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Status of Early Hearing Detection and Intervention Programs in Canada: Results From a Country-Wide Survey.

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 **Status of Early Hearing Detection and Intervention Programs in Canada: Results From a Country-Wide Survey**

 **État d'avancement des programmes de détection et d'intervention précoces des troubles auditifs au Canada : résultats d'une enquête nationale**

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Abstract

In Canada, early hearing detection and intervention programs go beyond population screening of newborn hearing and offer services to confirm the presence or absence of hearing loss and provide services should permanent hearing loss be detected. Early hearing loss identification and intervention is critical to promote language, literacy, and social skills in developing children. However, a report card issued in 2014 from the Canadian Infant Hearing Task Force indicated that comprehensive early hearing detection and intervention programs were not uniformly available across Canada. The current work aimed to update the status of early hearing detection and intervention programs in Canada through a 24-item survey completed by 19 representatives in all 13 provinces and territories. Since 2014, there have been some improvements in early hearing detection and intervention programs in some areas of Canada. In others, comprehensive infant hearing services are not available province- or territory-wide or have not been provided with the necessary resources to sustain a suitable early hearing detection and intervention program. Results revealed that Canada is insufficient in offering comprehensive, accessible, and sustainable early hearing detection and intervention programs. Babies born in Canada deserve access to all components of an early hearing detection and intervention program, regardless of where they live. Continued action from Canada's provincial and territorial governments in addition to federal policy leadership is needed to achieve sufficient and sustainable early hearing detection and intervention programs across the country.

Editor-in-Chief:
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Abrégé

Au Canada, les programmes de détection et d'intervention précoces des troubles auditifs vont au-delà du dépistage universel de l'audition des nouveau-nés; ils offrent également des services permettant de confirmer la présence ou l'absence d'une perte auditive et ils fournissent des services d'intervention lorsqu'une perte auditive permanente est détectée. L'identification et l'intervention précoces des pertes auditives sont essentielles afin de favoriser le développement des habiletés sociales, langagières et de littératie des enfants. Un bulletin de rendement publié en 2014 par le Groupe de travail canadien sur l'audition des nourrissons a toutefois indiqué que des programmes de détection et d'intervention précoces des troubles auditifs complets n'étaient pas disponibles de manière uniforme au Canada (Canadian Infant Hearing Task Force, 2014). Le présent article vise donc à mettre à jour l'état d'avancement des programmes de détection et d'intervention précoces des troubles auditifs du Canada grâce à un sondage composé de 24 questions et complété par un total de 19 représentants provenant des 13 provinces et territoires de ce pays. Depuis 2014, des améliorations ont été apportées à certains programmes de détection et d'intervention précoces des troubles auditifs du Canada. Dans certaines régions du Canada, des programmes de détection et d'intervention précoces des troubles auditifs complets ne sont toutefois pas disponibles à l'échelle de la province ou du territoire, ou encore, ceux-ci n'ont pas les ressources nécessaires pour fournir une offre de services adéquate. Les résultats du sondage ont révélé que le Canada n'offre pas des programmes de détection et d'intervention précoces des troubles auditifs complets, accessibles et viables. Les enfants qui naissent au Canada méritent d'avoir accès à tous les éléments d'un programme de détection et d'intervention précoces des troubles auditifs, peu importe leur lieu de résidence. Des actions de la part des gouvernements provinciaux et territoriaux, en plus d'un leadership politique fédéral, sont nécessaires pour permettre de mettre en place des programmes de détection et d'intervention précoces des troubles auditifs suffisants et viables dans tout le pays.

Healthy hearing and communication development have important implications for brain development, learning, behaviour development, personal and social relationships, and well-being (Bagatto & Moodie, 2016; Russ, Tremblay, Halfon, & Davis, 2018). Hearing loss in the early years of life is a “primary health condition that if not acted upon, can have a wide range of potentially adverse effects on the affected child, family and even society at large” (Hyde, 2017b, p. 316). The Life Course Health Development Model and the World Health Organization’s International Classification of Functioning, Disability and Health conceptualize health as not just the absence of disease but as a positive capacity for an individual’s participation in the usual aspects of everyday life (Russ et al., 2018; World Health Organization, 2001). With this conceptualization in mind, we believe that a child’s experiences early in life set a critical foundation for the entire life course (Bryant, Raphael, Schreker, & Labonte, 2011; Russ et al., 2018; Underwood & Frankel, 2012).

Early hearing detection and intervention (EHDI) programs have been implemented in many countries to proactively address hearing health in infants and children. One to three of 1000 babies are born with hearing loss; 50% have no risk indicators (Fortnum, Summerfield, Marshall, Davis, & Bamford, 2001). EHDI programs have been promoted worldwide and implemented in many countries (e.g., Australia, England, United States) to proactively address hearing health (Therrell et al., 2015; Wake et al., 2016; Williams, Alam, & Gaffney, 2015; Wood, Sutton, & Davis, 2015). Based on best practices for EHDI programs (see Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013), these programs should aim to (a) universally screen all newborns, regardless of the presence of risk indicators for early hearing loss; (b) identify babies with permanent hearing loss using appropriate diagnostic techniques; (c) provide intervention services which include support for technology (e.g., hearing devices) and communication development (i.e., spoken and/or signed languages) based on informed and engaged parental choice; (d) provide family support; and (e) monitor and evaluate the impact of the interventions (Bagatto & Moodie, 2016; Hyde, 2017a). These components should reflect the best available evidence and family-centred early-intervention principles (Moeller et al., 2013). Hyde (2017a, 2017b) provided in-depth descriptions of principles and methods of universal newborn hearing screening (UNHS) including a discussion of program evaluation and quality dimensions.

In Canada, the term *early childhood intervention* encompasses a broad range of policies, programs, and coordinated services that promote the healthy development of vulnerable children and their families from

birth to approximately 6 or 7 years of age (Underwood & Frankel, 2012). Health services in Canada, including EHDI, fall under the jurisdiction of each province or territory (Therrell et al., 2015; Underwood & Frankel, 2012). This means that funding, eligibility criteria, and the availability of EHDI services and programs across the 13 provinces and territories can and do vary widely (Canadian Infant Hearing Task Force [CIHTF], 2014, 2016, 2019 [see Appendix]; Eskander & Papsin, 2014; Martin et al., 2018; Patel, Feldman, Canadian Pediatric Society, & Community Pediatric Committee, 2011; Therrell et al., 2015). In addition, individual provinces and territories have their own policy contexts with varying degrees of public transparency (Therrell et al., 2015). The absence of federal legislation for EHDI programs also means that distributional imbalances exist because of the geographical challenges associated with having approximately 18% of Canada’s population living in rural or remote communities dispersed throughout 95% of the area of the second largest country in the world (Martin et al., 2018).

The CIHTF, Speech-Language & Audiology Canada, the Canadian Academy of Audiology, and the Canadian Paediatric Society provided evidence in 2014 that eight EHDI programs in Canada were insufficient and inequitable (CIHTF, 2014). Programs were either not available or not comprehensive in all provinces and territories. Evidence for the cost effectiveness and benefits of EHDI makes improved access to such programs across Canada an important goal (Hyde, 2017a; Patel et al., 2011; U.S. Preventive Services Task Force, 2002).

In the absence of national legislation and guidelines, the CIHTF, a national group of leaders and experts in EHDI, was formalized in approximately 2013 to promote, support, and advocate for comprehensive universal EHDI programs in all Canadian provinces and territories (www.infanthearingcanada.ca). The group is a joint effort of the two Canadian professional associations, Canadian Academy of Audiology and Speech-Language & Audiology Canada. Their Report Card on Early Hearing Detection and Intervention presented in 2014 revealed that five provinces (i.e., British Columbia, New Brunswick, Nova Scotia, Ontario, Prince Edward Island) of 13 provinces and territories included all the components of a suitable EHDI program. The remaining eight provinces and territories did not have all the components of an EHDI program. For some provinces, only screening was available and the services needed to confirm a permanent hearing loss and provide the necessary intervention were only offered locally or regionally, not province- or territory-wide. This lack of accessibility may mean inconsistent or no follow-up

and/or clinical protocols that are not implemented or monitored. Additionally, many of the provinces or territories with insufficient EHDI programs in 2014 lacked a database to track births and outcomes. This crucial part of an EHDI program helps to ensure babies are guided to the next stage of the program and the impact of the intervention is documented. Data of this kind offer more evidence of the impact EHDI programs have on newborn Canadians and help to identify areas of improvement for EHDI program managers and stakeholders.

The purpose of the current study was to (a) investigate the status of implementation of EHDI programs in Canada; (b) consider whether adequate programs were in place in 2018; and (c) update the CIHTF EHDI Report Card. The previous version of the report card (i.e., 2014) captured some different aspects of the Canadian EHDI picture. Changes in the questions and grading for the current work were derived from knowledge gained in the previous work as well as an evolving understanding of the flexible and varied nature of provincial/territorial healthcare implementation.

Results of this study will help us understand if children and their families have equal and sustainable access to hearing loss intervention and support so that each child can develop to their full potential. This work will also provide a starting point to define excellence in EHDI programs for Canada. Excellence is achieved by programs that ensure that the knowledge and skills needed to fulfill EHDI program aspects are aligned with operationally defined performance standards and that there is intentional and deliberate monitoring in place for actual EHDI program performance compared to expected performance (Dunst, 2017; Hyde, 2017a, 2017b).

Method

Study Design

A concurrent embedded mixed methods design was used. This methodology allows researchers to gain a broader perspective because the qualitative data provide enriched descriptions that are not otherwise available or easily quantified (Creswell & Plano Clark, 2011). In the current study, data were primarily collected through a survey of the provinces and territories in Canada. This work was an examination of policy issues and a quality assurance study with third-party interviews. As such, ethics review was not required. Every effort was made to follow the principles of ethical conduct for research involving humans such as informing respondents of the nature of the study and that by completing the survey they are providing their consent. Respondents were prompted to provide additional written details regarding their quantitative survey response choice.

This qualitative text was paired with the quantitative descriptive results from the survey. Triangulation of qualitative comments with quantitative data was facilitated by discussion among a sub-group of CIHTF members to reach a consensus on our understanding of universal EHDI programs in Canada.

Materials

A 24-item online survey (using Survey Monkey®) was created by the sub-group of CIHTF members to gather more specific information about the status of EHDI programs in Canada (see **Table 1**). For each item, respondents chose among multiple responses; they were also provided with a space to explain their response. Items 1 through 4 asked about the role of respondents in their province or territory's services for infant hearing as well as which province or territory they represented. Items 5 through 11 related to legislation, funding, and coordination for certain aspects of EHDI, and Items 12 through 23 related to access to the specific components of EHDI such as UNHS, early intervention, clinical protocols, and monitoring. Item 24 was an open-ended question inviting the respondent to provide additional information and/or comments.

Once the survey analysis was completed and reviewed, specific follow-up questions were derived (see **Table 2**) and emailed to each respondent to gather additional information and achieve clarification of survey responses. This was especially important to accurately inform the 2019 Report Card that the CIHTF released in April 2019 (see the Appendix). One CIHTF member (MB) interacted individually with each respondent through email or phone conversation until clarification and agreement upon responses was achieved.

Participants

The survey link was sent via email (June 1, 2018) to individuals that the CIHTF believed had a significant role and responsibility in managing their province or territory's EHDI program. The respondents for each province/territory were nominated within that region to respond to the survey. If individuals indicated that they were not best suited to respond to the survey, they were asked to provide the CIHTF with the name and email address of a more appropriate respondent. One of the strengths of the CIHTF is that the committee is familiar with infant hearing activities and the professionals involved across Canada. Within the initial communication, it was stated that if the individual did not feel that she/he has the appropriate knowledge or experience to respond to the survey, she/he should transfer the link to someone who did. The Survey Subcommittee

Table 1		
The 24-Items Included in the Canadian Infant Hearing Task Force 2018 Survey of Canadian EHDI Programs		
Items	Questions	Response Options
1	What is your role in your province's/territory's infant hearing program?	Audiologist providing services to children.
		Speech-Language Pathologist providing services to children.
		Ear, Nose, and Throat physician providing services to children.
		Local newborn hearing screening program manager.
		Regional newborn hearing screening program manager.
		Provincial/territorial newborn hearing screening program manager.
		Other.
2	What province/territory are you providing information for?	Open ended.
3	What region within your province/territory are you providing information for?	Open ended.
4	Please provide your name and email address in case we need to contact you to obtain clarification and/or additional information.	Open ended.
5	Are you aware of position statements, approved policies or legislation for your province/territory that recommend UNHS, and/or EHDI?	Yes, these exist for our province/territory.
		Yes, our province/territory had endorsed/adopted an external position statement.
		No.
		I do not know.
6	What is the status of legislative or policy support in your province/territory for universal newborn hearing screening?	Our province/territory has legislated or provided a program for universal newborn hearing screening.
		Regional or local sites in our province/territory have local policies for universal newborn hearing screening.
		Our province/territory does not currently have such legislation or programs.
7	What is the status of legislative or policy support in your province for EHDI programs? (e.g., intervention above and beyond a newborn hearing screen)	Our province/territory has legislated or provided a program for an EHDI program (services in addition to newborn hearing screening).
		Regional or local sites in our province/territory have local policies for an EHDI program (services in addition to newborn hearing screening).
		Our province/territory does not currently have such legislation or programs.
		Comments.

Items	Questions	Response Options
8	What is the status of funding in your province for universal newborn hearing screening and/or an EHDI program?	Sufficient funding exists for screening and/or an EHDI program. Insufficient funding exists for screening and/or an EHDI program. No funding exists for screening and/or an EHDI program. I do not know the status of the funding. Comments.
9	Is there a funded program in your province/territory that coordinates universal newborn hearing screening and/or EHDI?	Funding supports coordination or management of a province/territory wide program. Funding supports coordination or management of a regional program. Funding supports coordination or management of a local program. There are no programs for coordination. I do not know the status of coordination. Other (please comment).
10	Does your province/territory have newborn hearing screening initiatives of any kind, regardless of whether or not they are funded or coordinated?	Yes, province and/or territory wide. Yes, in local programs or hospitals. No. I do not know. Other (please comment).
11	If you answered Yes to the previous question, please describe these services.	Open ended.
12	Does your province/territory have early intervention services for infants who have hearing loss?	A program exists that refers children from screening for hearing loss through hearing assessment to identify permanent hearing loss to funded intervention programs across the province or territory. Specialized pediatric programs exist (for example at some centres or hospitals) that refer children from screening for hearing loss through hearing assessment to identify permanent hearing loss to funded intervention programs across the province or territory. Specialized pediatric programs exist (for example at some centres or hospitals) for screening for hearing loss and assessment/diagnostic follow-up only. No. I do not know. Other (please comment).
13	How are infants with identified risk indicators for late onset and/or progressive hearing loss monitored?	I do not know. Risk indicators are not identified. EHDI program records infant's risk indicator(s), and no audiological monitoring or surveillance occurs within the EHDI program. Audiological monitoring occurs within the EHDI program (infant/child is seen back at regular intervals for surveillance). Other (please provide comments).

Items	Questions	Response Options
14	For infants identified with permanent hearing loss within your EHDI program, how is assistive technology (hearing aids, remote mic systems, batteries, etc.) funded?	We do not have an EHDI program. Full cost is paid for by the family. Funding provided for families who qualify based on income level. Provincial/territorial funding - partial money provided to fund devices. Provincial/territorial funding - full cost of devices provided. Provincial/territorial funding - for batteries and/or earmolds. I do not know. Other (please provide comments).
15	If there is no EHDI program in your province/territory, how are assistive devices funded for children identified with permanent hearing loss?	Open ended.
16	Are service providers working within your EHDI program provided with specific training related to your desired service provision requirements?	We do not have an EHDI program. I do not know if they are provided with training. Yes - they are provided with in-person training. Yes - training is provided through sharing of paper or electronic procedures and documents. No - they are not trained in specific procedures related to service provision. Other (please provide comments).
17	Are service providers working within your EHDI program provided with practice monitoring related to ensuring desired service provision requirements are met?	We do not have an EHDI program. I do not know if they are monitored. Yes – they are monitored. No – they are not monitored. Other (please provide comments).
18	Do protocols exist within your EHDI program (e.g., hearing screening, assessment, hearing aid fitting/ verification, outcomes measurement)?	We do not have an EHDI program. I do not know. Yes. No.
19	If you answered Yes above, does the EHDI program provide training on the protocol?	We do not have an EHDI program. I do not know. Yes. No.

Items	Questions	Response Options
20	If you have protocols in place within your EHDI program, are service providers monitored for protocol adherence?	We do not have an EHDI program.
		We do not have specific protocols in place in our EHDI program.
		Yes - service providers are monitored for protocol adherence.
		No - service providers are not monitored for protocol adherence.
21	Please indicate which of the following parent-to-parent and/or family support services are provided within your EHDI program.	There are no formal parent/family support services currently in place within our EHDI program.
		We have a parent-to-parent support program.
		Training of parent peer support workers.
		Professional (e.g., social worker or similar) support program.
		Training of professional support workers.
		Funding available for support services.
		I do not know.
Other (please provide comments).		
22	Is there a provincial/territorial database in place that records and tracks children within your UNHS and EHDI programs?	I do not know.
		Yes.
		No.
		Other (please provide comments).
23	How are services monitored for children within your EHDI program?	We do not have an EHDI program.
		I do not know.
		Services for children with hearing loss are not monitored.
		Services for children with hearing loss are monitored at the local level (within our clinic[s]).
		Services for children with hearing loss are monitored at a regional level.
24	Please provide any additional information/comments that you believe will facilitate our understanding of EHDI program(s) in your area.	Services for children with hearing loss are monitored at a provincial/territorial level.
		Other (please provide comments).
24	Please provide any additional information/comments that you believe will facilitate our understanding of EHDI program(s) in your area.	Open ended.

Note. Most items provided a check-box list of responses and an area in which respondents could provide text to further expand on their quantitative response data. EHDI = Early hearing detection and intervention, UNHS = Universal newborn hearing screening.

was not able to adjudicate whether a respondent was the most appropriate for that province/territory and therefore accepted responses from the person identified for each region. Reminder emails were sent until data from all provinces and territories were received (October 24, 2018).

Data Analysis

Data analyses were descriptive in nature. The open-

ended written responses, email, and telephone information were combined with the quantitative results at the analysis stage and examined to determine whether descriptive results could be better explained.

Assigning an overall grade for EHDI programs: Sufficient or insufficient. A designation of *Sufficient* was assigned to a province or territory if it had all five EHDI components available at the provincial or territorial level,

rather than only in smaller regional or hospital-based programs. These are as follows:

1. UNHS;
2. Identification of babies with permanent hearing loss;
3. Intervention services which include support for technology and communication development;
4. Family support; and
5. Monitoring and evaluation of the program.

Regional or hospital-based delivery of any of these components can have varying standards, program characteristics, and coverage rates. Provinces and territories where any of these components were missing and/or not implemented province- or territory-wide were graded as *Insufficient*.

Rating differences from the 2014 EHDI report card. In 2014, ratings for EHDI programs in Canada were categorized using three grades: *Excellent*, *Good*, or *Insufficient*. Grades were assigned on the basis of program quality and coverage at the provincial/territorial level that included the same five EHDI components listed above. Screening coverage was given a high weighting in the 2014 Report Card. Excellent and Good categories were assigned for screening coverage of at least 95% or 90%, respectively. As this can be considered a

quality measure, the CIHTF decided not to weight screening coverage in this way for the 2019 Report Card. For the current Report Card, one goal was to understand the status of EHDI programs across Canada by investigating whether each of the five components were being offered in a province or territory. As such, in the 2019 EHDI Report Card, programs were assigned one of two grading categories: Sufficient or Insufficient.

Results

There were 19 survey respondents distributed across all 10 Canadian provinces and three territories. The CIHTF accepted each nominated respondent to be suitable for that region. A single respondent completed the survey and follow-up questions in each province and territory, except for New Brunswick and Newfoundland and Labrador. These two provinces had four respondents each from various regions of the province. The follow-up questions for these provinces were especially important in order to gain consensus from the multiple respondents. Of the 19 respondents completing the survey, five were audiologists providing services to children; one was a speech-language pathologist who provides services to children; one was a regional UNHS manager; three were provincial/territorial UNHS managers; six were audiologists who were local, regional, or provincial newborn hearing screening program managers while also providing services to children; one was the director of the provincial EHDI program; one was a

Table 2	
Follow-up Questions	
Items	Questions
1	If you have a UNHS that is province/territory-wide, what is the percentage of babies screened? This item informs the amount of coverage the program provides.
2	EHDI programs aim to proactively address hearing health and include: (1) screening of all newborns, regardless of the presence of risk indicators (UNHS); (2) identification of babies with permanent hearing loss; (3) intervention services which include support for technology and communication development; (4) family support; and (5) monitoring and evaluation of the impact of intervention. Based on this definition, are ALL of these services offered across the province/territory? That is, does your province/territory have an EHDI program?
3	If you have an EHDI program, do protocols exist and does monitoring that the protocols are being followed occur?
4	Does your program have a database to track program outcomes?

Note. EHDI = Early hearing detection and intervention, UNHS = Universal newborn hearing screening.

provincial EHDI program manager; one was a regional EHDI manager; and one was a local EHDI manager. It is common within EHDI programs to have representatives from a variety of backgrounds.

Only six provinces or territories in Canada have EHDI programs that are considered sufficient based on the five components previously described: Alberta, British Columbia, Northwest Territories, Nova Scotia, Ontario, and the Yukon. The remaining provinces and territories—Manitoba, New Brunswick, Newfoundland and Labrador, Nunavut, Prince Edward Island, Québec, and Saskatchewan—are considered insufficient despite some having localized or regional services. In these areas, any infant hearing programming that exists has poor or unknown coverage, lacks standardized protocols, and/or the area does not have a database and a process for monitoring services and outcomes. Further information gathered from the survey is described in the sections that follow. See **Table 3** for a summary.

One important distinction between a sufficient and an insufficient EHDI program is the province- or territory-wide availability of the relevant program components (e.g., screening, diagnostics, intervention, etc.). Although there are some provinces and territories that do not have province- or territory-wide access to all the necessary EHDI components, it is important to describe what hearing-related services are provided to infants and children across Canada. The following section describes the availability of EHDI components as reported in the survey, with a focus on those provinces and territories who reported an insufficient EHDI program.

EHDI Components

Universal newborn hearing screening. Ten Canadian provinces and territories offer UNHS (i.e., Alberta, British Columbia, Manitoba, New Brunswick, Northwest Territories, Nova Scotia, Ontario, Prince Edward Island, Saskatchewan¹, Yukon). Newfoundland and Labrador, Nunavut, and Québec do not currently offer UNHS. The intent to implement a program in Québec was announced by the provincial government in 2009 and it is currently in development (CIHTF, 2014). Although the lack of UNHS contributes to the provinces/territories of Newfoundland and Labrador, Nunavut, and Québec EHDI programs' ratings of insufficient, they do offer localized pediatric audiology services for infant hearing assessment and intervention. UNHS is a vital component of a comprehensive EHDI program designed to capture newborns who require further audiological assessment and early intervention should a permanent

hearing loss be detected. In addition, it is critical that infant hearing services continue after the UNHS stage. This is because newborn hearing screening does not diagnose or treat hearing loss. It simply indicates that further audiological assessment is required to determine the presence or absence of permanent hearing loss in early infancy. The UNHS component is necessary to support the triage of infants who need further follow-up.

Identification of infants with permanent hearing loss. Infants who do not pass hearing screening must be referred to an audiologist for a hearing assessment and the necessary audiology intervention services (e.g., hearing aid fitting), where available and desired by the family when permanent hearing loss is confirmed. In the absence of a UNHS system, the path to audiology assessment may not be seamless or easily accessible. It would be inappropriate to screen for a condition without having the necessary follow-up in place (World Health Organization, 2001). In addition, the Joint Committee on Infant Hearing (2013) emphasized the need for clinicians with the required experience and expertise to accurately assess infant hearing in a timely manner to support optimal intervention. Without UNHS or a coordinated EHDI system, it is difficult to accomplish timely and appropriate audiology assessment province- or territory-wide. There was not a specific question in the survey that targeted infant hearing assessment, though we did ask whether protocols and training exist for this service (see below). However, in the survey, respondents from all provinces/territories indicated that pediatric audiology assessment was available. The lack of UNHS in Newfoundland and Labrador, Nunavut, and Québec means that access to timely diagnostic and intervention services for infants may be compromised. These regions have regional access to audiology assessment services. For the provinces and territories who have UNHS, audiology assessment is either provided province/territory wide (i.e., Alberta, British Columbia, Northwest Territories, Nova Scotia, Ontario, Yukon) or regionally (i.e., Manitoba, New Brunswick, Prince Edward Island, Saskatchewan).

Intervention services: Technology and communication development. Early intervention is the goal of a comprehensive EHDI program. Without the initial contact of UNHS supported by an early and accurate hearing assessment, optimal and timely intervention is impossible. Furthermore, a coordinated system of services to ensure infants with hearing loss and their family are guided through the process is critical to reduce the impact of early hearing loss on the children's development. Within an EHDI program, intervention services, which include

¹ At the time of the survey, Saskatchewan was preparing to launch their UNHS program. It was launched in the spring of 2019.

Table 3

Summary of EHDI Components for Each Province/Territory in Canada

Province/Territory	UNHS	Identification	Intervention	Family Support	Monitoring/ Database
Alberta	✓	✓	✓	✓	✓
British Columbia	✓	✓	✓	✓	✓
Northwest Territories	✓	✓	✓	✓	✓
Nova Scotia	✓	✓	✓	✓	✓
Ontario	✓	✓	✓	✓	✓
Yukon	✓	✓	✓	✓	✓
Manitoba	✓	x	x	x	x
New Brunswick	✓	x	✓	x	x
Newfoundland and Labrador	x	x	✓	x	x
Nunavut	x	x	x	x	x
Prince Edward Island	✓	✓	x	x	x
Quebec	x	x	x	x	x
Saskatchewan	✓	x	x	x	x

Note. Check marks indicate that the component is implemented province/territory-wide. “X’s” indicate the lack of the component or that it is not available province/territory-wide. For Identification and Intervention, audiology assessment and hearing aids and/or communication development is available in regions denoted with an “X” but services are only available regionally. For Monitoring/ Database, some regions have monitoring of service provision but not a database. Both are required for a complete EHDI program. EHDI = Early hearing detection and intervention, UNHS = Universal newborn hearing screening.

technology (e.g., hearing aids, cochlear implants) and support for communication development (e.g., speech-language pathology, American Sign Language), must be linked with UNHS and infant hearing assessment to ensure all infants with hearing loss are supported. Provinces/territories that lack UNHS are less likely to be aware of infants who were born with hearing loss and jeopardize the opportunity to maximize the critical developmental period. A program that refers children from UNHS to hearing assessment and to a coordinated intervention program that is available province- or territory-wide is a required component of a sufficient EHDI program.

Through the survey, Manitoba, Nunavut, Québec, and Saskatchewan indicated that intervention services are offered in specialized centres and hospitals and not across the province/territory. This makes access to intervention services, which should occur with a skilled clinician on a routine basis throughout the child’s early years, a challenge. The provinces and territories that provide broad access to high quality intervention services are scaffolded by either UNHS and infant hearing assessment or are within a comprehensive EHDI program. These are Alberta, British

Columbia, New Brunswick, Newfoundland and Labrador, Northwest Territories, Nova Scotia, Ontario, Prince Edward Island, and Yukon.

Family support. Support for families of infants identified as having permanent hearing loss is a vital part of any EHDI program (Henderson, Johnson, & Moodie, 2014, 2016; Moeller et al., 2013) and can take many forms. British Columbia’s EHDI program offers parent-to-parent support, training of peer parent support workers, and provides funding for support services. The EHDI program in Ontario offers parent support through a professional (i.e., social worker) funded by the program. The Yukon provides a parent-to-parent support program as well as training of professional support workers. In the Northwest Territories, due to the low numbers of infants who have hearing loss, family support services are offered in neighbouring provinces. Alberta’s program is relatively new and is refining a program for parent-to-parent support services. Nova Scotia is similarly developing a parent-to-parent support program. Families in Saskatchewan may connect with a regional children’s centre, though it is not yet a formal part of the province’s UNHS program. The remaining provinces/

territories (i.e., Manitoba, New Brunswick, Newfoundland and Labrador, Nunavut, Prince Edward Island, and Québec) do not have formal programs for family support. A lack of formal parent-to-parent support programs means that the managing audiologist will have to continue their support by connecting families with community resources that are not a formal part of their program. As such, the clinicians supporting the family will have little or no control over the quality of these resources and the accuracy and appropriateness of information provided to parents using these resources. These connections occur regardless of the implementation of a sufficient EHDI program and demonstrate the importance of family support when an infant is identified as having a hearing loss. For provinces and territories with a UNHS component only, support is perhaps more critical for the family to be able to locate suitable follow-up services because they have not been implemented or supported in their province or territory.

Monitoring and evaluation of the program. Monitoring and evaluation of an EHDI program assures that services are of high quality so that infants are not being missed or misdiagnosed. Continuing quality assurance initiatives and tracking of infants through a provincial/territorial database ensure that good-quality EHDI programs are in place. A critical component of infant hearing healthcare is the use of evidence-based clinical protocols. Regardless of the existence of a sufficient EHDI program, all Canadian provinces and territories indicated that protocols exist for infant hearing screening, assessment, hearing aid fitting/verification, and outcome measurement. This speaks to the high quality of pediatric audiology services available in Canada. The downside is that for some areas of the country where EHDI programs are insufficient, access to these services and sustainability are lacking.

Provinces that have EHDI programs reported providing in-person training on clinical protocols for hearing screening and audiology assessment, and the provision of hearing aids to infants who have hearing loss (Alberta, British Columbia, Nova Scotia, Ontario). There is also sharing of electronic resources, which is a strategy that the Northwest Territories and Yukon rely on for training and monitoring service providers. Importantly, some provinces and territories that do not have an EHDI program still provide in-person training or sharing of resources for training, especially for hearing screening and audiology assessment (Manitoba, New Brunswick, Newfoundland and Labrador, Prince Edward Island, Québec, Saskatchewan). Of the provinces and territories that provide training, practice monitoring to ensure that the desired service provision requirements are met in all components of care is being conducted by British

Columbia, Ontario, Nova Scotia, Northwest Territories, and the Yukon. Only screening performance is monitored in Manitoba and Québec and both screening and assessment are monitored in Alberta. Prince Edward Island has a single audiologist who upgrades her knowledge regularly and Saskatchewan has plans to monitor screening performance. New Brunswick and Newfoundland and Labrador do not monitor service provision for adherence to clinical protocols. Nunavut has not implemented clinical protocols.

Database. A data management system to track infants through each stage of an EHDI program helps to ensure that all necessary services are accessed by the family. Mechanisms to identify timelines and outcomes for each EHDI service, for each child, allows for the determination of whether the program is meeting recommended benchmarks and is having a positive impact for infants with hearing loss. These data are important for stakeholders in order to evaluate the quality of the program and adjust procedures and services as needed. Sufficient EHDI programs in Canada (i.e., Alberta, British Columbia, Northwest Territories, Nova Scotia, Ontario, Yukon) have a provincial or territorial database that records and tracks infants and their outcomes within the program. Manitoba's database tracks the UNHS outcomes as well as the results of the audiology assessment and intervention recommendations. New Brunswick's database is built for the UNHS component of their program only. Newfoundland and Labrador, Nunavut, and Prince Edward Island do not have databases to track infants or outcomes. At the time the survey was completed, it was indicated that Saskatchewan did not have a database to track infants or outcomes. Databases evolve as the data are analyzed and interpreted. Their accuracy and meaningfulness help support the quality improvement and continuation of EHDI programs.

Other Important EHDI Components

Within the survey, respondents were asked to respond to other questions relevant to the implementation and sustainability of EHDI programs. The information gathered from these sections was not used to rate a province/territory's EHDI program. The topics below are useful for understanding other important components of EHDI programs.

Legislation. It was not the intent of the survey to evaluate the quality of any legislation, but only to determine if legislation exists. Existing legislation indicates provincial/territorial government support for a program and elevates it beyond a regional effort in addition to supporting the sustainability of the EHDI program.

Of the 13 provinces and territories in Canada, seven (i.e., Alberta, Manitoba, New Brunswick, Ontario, Prince Edward Island, Québec, Nova Scotia) have position statements, approved policies or legislation specific to their province or territory that recommend UNHS and/or EHDI, and one (i.e., Northwest Territories) has endorsed external policies or legislation. The Northwest Territories have adopted Ontario's policies and procedures for all but high-risk monitoring, which is modelled after British Columbia's procedures. It was indicated that resources are limited in the Northwest Territories and developing new policies was not necessary. In five others (i.e., British Columbia, Newfoundland and Labrador, Saskatchewan, Nunavut, Yukon), the respondents were not aware whether such documents are used or endorsed in their province or territory. These respondents often reported that policies and legislation are available regionally or locally or are in the process of being developed. Differences in legislation would be expected across provinces/territories because healthcare is not administered on a federal level.

The distinction between UNHS and a complete EHDI program is important because population screening of newborns for hearing loss without province- or territory-wide services for hearing assessment, intervention, family support, monitoring, and tracking does not support babies who are referred from screening for audiologic assessment or who are at risk for developing hearing loss after the newborn period. The existence of legislation that makes the distinction between UNHS and EHDI is critical for support and implementation of optimal hearing health care for children.

Through the survey it was determined that seven provinces or territories (i.e., Alberta, British Columbia, Northwest Territories, Nova Scotia, Ontario, Prince Edward Island, Yukon) have legislation for or provide an EHDI program. Newfoundland and Labrador, Nunavut, and Québec currently do not have legislation for nor provide UNHS or EHDI programs. Despite the legislation or provision of EHDI, New Brunswick, Prince Edward Island, and Saskatchewan lack important components (noted above) that render their EHDI program insufficient.

Funding. For the provinces and territories that provide UNHS or EHDI programs, seven reported sufficient funding (i.e., British Columbia, Northwest Territories, Ontario, Prince Edward Island, Québec, Nova Scotia, Yukon), though for some with long wait lists for audiology and speech-language pathology services, more funding is indicated (e.g., Nova Scotia). This funding also supports coordination or management of EHDI programs in these

provinces and territories. New Brunswick provided funding for equipment and staffing when their EHDI program was initiated in 2002. No further funding was reported at the time of the survey and the respondents indicated that the equipment is now in need of replacement. As such, their funding was reported as insufficient. Manitoba provides sufficient funding for a province-wide UNHS program as well as screening and diagnostic equipment, but provides no funding for the regional coordination of the program or for regionally-based intervention services. Manitoba funds intervention services in two major cities: Winnipeg and Brandon. Funding is also provided for three regions to provide Auditory Brainstem Response assessment to newborns who refer on hearing screening. Alberta provided funding to implement and coordinate a province-wide EHDI program in 2018 and it is premature to determine whether it is sufficient. Saskatchewan provided funding to implement and regionally coordinate a province-wide UNHS program by the spring of 2019; however, funding was not provided for a comprehensive EHDI program. Newfoundland and Labrador has not provided province-wide funding for UNHS or EHDI, though it has local programs that provide UNHS. The representative from Nunavut was unaware of the funding status for any program, though targeted hearing screening of infants at risk of hearing loss is attempted. Many of these babies are referred to Ottawa, Ontario, for hearing assessments.

Hearing aid funding. The funding of personal hearing aids for infants with permanent hearing loss varies across the country, regardless of whether the province or territory has a sufficient EHDI program. In New Brunswick and Nova Scotia, the full cost of the hearing aids is paid for by the family if they do not qualify for income-based funding. Since 2015, the Northwest Territories has provided funding for earmolds and hearing aids for all children with hearing loss until the child's 18th birthday. The Yukon provides hearing aid funding for children based on family income or when other third-party options have not been successful. Partial provincial funding is provided through separate provincial funding sources in Alberta (Aids for Daily Living), Ontario (Assistive Devices Program), and Manitoba (Children's Hearing Aid Program). The Provincial Hearing Aid Program provides funding for the full cost of hearing aids and earmolds in Newfoundland and Labrador. The British Columbia Early Hearing Program includes full funding of the first hearing aid(s) and batteries and earmolds for 3 years. Prince Edward Island provides full funding for hearing aids until the child turns 18 years of age, as does Québec, although details were not provided in the survey responses. Nunavut's funding for hearing aids and earmolds is limited to federally funded Non-Insured Health Benefit status,

as is also available in other provinces and territories. This includes Saskatchewan, which also offers hearing aid funding based on income level.

Coordination. There is availability of hearing assessment and intervention in New Brunswick, although family support and monitoring are not formalized or centrally located. Lack of funding since program inception in 2002 has threatened the sustainability of the New Brunswick program. Prince Edward Island offers province-wide UNHS, audiology assessment, and intervention. Clinical protocols exist although their implementation is not monitored. Prince Edward Island also does not have a database to track infants through the program. This impacts their ability to monitor and manage the quality of the program. Saskatchewan launched their UNHS program in the spring of 2019. This does not include other EHDl components such as audiology assessment or intervention. These services are available only in particular parts of the province, which limits accessibility to infants born in Saskatchewan. Furthermore, the lack of standardized protocols for regional implementation of EHDl components means that service quality in this province will vary from region to region.

Discussion

Research has unequivocally shown that, if not acted upon early in life, hearing loss in infancy can significantly impact speech, language, literacy, and social-emotional development and can have a wide range of potentially adverse effects on the family and society (Ching, Dillon, Leigh, & Cupples, 2018; Tomblin et al., 2015). All children in Canada deserve access to proper hearing screening and timely diagnosis and intervention to reach their full potential. Continued action from Canada's provincial and territorial governments in addition to federal policy leadership is needed to achieve sufficient and sustainable EHDl programs across the country.

There has been some progress in the status of implementation of EHDl programs across Canada since the 2014 Report Card issued by the CIHTF. In the 2019 Report Card, six provinces and territories in Canada were graded as having Sufficient EHDl programs (i.e., Alberta, British Columbia, Northwest Territories, Nova Scotia, Ontario, and Yukon) compared to five in 2014 (i.e., British Columbia, New Brunswick, Nova Scotia, Ontario, and Prince Edward Island). British Columbia, Nova Scotia, and Ontario have managed to sustain sufficient EHDl programs over the 5-year period. British Columbia's EHDl program started in 2006 and Ontario's EHDl program started in 2002, which demonstrates a remarkable ability to maintain high quality hearing health care services for infants and their families

across these provinces over time.

Alberta, Northwest Territories, and the Yukon have achieved a Sufficient grade for their EHDl programs in 2019, which is an improvement from the 2014 Report Card. Alberta's EHDl program was recently implemented in 2018 and reflects all important components of an EHDl program across the province. Prior to receiving the necessary resources for an EHDl program, most babies in Alberta were not screened for hearing loss, audiology services for infants were not province-wide, and tracking of births and outcomes varied. Significant gains were made in this province after the government announced in 2013 their intention to implement a province-wide EHDl program. In the 2014 Report Card, the Northwest Territories EHDl program was graded as *Under Review*. In the 2019 Report Card, similar to Alberta, the Northwest Territories achieved a Sufficient grade for their EHDl program. EHDl components were not available territory-wide in the Yukon in 2014, and they did not have a mechanism to track births or outcomes. In 2019, the Yukon offered all EHDl program components and they have innovatively arranged support from southern provinces (e.g., British Columbia). The Yukon now has a database that tracks infants and outcomes.

In the current report card, the EHDl programs in New Brunswick and Prince Edward Island are graded as Insufficient, which is unfortunate for families since these provinces were graded as Sufficient in 2014. All EHDl program components are available province-wide in Prince Edward Island. Although clinical protocols exist, their implementation is not monitored and they do not have a database to track infants or outcomes. New Brunswick offers some EHDl program components but again they are not available across the province. In particular, family support and monitoring are not formalized or centrally coordinated. In addition, it was reported that New Brunswick's audiological clinical protocols and equipment require updating to meet new practice standards seen in those provinces graded as Sufficient.

Five provinces continue to demonstrate insufficient EHDl programs since the last report card was issued in 2014: Manitoba, Newfoundland and Labrador, Nunavut, Québec, and Saskatchewan. The primary reason for continuing to receive an Insufficient grade is that they lack the components for a complete EHDl program. Manitoba has province-wide UNHS (hearing screening component of an EHDl program) and audiology assessment and intervention services available in some regions. Saskatchewan began offering UNHS in the spring of 2019. Screening alone does not ensure early identification of permanent hearing

loss or early access to intervention. It is not diagnostic or therapeutic for infant hearing loss. Without audiological assessment and intervention, delays in confirming hearing loss in babies will occur and they will not have access to the breadth and quality of early services needed for optimal outcomes. UNHS programs only offer newborn hearing screening. Consequently, when a baby does not pass the screening, the result indicates the need for further audiological assessment and intervention—nothing more. From the survey results, it is apparent that each of these provinces has access to well-trained pediatric audiologists. There is a need for complete EHDI services to be coordinated, resourced, and implemented within all regional health authorities in Manitoba and Saskatchewan to optimize services for babies and their families. Often with UNHS-only programs, databases that track infants and screening outcomes are available. Existing databases could be expanded if a complete EHDI program were implemented. Ideally, a comprehensive national database could provide appropriate tracking, monitoring, and outcome measurement for all provinces and territories.

Nunavut and Newfoundland and Labrador have essentially remained unchanged in their EHDI program implementation since 2014. It is worth repeating that pediatric audiologists are available within this territory and province. Other provinces and territories in Canada have well-defined systems-of-care and they are willing to share strategies for implementation. What appears to be lacking in Nunavut and Newfoundland and Labrador are the resources for territory- and province-wide EHDI development and implementation. Finally, it is noteworthy that the government of Québec announced their intention to implement a UNHS program in 2009 (CIHTF, 2014). Results of the 2019 report card (10 years later) indicate that Québec is still “in the process of program planning” for a UNHS program and has yet to implement province-wide UNHS or EHDI services for babies and their families.

An important finding in our survey is that many of the EHDI programs in Canada were implemented as early as 2002 and in order to sustain access to services and support for children and their families it is imperative that equipment, protocols, staffing, and training of professionals is sustained through appropriate provincial, territorial, and federal funding mechanisms.

Limitations of Current Work

This work has some limitations that are noteworthy. The lack of coordinated and comprehensive EHDI programs across Canada may have resulted in variations in responses for some items depending on the region. This

was addressed as much as possible by having a variety of questions to gather pertinent information from all regions, regardless of the presence of an EHDI program. Further, the respondents had varying backgrounds and roles within infant hearing health care in the region for which they were responding and there were multiple respondents from some regions. Although we asked follow-up questions to clarify as needed, responses may have differed based on these response characteristics. We did not pilot the survey to ensure clarity of the questions, so this may have been a limitation especially as it relates to important constructs such as the difference between UNHS and EHDI and regional versus provincial/territorial implementation. These concepts are critical in the understanding of comprehensive and coordinated EHDI programs.

Call to Action

The findings from the current survey point to a somewhat more encouraging situation for EHDI programs in Canada compared to the status in 2014. However, it is concerning that seven provinces and territories representing approximately 35% of Canada’s population (Statistics Canada, 2018) still have EHDI programs that are insufficient. As a result of this work, the CIHTF calls for action to improve access to comprehensive infant hearing services across Canada. All stakeholders including parents, physicians, nurses, audiologists, speech-language pathologists, researchers, and government policy makers, whether provincial, territorial, or federal, can participate in the following ways:

1. Within a province or territory that has insufficient EHDI implementation:
 - a. Reach out to provinces and territories who have implemented a sufficient EHDI program to gain an understanding of the resources needed to develop and implement a comprehensive and sustainable program.
 - b. Request access to standardized clinical protocols and guidelines to begin to support the babies who have hearing loss in your region immediately.
2. Within a province or territory that has sufficient EHDI implementation:
 - a. Continue to commit and invest in your EHDI program to ensure it remains coordinated and comprehensive across the province or territory.
 - b. Maintain attention on program quality improvement and sustainability by reviewing data

and implementing appropriate action as needed.

- c. Work collaboratively with other provinces and territories in Canada who have an insufficient EHDI program to support the development and implementation of comprehensive infant hearing services.

All provinces and territories are encouraged to work towards the development of a federally supported national-level database to track outcomes. With these actions in mind, Canada has an opportunity to broaden access to comprehensive EHDI programs across the country.

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Appendix: 2019 Report Card on Canadian Early Hearing Detection and Intervention Programs



2019 Report Card on Canadian Early Hearing Detection and Intervention Programs

CANADA'S GRADE: INSUFFICIENT

This report card was developed by the Canadian Infant Hearing Task Force (CIHTF).

Early Hearing Detection and Intervention (EHDI) programs aim to proactively address infant hearing health and include the following components: **1) universal hearing screening of all newborns; 2) identification of babies with permanent hearing loss; 3) intervention services which include support for technology and communication development; 4) family support; and 5) monitoring and evaluation of the program.**

Grades were assigned based on all five of the components being available province or territory-wide.

PROVINCE/TERRITORY (IN ALPHABETICAL ORDER)	GRADE	DESCRIPTORS
Alberta	SUFFICIENT	<ul style="list-style-type: none"> 89%+ babies screened* All EHDI components province-wide Clinical protocols are implemented and monitored Database tracks infants and outcomes <p>*program recently implemented</p>
British Columbia	SUFFICIENT	<ul style="list-style-type: none"> 97%+ babies screened All EHDI components province-wide Clinical protocols are implemented and monitored Database tracks infants and outcomes
Manitoba	INSUFFICIENT	<ul style="list-style-type: none"> 92%+ babies screened Some EHDI components but not province-wide Clinical protocols exist for some components but implementation is not monitored Database tracks screening component only
New Brunswick	INSUFFICIENT	<ul style="list-style-type: none"> 98%+ babies screened Some EHDI components but not province-wide Family support and monitoring are not formalized or centrally coordinated Clinical protocols from 2002 are being used and not monitored Regional databases mostly track screening numbers but not outcomes
Newfoundland and Labrador	INSUFFICIENT	<ul style="list-style-type: none"> Screening coverage unknown Some EHDI components but not province-wide Clinical protocols exist but implementation is not monitored No database to track infants or outcomes
Northwest Territories	SUFFICIENT	<ul style="list-style-type: none"> 99%+ babies screened All EHDI components territory-wide Clinical protocols are implemented and monitored Database tracks infants and outcomes

PROVINCE/TERRITORY (RANKED IN ALPHABETICAL ORDER)	GRADE	DESCRIPTORS
Nova Scotia	SUFFICIENT	<ul style="list-style-type: none"> • 96%+ babies screened • All EHDI components province-wide • Clinical protocols are implemented and monitored • Database tracks infants and outcomes
Nunavut	INSUFFICIENT	<ul style="list-style-type: none"> • Screening coverage unknown • Some EHDI components but not territory-wide • Clinical protocols are not implemented • No database to track infants or outcomes
Ontario	SUFFICIENT	<ul style="list-style-type: none"> • 94%+ babies screened • All EHDI components province-wide • Clinical protocols are implemented and monitored • Database tracks infants and outcomes
Prince Edward Island	INSUFFICIENT	<ul style="list-style-type: none"> • 97%+ babies screened • All EHDI components province-wide • Clinical protocols exist but implementation is not monitored • No database to track infants or outcomes
Quebec	INSUFFICIENT	<ul style="list-style-type: none"> • 30%+ babies screened (in the process of universal newborn hearing screening program planning) • Some EHDI components but not province-wide • Clinical protocols exist for some components but implementation is monitored for screening only • Regional databases exist to track infants up to 6 months of age
Saskatchewan	INSUFFICIENT	<ul style="list-style-type: none"> • Screening coverage unknown (universal newborn hearing screening is targeted for spring 2019) • Some EHDI components but not province-wide • Clinical protocols are not implemented • No database to track infants or outcomes
Yukon	SUFFICIENT	<ul style="list-style-type: none"> • 99%+ babies screened • All EHDI components available with support from southern provinces (e.g., BC) • Clinical protocols are implemented and monitored • Database tracks infants and outcomes

CIHTF is a national group of leaders in hearing health who promote and advocate for comprehensive EHDI programs across Canada. The Task Force is a collaboration of Speech-Language & Audiology Canada (SAC) and the Canadian Academy of Audiology (CAA): www.infanthearingcanada.ca

All children in Canada deserve access to proper hearing screening, timely diagnosis and appropriate intervention to reach their full potential. Continued action from Canada's provincial and territorial governments, in addition to policy leadership at the federal level, is needed to achieve sufficient and sustainable EHDI programs across the country.

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