



**Position Statement and Recommendations for Family Support
in the Development of
Newborn Hearing Screening Systems (NHS)/
Early Hearing Detection and Intervention Systems (EHDI)
Worldwide**

June 2010

This Position Statement and Family Support Recommendations by GPOD are the synthesis of input from parent leaders and family support organizations worldwide who have contributed to this document. They reflect feedback on the most effective and appropriate practices from the parents' perspective, as well as a foundation in current research supported data.

" Family Support" is often the term used to define the practices that ensure that the holistic nature of the process for families is sustained through the timelines, policies and procedures by the varying entities that the family encounters through screening, diagnosis, early intervention and beyond. Each family's needs for support are unique, but there are common themes to this crucial aspect of Universal Newborn Hearing Systems. The distinctive nature of families - their configuration, cultural considerations, beliefs, values, emotional reactions, coping styles, family dynamics and other issues - play a role in how effectively a family will be able to navigate the system, and help to define which sorts of support will be most beneficial to that family.

Additionally, family support should necessarily come from a variety of places and can be categorized as coming from five distinct sources: professionals, other families who have children who are deaf or hard of hearing, deaf and hard of hearing adults, information and resources, and existing communities surrounding a family before a child is diagnosed. Cultural considerations can and should be inherently incorporated into these areas for families.

The Necessity for Family Support

Fact: At least 58 countries worldwide are providing some form of NHS and have, or are in the process of building, systems of early identification of hearing loss through newborn hearing screening [1, 2].

"Information should go out to every single family the minute their child is diagnosed. The sooner the information is received the sooner help is available to that child. No parent should be left to flounder on their own in an unknown world."

Fact: Children who are early identified and receive intervention prior to six months of age have significantly better receptive language, expressive language, personal-social skills, receptive vocabulary, expressive vocabulary and speech production [3].

Fact: On reflection of the early intervention years, a 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 [4].

Fact: Social networks with other parents of children who are deaf were associated with less isolation, acceptance of their child, and improved interactional responsivity [5].

Fact: Families gain knowledge, insight, and experience by accessing resources as well as through participation in scheduled early intervention appointments including audiologic, 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 [6].

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 [7].

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: that is 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: that is to focus upon the support and care that each individual child and family require. Such an evolution is a pre-requisite for successful audiological habilitation of children and families and for the introduction of Universal Neonatal Hearing Screening" [8]

Background Information

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 has a 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 they adjust to their 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; many feel isolated within their own extended family. And most do not know about support opportunities in their local community, or such resources simply don't exist.

No one quite understands this dynamic as well as another family who also has a child who is deaf or hard of hearing. Their 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". Parents have a lot to say about how they were helped or hindered in their journey of coping with and raising their children who are deaf or hard of hearing. In 2009, GPOD conducted a worldwide online survey to harness the views of 587 parents reporting from 23 different countries about their journey. Family support factored significantly in their emerging sense of efficacy. These themes were predominant:

Opportunities for Direct Parent-to-Parent Support

- 54.2% of parents were prompted by professionals to connect with other parents
- 47.8% of families were actually told how to contact or be contacted by other parents
- 60 % had used some kind of family-to-family support
- 84% wanted programs to connect them with other parents
- Just under half (46%) rate the support they received as excellent or good.
- One third (33.6%) have not received any support or rate the support they have received as poor or very poor.
- When parents are told how to contact or be contacted by other parents, they are almost three times more likely to have followed through and used family-to-family support services.

Families' Experience with Information Provision

Families must be provided with information to make appropriate decisions regarding their child. Accurate information enables parents to make informed decisions and take an active role in the management of their child's hearing loss [9-11]. Information and support provided to parents should strive to be comprehensive in its scope, outlining the full range of options on any particular issue and avoiding partiality or bias [12] .

Information empowers parents and provides them with a sense of self-esteem and confidence in their ability to raise a deaf child [9,13]. When parents make informed decisions for their child after a process of comprehensive self-education, their personal investment in the decision is stronger - a critical component of the level of commitment that is required to make that choice work for their child.

The strengths and needs of families vary enormously and it therefore needs to be recognized that the routes to informed decision-making will require different approaches to meet differing family needs and competencies [7].

GPOD survey results show that:

- 50.9% of families were given 'complete and balanced information about all communication options'
- 47.3% were given 'complete and balanced information about all educational programs'.

Where parents find information:

- 84% through face-to-face interaction with professionals
- 81% receive written information
- Three-quarters are using the internet for information
- Two-thirds (66.5%) get information from discussion with other parents
- Over half (57.6%) get information from online parent support groups.

How important is the source of information to parents?

On a scale of 1 to 7 with 1 being "most important" :

- 80% of parents ranked "face-to-face interaction with professionals" as 1, 2 or 3 in importance.
- 70.3% of respondents ranked "discussion with other parents" as 1, 2 or 3 in importance.

"I have asked multiple providers to provide me with the names of support groups, play groups, anything, and all of them give vague answers about getting around to it, but none of them have ever produced anything... It would be great to know HOW to get involved in something."

The Outcomes of a Supported Family

A well-adjusted, successful child who is deaf or hard of hearing is the product of a well adjusted, successfully supported family. While the definition of a child's success will vary from family to family, UNHS and EHDI effectiveness will be reflected in the eventual success - or in the struggle - of the child and his/her family. Beyond the 1-3-6 goals, equipment needs, professional training and so many other administrative protocols, those systems must be effective in their holistic support to the family. Parents must be empowered and vested in their informed decision making process.

EHDI and UNHS systems must accommodate the child's access to early intervention and education emphasizing fluent language and communication training; and UNHS and EHDI systems must ultimately deliver hope for a brighter future for children with hearing loss and their families.

The complexity of the process for families leads to an understanding that there must be multiple layers of support that envelop a family on their path to success. A respectful and collaborative approach from all stakeholders in the system and an understanding of the important role that each one plays contributes to the degree a family may feel supported as they begin the long and demanding, yet rewarding, journey of raising their child who is deaf or hard of hearing.

Recommendations

The time has come for the visioning and implementation of NHS systems that are more supportive for families and therefore better calculated to produce successful outcomes for children with hearing loss.

The keys to achieving this goal are:-

1. Formalized acknowledgment and incorporation of parent perspective into the development and monitoring of the systems that serve them; and
2. Systemic family support programs that emphasize direct parent-to-parent contact.

The Global Coalition of Parents of Deaf and Hard of Hearing Children (GPOD) therefore recommends the following steps for UNHS programs worldwide:

- **Improve** the quality of Universal Newborn Hearing Screening Systems through ensuring formalized, measurable, family support systems in the 1-3-6 UNHS Goals (screening by one month, identification by three months, entry into early intervention by six months of age).
- **Acknowledge** that the single most important predictor of a newly identified child's success is the meaningful and effective involvement of his or her parents and family [14].

- **Ensure** that all families have access to direct parent-to-parent support from other families with children who are deaf or hard of hearing, and to deaf or hard of hearing adult role models/mentors who are trained to provide their specialized knowledge and skills to appropriately mentor and guide other families in culturally and linguistically sensitive ways.
- **Build** accessible and responsive UNHS systems which incorporate family input into the system itself.
- **Integrate** parents as part of Systems Development
 - Intervention professionals should seek to involve parents at every level of the EHDI process and develop true and meaningful partnerships with parents. To reflect the value of the contributions that selected parents make to development and program components, these parents should be paid as contributing staff members. Parent representatives should be included in all advisory board activities. They should be participants in the regular assessment of program services to ensure ongoing improvement and quality assurance[5].
 - Increase awareness of family support among stakeholders as an integral part of UNHS programs.
- **Recognise** that the well-being of families depends upon the availability of high quality formal and even informal support imbedded in EHDI systems.
- **Expect** professionals working with families to undertake on-going professional learning; support efforts to develop their knowledge and skills to support families appropriately and sensitively.
- **Provide** high quality information to families that is comprehensive, relevant, meaningful, timely and unbiased towards communication modes or methods.
- **Discuss** honestly the range of provisions that are possible for families; do not limit information sharing to just what is locally available.
- **Promote** self-efficacy within families; empower and help them to develop new strengths and competencies to meet the ongoing needs of their child with a hearing loss.

Call to Action

With these recommendations in mind, the GPOD urges UNHS and EHDI worldwide with this CALL TO ACTION:

1. Write a letter of endorsement from your agency, organization or personal point of view for the GPOD Family Support Recommendations and Position Statement and send it to us at: gpodhh2010@gmail.com
2. Share the GPOD Recommendations and Position Statement with colleagues and leaders in your field.
3. Recruit parent leaders in your country to take their necessary part in the thought leadership of this field.
4. Support a research agenda through collaboration or examination of your own practice in this area.
5. Embed these Family Support Recommendations in legislation, guidelines, consensus papers, and position papers regarding UNHS and EHDI systems.

About GPOD

The Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPOD) is an international collaboration of parent groups dedicated to promoting improved systemic protocols and practices which encourage informed choice and the empowerment of families with a deaf or hard of hearing child throughout the world. More information at: <http://www.gpodhh.org>

Founding members of GPOD

Aussie Deaf Kids (Australia)
Deaf Children Australia
Hands & Voices (Italy)
Hands & Voices (USA)
National Deaf Children's Society (UK)

References

1. White, K.R (2008). *Status of Universal Newborn Screening Programs*. Paper presented at the NHS Conference, Lake Como, Italy.
2. W.H.O Report. *Newborn and infant hearing screening. Current issues and guiding principles for action: Outcome of a W.H.O. informal consultation held at W.H.O. Headquarters, Geneva, Switzerland)9/10 September 2009*. In press)
3. Yoshinaga-Itano, C., Sedey, A., Coulter, D., & Mehl, A. (1998). Language of Early- and Later-Identified Children with Hearing Loss. *Pediatrics*, 102(5), 1161-1171.
4. Jackson, C. (2009). *Family Support and Resources for Parents of Children who are Deaf or hard of Hearing*. Jacksonville, Florida: Florida State University.
5. Hintermair, M. (2000). Hearing impairment, social networks, and coping: The need for families with hearing-impaired children to relate to other parents and to hearing-impaired adults. *American Annals of the Deaf*, 145(1), 41-53.
6. JCIH. (2007). Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics*, 120(4), 902.
7. Young, A., Carr, G., Hunt, R., McCracken, W., Skipp, A., & Tattersall, H. (2006). Informed choice and deaf children: Underpinning concepts and enduring challenges. *Journal of Deaf Studies and Deaf Education*, 11(3), 322-336.
8. Baguley, D., Davis, A., & Bamford, J. (2000). Principles of family-friendly hearing services for children. *BSA News*, 29, 35-39.
9. Bemrose, S. (2003). Giving information to parents - factors to consider Retrieved 4.1.2007, from <http://www.deafnessatbirth.org.uk/content2/support/info/02/index.html>
10. DesGeorges, J. (2003). Family perceptions of early hearing, detection, and intervention systems: Listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(2), 89-93.
11. Luterman, D. M., Kurtzer-White, E., & Seewald, R. C. (1999). *The young deaf child*. Baltimore, Maryland: York Press, Inc.
12. Young, A., Jones, D., Starmer, C., & Sutherland, H. I. (2005). Issues and dilemmas in the production of standard information for parents of young deaf children - parents' views. *Deafness & Education International*, 7(2), 63-76.
13. Young, A., Grealley, A., & Nugent, J. (2003). *Parenting and deaf children: Report on the needs assessment study undertaken as part one of the NDCS parents' toolkit development project*. Retrieved 4.1.2007, from http://www.ndcs.org.uk/information/ndcs_publications/parenting_and_1.html
14. Yoshinaga-Itano, C., Coulter, D., & Thomson, V. (2000). The Colorado Newborn Hearing Screening Project: Effects on speech and language development for children with hearing loss. *Journal of Perinatology*, 20, S132-137.