

■ The Role of the Audiologist and Family Support Worker in the Ontario Infant Hearing Program: A Team Approach

■ Rôle de l'audiologiste et du travailleur de soutien à la famille dans le cadre du Programme ontarien de dépistage néonatal des troubles auditifs et d'intervention précoce : une approche multidisciplinaire

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Abstract

The Infant Hearing Program is an Ontario provincial initiative funded by the Ministry of Children and Youth Services. The program's aim is to identify children born deaf or hard-of-hearing and facilitate early access to habilitation services by six months of age to support age-appropriate communication development. This article outlines the value of coordinating the roles of service providers across the habilitation continuum. The importance of following the child and family through the process of screening, identification and habilitation are outlined from one regional program's experience.

Abrégé

Le Programme de dépistage néonatal des troubles auditifs et d'intervention précoce est une initiative du gouvernement ontarien financé par le ministère des Services à l'enfance et à la jeunesse. Ce programme vise à identifier les bébés qui naissent sourds ou malentendants et à leur fournir l'aide dont ils ont besoin avant l'âge de six mois pour faciliter l'acquisition du langage. Le présent article met en lumière l'importance de la coordination du rôle de tous les fournisseurs de services. Il se sert d'un programme régional pour faire valoir l'importance de suivre l'enfant et sa famille lors du dépistage, du diagnostic et de la réadaptation.

Key Words: universal newborn hearing screening, early hearing detection and intervention, program evaluation, family-centred care, interdisciplinary collaboration

Introduction and Background of the Ontario Infant Hearing Program (OIHP)

The first years of a child's life are critical to ensuring the normal development of speech and language. Hearing loss can be one cause for delayed language development. Because of this, the development and implementation of universal hearing screening programs has become the prime method for identifying infants at an earlier age (American Academy of Pediatrics, 1999; Durieux-Smith, Seewald & Hyde, 2000; Durieux-Smith & Whittingham, 2000; Hyde & Riko, 2000; Yoshinaga-Itano & Gravel, 2001). Recent evidence suggests that early identification is the key to decreasing potential delays in speech and language resulting from hearing loss (Downs & Yoshinaga-Itano, 1999; Moeller, 2000; Yoshinaga-Itano, 2003, 1999; Yoshinaga-Itano, Sedey, Coulter & Mehl, 1998). In Ontario, health care administrators and audiologists have lobbied on behalf of infants and young children with permanent childhood hearing impairment (PCHI). In 2000, the Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA) and the Canadian Academy of Audiology (CAA) published a joint position statement supporting Universal Newborn Hearing Screening followed by habilitation (Durieux-Smith et al., 2000). In response to these initiatives, and following an intensive process of consultation and planning, Ontario provincial health funding was secured to permit the establishment of a premier universal infant hearing program. The Ontario Infant Hearing Program (OIHP) was developed and implemented in 2002. A more thorough description of the program is available through the Ministry of Children and Youth Services website (www.children.gov.on.ca/CS/en/default.htm).

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OIHP Screening, Diagnostic Assessment and Habilitation

The OIHP consists of three phases of service: screening, identification and habilitation. In the screening phase, trained healthcare workers use automated technology to screen newborn hearing prior to hospital discharge. Infants receive either a "pass" or "refer" result from the initial screening. Infants may also be identified as at risk for developing hearing loss during the neonatal period, due either to family history of hearing loss or a complicated birth history. These infants are rescreened during the first year. Infants who receive a pass result are assumed to have normal hearing while a refer result suggests the need for further audiologic testing as no response was detected at screening levels. Automated Distortion Product Otoacoustic Emission (ADPOAE) screening is conducted with all healthy newborns while Automated Auditory Brainstem Response (AABR) testing is conducted with infants considered to be at risk for hearing loss based on a number of predetermined factors. Healthy newborns that obtain a "refer" result on the initial DPOAE screen will proceed to a second level of screening using the AABR technology. This article focuses on the professional experiences of the audiologist and family support worker from the southwest region of the province including the following counties: London-Middlesex, Elgin-St. Thomas, Grey Bruce Owen Sound, Huron, Perth and Lambton.

OIHP Audiologist's Role

Infants with a "refer" result from screening are referred to OIHP audiologists who are specially trained in the diagnostic assessment of infants. The OIHP Audiological Assessment Protocol includes tympanometric evaluation (including high-frequency tympanometry), diagnostic DPOAE and ABR assessment using frequency-specific tone pips via air and bone-conduction as indicated. Visual reinforcement audiometry (VRA) may also be used diagnostically as the age of the child dictates as part of this comprehensive protocol. Electrophysiological assessment under sedation is conducted at community hospitals as necessary for testing older infants. Diagnostic assessment can be conducted as early as 2 to 3 months corrected age. An otolaryngology consultation is then required as part of the confirmation of a permanent hearing impairment prior to hearing aid fitting.

Habilitation can begin following medical clearance. As with the identification component of the program, audiologists have received additional training in hearing aid fitting and management to assist in their care of these young infants. Habilitation begins by discussing the impact of the hearing loss on speech and language learning. Unbiased information is presented in order to

ensure that the parents can make a well-informed choice. Families receive information on hearing aids and cochlear implants. Should the parents wish to proceed with amplification, the Desired Sensation Level (DSL) prescriptive approach developed at the University of Western Ontario by Richard Seewald forms the basis of the OIHP Protocol for amplification (Seewald, 1995). The audiologist also refers families to provincial home-visiting programs provided by the Provincial Schools for the Deaf and/or specialized regional programs for children who present with multiple disabilities as these programs may also help meet parents' needs. At a minimum, the audiologist sees the infant every 3 months during the first year and every 6 months in the second year. This schedule affords an opportunity to assess the child's hearing and connect with the parents regarding their challenges related to the hearing loss.

The support of the IHP audiologist is valued by parents. This view is compatible with the findings of Luteran and Kurtzer-White (1999) who surveyed parents regarding their needs when their child was identified with a hearing loss. Respondents wanted a skilled clinical audiologist who was also an empathetic, supportive counselor. The challenge for the audiologist is to convey difficult information so that parents are supported and receptive to the involvement of other members of the habilitation team. This can be accomplished as the family realizes that the audiologist will continue to be an involved team member.

OIHP Family Support Worker's (FSW) Role

The OIHP recognizes the importance of ensuring timely habilitation and therefore provides a system whereby the family can access the services of a Family Support Worker (FSW) to support them in making decisions regarding their child's communication development. A FSW must be a regulated health professional, such as a registered nurse or registered social worker, who has clinical counseling experience and values a team approach to service provision. The FSW remains involved with families until they are comfortable with communication strategies and are integrating the infant, who has the challenges of hearing loss, into their family system. This process takes time, and the FSW is often involved with the family for a year or more. The caseload is dependant upon the numbers of infants diagnosed in the region at any given time.

The FSW counsels, educates and guides the family (Matkin, 1994). This intervention occurs in the context of the family system. Barrett (1998) discusses the importance of empowering people to reach their individual and collective dreams. The FSW supports families as they engage in this process. The FSW listens to the family story. The dialogue centres on the family context, their support systems, their understanding of and meaning of the diagnosis of hearing loss and their need for information about communication options. Some of the spontaneous opinions expressed by parents

during their meetings with the FSW are used to illustrate the parents' lived experience with the child.

Grief Work

If indicated, the FSW assists the family with their grief work. During their pregnancies, women wish for a "perfect child" (Bondas & Eriksson, 2001; Fajardo, 1987; Mahan, Krueger & Schreiner, 1982). Thus, when an infant with physical or cognitive challenges is born, the family will grieve the loss of the "perfect child". Grief work refers to the process, or work, that individuals or families engage in as they acknowledge their loss and incorporate the reality into their life journey (Eakes, Burke & Hainsworth, 1998; Kubler-Ross, 1969; Levine, 1982).

This work is unique for each family. Some families grieve the loss of their "perfect child" immediately; others do not acknowledge any sadness. This experience is reflected in one mother's comment: "...in my head, I know he is deaf, but in my heart it isn't real. He is just a cute, cuddly, cooing 10 month old. It will become real when he has challenges communicating." Her words also reflect the chronicity of grief work (Matkin, 1994). These families are busy attending to the needs of the family members, one of whom is a busy infant who has the challenge of a hearing loss. It is no surprise, then, that families may delay their grieving as they focus on their infant's habilitation needs. However, it is important that the family members have access to a team member who will support them with their grief. All members of the professional team must be available and willing to assess individual readiness to grieve. Interventions must be wholistic and family-centred (Ellis, 1989; Riski, 1991). Families and clinicians must be helped to realize that understanding and dealing with grief is just as important as understanding and dealing with hearing aids and language development.

Communication Development Options

Parental access to unbiased information on all available methods of communication and their right to decide about a method or methods are cornerstone principles of the OIHP. The OIHP supports three communication development options: Auditory-Verbal Therapy (AVT), American Sign Language (ASL) and a Dual Approach that develops skills in both sign language and oral language. Families consider their options and select a methodology that meets their individual child's needs. At this time, parents want to know how to contact the ASL Literacy Consultant, the Auditory Verbal Therapist, area support groups and parents who have chosen various options. It is important to place the meeting with other parents in a context. Parents may need a helpful reminder that each family's journey is unique. When families choose a communication option, the FSW makes a formal referral to the ASL Literacy Specialist, AVT and/or Regional Preschool Speech and Language Pathologist who will contact the family directly to arrange an intake appointment.

Access to Funding

Families also need information about subsidies available to offset the costs associated with the permanent childhood hearing impairment (PCHI). In particular, families are responsible for the purchase and maintenance of hearing aids, varying in price from \$500 to \$2000 per behind-the-ear device, dispensing fees averaging \$600 per device, earmolds averaging \$70 per mold, and travel costs associated with routine audiological followup and speech and language therapy. Families have access to the Assistive Devices Program (ADP) and/or the Ministry of Community and Social Services Assistance to Children with Severe Disabilities (ACSD) to assist with offsetting such costs. The latter is tied to family income with lower income families receiving subsidy support as needed.

The FSW provides the above information and then becomes a resource and guide to the family as they engage in the decision-making process. This family-centred approach occurs within the system of multiple service providers. If families are to experience seamless care, the providers must collaborate.

Provision of Coordinated, Seamless Family-Centred Care

A mutual relationship based on respect and partnership is essential to the success of the audiologist/FSW working together. Thus, it is important that the audiologist and FSW take time to establish this working relationship. We believe that families would see our coordinated effort as a benefit to the attainment of their goals for their children.

This partnership is achieved through dialogue about family intervention and clinical issues. Prior to beginning to work with families, the FSW engaged in a process of self-directed learning with respect to the effect of hearing loss on a family system. The audiologist functioned as an expert resource to this learning. The audiologist clarified questions, suggested further reading and enabled the FSW to attain a beginning comfort with the issues and terminology.

The FSW helped the audiologist to understand the dynamics of the family through the use of family ecomaps and genograms. An ecomap is a diagrammatic representation that pictures the family in the context of the community. It identifies their social support systems and relationship with the larger community. Genograms are diagrammatic representations of family members and their relationships over at least three generations. Genograms describe the strength of the family bonds, conflictual relationships and significant events in the family's life (Hartman, 1978). These graphics illustrate the support systems and challenges facing the family. These schematics furthered our understanding of the infant in the context of a family system as opposed to "an infant with a hearing loss". A secondary outcome of this process resulted in the desired working relationship based on dialogue, mutual values and commitment to the primacy of the client. It is our belief that the formation

of this relationship is integral to the success of the program.

Because the OIHP is in its infancy, collaboration and meetings with key stakeholders is important. The audiologist and FSW provided in-service to the staff at the various hospitals, health units, regional schools for the deaf, developmental clinics and home visiting programs. The primary agenda was to provide information about the OIHP. The secondary agenda was to establish or build on existing relationships with service providers. This investment of time was worthwhile as it facilitated further dialogue and advocacy on behalf of families. The opportunity to co-facilitate these meetings helped stakeholders to see the FSW and audiologist as a coordinated team.

Equally important as the FSW/audiologist's relationship is the importance of strong relationships with community partners. It is critical to attend to any perceived barriers to the provision of objective, client-focused care. Our colleagues in the Deaf community presented the FSW with an opportunity to reflect on this objectivity by asking about the introduction of American Sign Language (ASL) as a communication approach with families. The FSW, the ASL literacy consultant, and the preschool home-visiting teacher at the Regional School for the Deaf met to share their perspectives. At this meeting, the roles and relationships were clarified and each professional verbalized a greater understanding and commitment to dialogue about perceptions of barriers to client care. This ability to engage in conflict resolution in an atmosphere of respect and support will strengthen the program and ensure excellence in care.

Another example relates to the complexity of the IHP families. In addition to hearing loss, many of the infants present with additional physical, developmental and cognitive challenges. There are many services involved with families. The professionals involved have a responsibility to coordinate their service delivery and ensure that the families are the leaders in this process. An ability to listen to the family, honour their decisions, clarify respective roles and conjointly develop a plan with the family is innate to this process. This may require that the FSW and/or audiologist delay their intervention with the family until the family is able to engage in the process. The FSW has monthly contact with the family prior to their referral to a communication specialist. Following that, contact may be reduced to every 2 months as the family connects with habilitation supports.

Regular contact and follow up with families minimizes the risk of delays in intervention. Some delays to habilitation are inevitable based on a child's health. However, delays related to lack of understanding or family readiness to engage in habilitation must be explored so that the benefits of early identification are not lost.

In order to ensure coordinated, seamless care, the audiologist and family support worker commit to

ongoing contact. This process begins with the initial referral from the audiologist to the FSW. The audiologist provides preliminary information regarding the degree of the child's loss. The FSW then meets with the family to assess their knowledge base, interest in communication options, and support systems. This assessment is shared with the audiologist. It is understood that the parents have consented to the sharing of this information. Information sharing is achieved through phone consultation, monthly meetings and written progress notes to document family progress. Community partners are also updated on the child's progress through release of audiological reports. Case conferences may also be held to ensure coordination of services with community providers.

Client Acceptance of the Program

An OIHP goal is to provide family-centred services to support communication development. Hyde and Riko (2000) suggest that intervention is any act of service provision intended to change the child's communication development. The majority of parents are receptive to involvement with the program. They appreciate the clinical expertise and the inclusive approach of the audiologist and the FSW. They value the dialogue, the opportunity to ask questions, flexible appointment times and the opportunity to work with the FSW at their home, at the audiology clinic or by phone. As an example of the value of the coordinated roles, one parent shared her experience: "I like that you and the audiologist talk together about issues as this saves me some time and phone calls." Another parent said: "I can call you to discuss things and this reduces my need to involve other professionals."

However, some parents are less receptive. Although they agree to FSW/audiologist involvement, they require time to incorporate the diagnosis and habilitation suggestions. They express doubts about the severity of the loss and the benefits of hearing aids at such a young age. This is exemplified in one parent's comment: "Her ears are too small to have aids." Although they verbalize an understanding of the communication options available, they delay contact with the service providers for a consultation about these options. As one parent noted: "If I choose ASL, I worry that I'll be giving up on her [child's] ability to verbalize in the future." The audiologist and FSW honour the family's need to take time to incorporate the reality of the diagnosis and the implications for the family. The challenge is to gain the family's trust in order to stay involved as they continue their journey. The readiness and the pace with which they engage in the diagnostic and habilitation process varies. It is our responsibility to engage with the family as their needs dictate. Further, it is our responsibility to facilitate the process so that the family is able to attend to the child's needs.

Program and Client Profile

An integral part of the OIHP is the Integrated Services for Children Information System (ISCIS) created and maintained by the Ministry of Children and Youth Services. This database is updated by program providers and can be accessed to assist with local program management and outcome measures.

The southwest OIHP developed its own local database, in addition to accessing ISCIS, to capture information on infants identified with permanent childhood hearing impairment (PCHI). Since the start of the program in January of 2002 to October 2004, 36 infants have been identified with PCHI. Only four of these children had a unilateral hearing loss. The majority of these infants (25) were screened in hospital or community by OIHP staff. The remaining 11 infants were born prior to the inception of the program and were referred directly to audiology at an older age (12 months plus) based upon physician, community audiologist, or parental concern. It is anticipated that as routine screening of all newborns continues, late identification of PCHI will be eliminated.

The OIHP strives to identify infants with PCHI by 4 months of age. Of the 25 infants screened by the southwest OIHP, 68% were identified by 4 months of age. Four children were identified with a mild loss, five with a moderate loss, three with a moderately severe loss and 10 with a severe to profound loss. Three children were identified with auditory dys-synchrony. Infant health was the most common cause for delay in identification. In fact, six of the children identified with PCHI also present with additional challenges including cerebral palsy, cognitive delays and/or developmental delays. Consequently, frequent hospital readmissions to deal with urgent medical issues delayed the identification of the hearing loss.

The OIHP also strives to begin habilitation supports, including hearing aid fitting and communication development, by 6 months of age. Of those families who chose amplification, 68% of infants were fit by 6 months. Again, infant health was a factor contributing to the delay. Additionally, time was lost awaiting medical clearance to proceed with habilitation and/or secure funding for hearing aids. The OIHP recently began a program that provides the regions with loaner hearing aids to eliminate delays in hearing aid fitting associated with financial constraints.

Finally, the OIHP strives to have all families meet with the FSW. Of the 36 infants identified with a hearing loss, all but one family accessed the services of the FSW. It is interesting to note the status of other provincial initiatives with respect to universal hearing screening and how they differ from the Ontario model. In particular, Prince Edward Island, the Yukon and New Brunswick have implemented universal screening programs. While the screening and assessment phase are similar in their approach to the OIHP, these provincial initiatives do not include the role of a counselor, such as

the FSW, to work cooperatively with the audiologist in the area of habilitation. Ontario is unique in this regard.

Lessons Learned from Clients and Community Partners

Implementation of the OIHP at the regional level has been exciting, challenging and rewarding. We have "lessons learned" from the process.

- Communication with regional service providers, including screening site and habilitation providers, is key to ensuring program success. A variety of methods have been used to date including update letters to physicians and audiologists, surveys to community screening sites and a proposed newsletter to keep partners of the program fully informed.
- It is important to take the family's lead in the provision of information regarding habilitation options. Families vary in their need for information at the time of diagnosis. While some are prepared to take in any and all information, others prefer to have information shared only as it becomes relevant to their child's care.
- Coordination of both assessment and habilitation services at one site has resulted in improved continuity of care.
- Families are resilient. They will demonstrate this capacity if they are invited to full partnership in the IHP system.
- The families are busy. They are task and information focused. The audiologist and FSW have a responsibility to provide timely, accessible information based on the parent need. When families are ready to grieve, they want access to members of the team who will support them with their grief work.
- Interventions should be scheduled at intervals which acknowledge the family's need to cognitively and emotionally process the experience.
- Linkage with other service providers and services must occur in a context of partnership and collaboration.
- While face-to-face contact is preferred, phone counseling is a viable option provided that an initial face-to-face meeting with the FSW has occurred.

Summary

The OIHP has been implemented throughout the province. The program vision is to identify and serve infants with PCHI and their families in order for the children to acquire communication skills allowing them to attain personal and social sufficiency at home and school. When service providers collaborate and practice family centred care, the child and families' capacity to attain this vision will become a reality.

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