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Infant Hearing in Canada and the Canadian Infant Hearing Task Force

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The prevalence of hearing loss in newborns is approximately 2-3/1000 births.[1] Unidentified hearing loss in a child leads to delays in the development of spoken language, but early identification and intervention for hearing loss has been shown to improve outcomes in terms of communication, education, and social and family development.2 Hearing deficits can be detected in a sleeping or resting infant with a variety of automated screening devices. An infant who is referred from the screening process can be tested efficiently and accurately by professionals skilled in the diagnosis of hearing loss in infants and children.

Prior to 2001, Early Hearing Detection and Intervention (EHDI) programs in Canada were localized or regional efforts, developed by hospitals or public health regions. Because funding was generally limited or inconsistent, most programs were restricted to the screening or testing of infants considered to be at high risk for hearing loss. Many of these programs ceased to exist as funding priorities changed. A wide variation of screening and diagnostic testing methods could typically be found across programs. Historically, program protocols were developed locally by clinicians and adopted by funding agencies. Diagnostic protocols were generally dictated by the availability and type of equipment available. The Joint Committee on Infant Hearing (JCIH)[2] has indicated that the best developmental outcomes for children with permanent childhood hearing loss may occur if there is screening for hearing loss by one month of age, audiological evaluation by three months of age, and appropriate audiological and/or communication development services by six months of age. These targets are hard to hit without a comprehensive EHDI program.

A complete and comprehensive EHDI program has many facets. Simply screening and identifying hearing loss in infants is one core component, however multiple factors must be in place for a program to operate effectively with positive outcomes. The JCIH2 identifies several factors that make up an effective program, including guidelines for screening, diagnostic audiology, medical evaluation, audiological intervention, communication development, outcome measures, and information infrastructure. A 2013 review of best practice principles[3] clearly outlines a more detailed view of EHDI programming in the context of family centered early intervention. In the past decade, several key articles have emerged that outline critical features of EHDI programming, drawing on emerging data and information gathered as programs develop and mature internationally.

In 2013, the Canadian Infant Hearing Task Force (CIHTF) was created in order to gather and share information about the status of EHDI programs across Canada, and to act as an advocacy and advisory group for national and provincial/territorial efforts in EHDI program development. The CIHTF consists of professionals, academics, and clinicians representing all provinces and

territories in Canada. Members come from a wide range of backgrounds and include otolaryngologists, pediatricians, audiologists, and scientists. The members are involved in various aspects of EHDI programming, including direct service delivery, research, program administration, and program development. The CIHTF is supported by both national audiology associations, the Canadian Academy of Audiology (CAA) and Speech-Language and Audiology Canada (SAC).

In the spring of 2014, the CIHFT released a “report card” evaluating the current status of EHDI programming in the provinces and territories of Canada. The report card was the culmination of an informal review of provincial and territorial EHDI programs that currently exist. EHDI programs exist across Canada, but vary significantly in terms of how the programs are funded, the type of screening that occurs, the diagnostic process, and the collection of data within the program. The CIHTF report card was a snapshot of EHDI programming across Canada, with the goal of evaluating the status of current EHDI program parameters and activities. The CIHTF developed this initial review with several objectives in mind. A first, objective was to learn where effective programs are in place that might act as templates for regions that are in the process of developing new programs or improving on existing frameworks. A second objective was to identify regions where programming exists or is in planning stages. but might not have complete coverage or be missing key components essential for success. This includes provinces and territories where pockets of EHDI exist, and where government actions are in place with the intent of formalizing such programs or developing region-wide programming with stable funding and support. The CIHTF hoped to identify gaps in EHDI programming where information and support would facilitate program improvement. Of primary importance was the goal of raising awareness on a national scale to help move us closer to a Canadian strategy for EHDI programming.

The 2014 report card looked at several aspects of EHDI programming based on JCIH guidelines with additions relevant to Canadian provincial and territorial particulars. In the first stage, key respondents were identified in each Canadian province and territory. These respondents were typically clinicians or administrators actively involved in EDHI programs or efforts in their region. Although attempts were made to contact appropriate respondents in each province and territory, some areas were under-represented or had minimal information submitted for evaluation. Because the status of EHDI programming across the country was largely unknown, it was initially difficult to identify the appropriate participants in all regions. Fortunately as a result of the initial report card, provinces and territories that were not appropriately contacted responded by identifying key individuals for future reference and follow up.

Items addressed in the 2014 report card were as follows:

- Existence of EHDI programming, and the active aspects of that programming including screening, diagnostic assessment and communication development.
- The coverage of the EHDI program in terms of numbers of infants screened.
- The nature of the EHDI program in terms of provincial/territorial mandate, funding, management and supports.
- The existence of evidence based protocols dictating screening, diagnostic assessment, and communication development.
- The existence of a comprehensive database in the EHDI program.

If a program did not exist, the respondent was asked if a program was planned and if legislation was in place for program development.

In general, the outcomes of this review of EHDI programming in Canada found:

    - Two provinces had programs that were mandated, managed, and funded by the provincial

government. These programs had protocols in place governing screening, assessment, amplification (if required) and communication development protocol. Both programs had a comprehensive information infrastructure in place.

- Four provinces/territories had programs in place that provided excellent coverage (>95%) in terms of screening. These programs had standard protocols in place for screening, assessment, and communication development. However, these programs had gaps in terms of information infrastructure and tracking, as well as outcome measures.
- Two provinces/territories had programs in place that screen >90% of infants, but these programs were not mandated with clear government funding or supports. Information infrastructure gaps existed in these programs as well.
- Three provinces had regional or localized programs in place, with legislation or government intent to develop complete programs. The planning and development of the intended programs varied significantly across the three provinces.
- One province and one territory did not have programs in place, nor was there government intent (at present time) to develop a program.

The CIHTF now plans to follow up on this initial review of Canadian EHDI programs. This more in-depth and thorough evaluation will examine programs based in part on the information received and the new contacts and respondents garnered as a by-product of the release of the initial report. The planned report will look at programs in greater detail, obtaining specific information regarding screening practices, protocols for assessment and amplification, communication development streams and protocols, as well as the ability of a program to track and measure outcomes and objectives.

Moeller et al.[3] lists several best practice principles that build upon the foundations of Family Centered Early Intervention in EHDI programs. A key principle is the “early, timely, and equitable access to services.” The updated CIHTF status report will evaluate programs on their ability to deliver appropriate screening coverage for their population and to deliver referrals from screening to diagnostic services, family support, and intervention in a timely and equitable manner. This principle combines several key factors critical to any EHDI program. A program must be able to effectively screen new births, and move referred infants to diagnostic services in an equitable manner. Engagement of the family is important at all steps of the process, to the extent that a family must have an understanding of the screening process prior to the birth of their child. If a referral is necessary, the family should be fully engaged throughout the process of assessment and interventions in order to maximize outcomes for the child.

Additionally, and also key to program success, best practice principles indicate the importance of monitoring the child, family, and service providers throughout the process of assessment and intervention in order to ensure appropriate outcomes. EHDI program protocols must be flexible enough to facilitate strategy changes in response to outcome measures delivered at appropriate times throughout the process. Input from standardized measures, family observations, audiologic data, and informal observations should provide an intervention team with the information needed to address interruptions in the developmental path. This principle links back to the primary guideline of family involvement in the entire process.

The concept of program monitoring takes many forms and is often overlooked in EHDI program planning. A program database must be comprehensive and able to track and report in an efficient manner, all aspects of the program from screening to discharge. Confidence in the information obtained from the data gathering and reporting system is key to ongoing program success, development, and sustainability. The ability to retrieve and analyze program data is used to

monitor components and apply ongoing quality assurance measures. Data analysis is critical in maintaining the third key aspect of an EHDI program, efficiency. If a program fails to meet protocol-specified goals, the result is a program that fails to deliver the goal of early identification and intervention for the target population.

The CIHTF intends to continue to evaluate Canadian programs with the vision of nationally mandated EHDI program standards and outcomes. The pending report will be the next critical step in moving towards nation-wide EHDI programming that maximizes outcomes for children born deaf or hard of hearing.

References

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