the tertiary care service and external networks of care. This approach is endorsed by the current international guidelines on paediatric audiology.

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# Calendar of events – Italian and International Meetings and Courses

Acta Otorhinolaryngol Ital 2016;36:1

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### INFLAMMATION – WINTER SYMPOSIUM • *January 24-27, 2016 • Miami – USA*

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### 7<sup>th</sup> INTERNATIONAL SYMPOSIUM ON SENTINEL NODE BIOPSY IN HEAD AND NECK CANCER

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### XXVIII CORSO “RINOPLASTICA- CHIRURGIA FUNZIONALE ED ESTETICA DEL NASO”

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### ENDOCHICAGO 7<sup>th</sup> WORLD CONGRESS FOR ENDOSCOPIC SURGERY OF THE SKULL BASE AND BRAIN • *May 15-18, 2016 • Chicago (IL) – USA*

Course Directors: Amin B. Kassam, Martin Corsten, Ricardo L. Carrau, Daniel M. Prevedello, Vijay Anand, Theodore H. Schwartz – Website: www.endoworld.org/d-1\_7TH\_WORLD\_CONGRESS

### 103° CONGRESSO NAZIONALE SIO SOCIETA ITALIANA DI OTORINOLARINGOLOGIA E CHIRURGIA CERVICO-FACCIALE • *May 25-28, 2016 • Rome – Italy*

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A cura di: A. Tombolini, F. Baricalla – Coordinato da: A. Tombolini

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