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## How to motivate newborn hearing screening in the absence of a national programme: a collaboration between parents and professionals

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The establishment of the Italian Pediatric Federation Newborn Hearing Screening Network and the Italian Society of Neonatology Infant Hearing Study Group is the result of an international collaboration between Parents and Medical Professionals in order to promote an effective model in developing Early Hearing Detection Intervention Programs that recognize the role of parents as partners in the process.

Among other factors, one important component frequently underestimated in most early intervention programs, both in the USA and other countries, involves the role of parental involvement within the Early Hearing Detection Intervention (EHDI) process. When a parent receives the news of their child's hearing loss, reactions may include, but are not limited to denial, grief, guilt, shame, fear and impotency. A parent may begin to ask certain questions: How do we know if the professionals in our children's lives are capable, educated, trained, up to date in their chosen fields of expertise? Do they respect our children and us as parents? Do they understand the needs of children who are deaf or hard of hearing? A life-long health professional – parental collaboration begins at the moment of the diagnosis of that child.

When analyzing the habilitation process of a deaf child, the relationship between health professionals and the crucial role of parents in raising that child is a 50–50 shared responsibility. An objective of EHDI programs must be to empower parents by providing support from the beginning of the process. Distributing informative literature regarding the newborn hearing screening process and providing parents with access to resources such as parental support groups upon diagnosis equips parents with the tools necessary to immediately begin advocating for their children. The Italian Federation Pediatric Audiology Network was created by combining the parental perspective and medical protocols in order to establish the roots for stronger EHDI programs.

**Keywords:** Newborn Hearing Screening, Early Hearing Detection Intervention, Parental Support, Early Intervention, Hearing Loss

In the absence of a national newborn hearing screening programme in Italy, the Global Coalition of Parents of Children who are Deaf and Hard of Hearing (GPOD) has been working with the Italian Paediatric Federation (FIMP), the Society of Neonatology (SIN) and members of the Italian Society of Audiology and Phoniatrics (SIAP) to promote guidelines, best

practice and training courses in early hearing detection intervention that incorporate sensitivity training for professionals working with families of deaf children.

The establishment of the Italian Paediatric Federation's Audiology Network is the result of an international collaboration between parents and medical professionals designed to promote an effective model in developing Early Hearing Detection Intervention Programmes (EHDI) that recognize the role of parents as partners in the process. Among other factors, one important component frequently underestimated in most early intervention programs, both in the USA and in other countries, involves the role of parental involvement within the EHDI process.

From screening to identification and intervention, families must navigate through medical institutions, government and private agencies, their own family construct and community and other dynamics in order to successfully begin the journey of raising a child who is affected by hearing loss. Family support is the "map" that keeps this process moving effectively, with sensitivity to the social and emotional needs a family will have as it adjusts to its baby's diagnosis.

The family is the social context into which children who are deaf/hard of hearing are born. The impact of a child's hearing loss affects not only the child, but the parents, siblings, extended family and community as well. When this experience "happens" to a family, everyone is impacted. Because of the low incidence of hearing loss, families of children who are deaf or hard of hearing often feel isolated from each other, and many feel isolated within their own extended families. Most do not know about support opportunities in their local communities, or such resources simply do not exist.

No one quite understands this dynamic as well as another family that also has a child who is deaf or hard of hearing. This common experience creates a unique connection and shared understanding that bonds parents, who are instinctively seeking role models and insight from others who have "been there, done that" [1].

### The need for family support

*Fact:* At least 58 countries worldwide are providing some form of newborn hearing screening (NHS) and have, or are in the process of building, systems for early identification of hearing loss through NHS [2,3].

*Fact:* Children who are identified early and receive intervention prior to 6 months of age have significantly better receptive

language, expressive language, personal-social skills, receptive vocabulary, expressive vocabulary and speech production [4].

*Fact:* When reflecting on the early intervention years, the majority of families cite contact with other parents of children with hearing loss as the most helpful support they received after learning their baby was deaf or hard of hearing. Direct parent-to-parent support ranks as one of the strongest measures of family support [5].

*Fact:* Social networks with other parents of children who are deaf were associated with less isolation; greater acceptance of children affected and improved interactional responsiveness [6].

*Fact:* Families also gain knowledge, insight and experience by accessing resources through participation in scheduled early intervention appointments, including audiological, medical, habilitative and educational sessions. This experience can be enhanced when families choose to become involved with parental support groups, individuals who are deaf or hard of hearing and/or their children's deaf or hard of hearing peers [7].

*Fact:* "The nature, purpose, provision and use of information are fundamental considerations in the practice of informed choice. Although information alone does not facilitate choice, without it, it is largely impossible to weigh up alternatives, be aware of options or even simply engage with the processes involved in making decisions. For information to be effective it should be current, unbiased, evidence-based, relevant, meaningful and accessible to those families for whom it is intended [8]."

*Fact:* "There is a possibility that, at worst, the emotional, psychological and social consequences of the early diagnosis of a childhood hearing impairment might undermine the purpose of the Hearing Service: to facilitate the social, emotional and language development of children with hearing impairment, there is an opportunity for Hearing Services for Children to become family-friendly in their approach: to focus on the support and care that each individual child and family require. Such an evolution is a prerequisite for successful audiological habilitation of children and families and for the introduction of universal neonatal hearing screening [9]."

When analyzing the habilitation process for a deaf child, the relationship between health professionals and the crucial role of parents in raising that child is a 50–50 shared responsibility. An objective of EHDI programmes must be to empower parents by providing support from the beginning of the process. Distributing informative literature regarding the newborn hearing screening process and providing parents with access to resources such as parental support groups on diagnosis equips parents with the tools necessary to immediately begin advocating for their children.

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## References

1. Cutler J, Des Georges J, Keenan R, Porter A, Seaver L, Walker P. Position Statement and Recommendations for Family Support in the Development of Newborn Hearing Screening Systems (NHS)/Early Hearing Detection and Intervention Systems (EHDI) Worldwide. Paper presented at the NHS Conference, Lake Como, Italy; 2010.
2. White KR. Status of universal newborn screening programs. Paper presented at the NHS Conference, Lake Como, Italy; 2008.
3. WHO Report. Newborn and infant hearing screening. Current issues and guiding principles for action: outcome of a WHO informal consultation held at WHO. Geneva, Switzerland: WHO; 2009.
4. Yoshinaga-Itano C, Sedey AL, Coulter DK, Mehl AL. Language of early- and later-identified children with hearing loss. *Pediatrics* 1998;102: 1161–1171.
5. Jackson C. Family support and resources for parents of children who are deaf or hard of hearing. Jacksonville, Florida: Florida State University; 2009.
6. Hintermair M. Hearing impairment, social networks, and coping: the need for families with hearing-impaired children to relate to other parents and to hearing-impaired adults. *Am Ann Deaf* 2000;145:41–53.
7. JCIH. Year 2007 position statement: principles and guidelines for early hearing detection and intervention programs. *Pediatrics* 2007; 120(4):902.
8. Young A, Carr G, Hunt R, McCracken W, Skipp A, Tattersall H. Informed choice and deaf children: underpinning concepts and enduring challenges. *J Deaf Stud Deaf Educ* 2006;11:322–336.
9. Baguley D, Davis A, Bamford J. Principles of family-friendly hearing services for children. *BSA News* 2000; 29:35–39.