

Early Hearing Detection & Intervention Program  
Annual Performance Report

# EHDI Program

## Annual Report

(April 1, 2019 to March 31, 2020)

December 2020

## Early Hearing Detection & Intervention Program Annual Performance Report

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This report has been prepared by Screening Programs.

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## Executive Summary

The Early Hearing Detection & Intervention (EHDI) Program is a provincial, population-based screening program that identifies permanent congenital hearing loss (PCHL) early on in an infant's life. This ensures that follow-up and support can be provided sooner to infants and their families.

After a four-year government-funded project to develop and implement this program in Alberta, the EHDI Program became an operational Alberta Health Services (AHS) program in October 2018. (See Appendix 1 for a list of screening and diagnostic sites.) Program activities are coordinated by a dedicated team within AHS Screening Programs.

The measures described in this report reflect the EHDI Program's performance during the 2019-2020 reporting year (April 1, 2019 to March 31, 2020):

- Hearing screening was completed for 79.0% of infants born in Alberta
- 94.0% of those screened infants had their screening completed by 30 days of age
- 73.6% of infants who did not pass their hearing screening received a diagnostic assessment
- 66 infants born during the reporting year were confirmed to have PCHL

The COVID-19 pandemic had a minor impact on program performance due to its late onset in the reporting year. A slight drop in screening participation was seen due to the enacted public health measures.

The ability to report on these measures, described further in this report, demonstrate the program's ability to overcome data limitations presented by the current method of data collection. Being limited to what is reported to the program by hearing screeners and audiologists, and the timeliness and completeness of data submissions, impacts the accuracy and depth of our analysis.

The EHDI Program is proud of its accomplishments, especially in such early days of a brand new program; and is working to improve performance for the next reporting year.

## About this report

This report covers the period April 1, 2019 to March 31, 2020.

The purpose is to report on performance measures identified by Alberta Health in the EHDl Policy Document (2016) and key performance indicators identified by the EHDl Program.

Data was retrieved from the EHDl Database on October 30, 2020.

A **glossary of terms** and complete list of **key performance indicators** are included in this report as Appendices 2 and 3, respectively.

NOTE: In cases where an AHS Zone cannot be identified due to poor data collection or geographical ambiguity, the data is reported as “unknown”.

### *Limitations of reporting*

The EHDl Program’s current data collection system involves completion of Screening Reports and Diagnostic Summary Reports that are submitted to the program and manually entered into the EHDl Database. Working within the limitations of this type of system (accuracy, completeness and legibility of information provided on forms, and timeliness of their receipt and entry) the EHDl Program can report only on certain performance measures. The ability to drill down to site level data or identify infants who are lost to follow-up is not possible due to our paper-based reporting system, and therefore cannot be reported on at this time.

The development of Connect Care, an AHS electronic clinical information system that will be implemented province-wide, will help alleviate the current issues with data collection and accuracy and will improve the effectiveness of program reporting. The EHDl Program team is working with planners and architects to ensure our ability to identify and track infants who are lost to follow-up for screening or diagnostic assessment, to ensure the program’s ability to report on key performance indicators, and to identify and address potential gaps in screening data.

## Alberta's EHDI Program

Alberta's Early Hearing Detection and Intervention (EHDI) Program is a provincial, population-based screening program provided by Alberta Health Services (AHS). The program identifies permanent congenital hearing loss (PCHL) as early as possible in an infant's life, ensuring families receive timely access to follow-up and support.

PCHL is one of the most common congenital conditions found in newborns. Without screening, there are no obvious signs early on to tell if an infant has hearing loss. In these cases, the average age of diagnosis is between 2½ and 3 years, and mild to moderate losses will often go undiagnosed until school age. When found early, infants and their families are able to access follow-up and support sooner, to prevent developmental delays.

The EHDI Program was fully implemented in October 2018. Through a collaborative partnership across all five AHS Zones, newborn hearing screening is available, free of charge, at many hospitals and community-based screening sites throughout Alberta. Diagnostic services to confirm or rule out PCHL, and intervention services to support infants and families identified with PCHL, are also accessible province-wide.

### The EHDI Program pathway

Organized population screening activities are coordinated along a pathway that identifies the critical steps from recruitment and screening, through to diagnosis and treatment. The EHDI Program pathway is shown below.



### *EHDI Program performance measures*

Alberta's EHDI Program adheres to the international standard of 1-3-6: screen hearing by 1 month of age; diagnose permanent hearing loss by 3 months of age; and, ensure access to intervention by 6 months of age.

The performance measures reported here are in alignment with this international standard and reflect, in part, the standards set by Alberta Health and, in part, the standards and key performance indicators set by the EHDI Program.

Certain performance measures and indicators cannot be reported at this time as the EHDI Program does not have access to certain sets of data, in particular, data related to intervention services and lost to follow-up. The current manual entry system does not allow for accurate or timely identification and tracking of infants who require follow-up. At this time, follow-up (for screening, diagnostics and intervention) is coordinated at site and zone levels until an electronic data management system is in place. As standardization of intervention services and implementation of Connect Care proceed across the province, data availability and quality will improve and will allow the EHDI Program to expand the scope of performance reporting to include all elements of the program pathway.

## Newborn Hearing Screening

Screening is one component of an effective EHDI Program. All infants born in Alberta, or to parents who are Alberta residents, are eligible for hearing screening up to 90 days of age. The goal of Alberta's EHDI Program is to screen infants by one month of age.

Screening is offered in all 14 neonatal intensive care units (NICUs) and in 17 postpartum units in Alberta. As well, there are 33 community-based hearing screening sites available to facilitate screening of infants who are missed in hospital, or born in hospitals where screening is not offered, or born outside of hospitals. Referrals to community-based hearing screening sites is coordinated by AHS Zones across the province based on operational requirements.

During the reporting period, 81.4% (n = 44,832) of eligible infants in Alberta were offered hearing screening. The screening test was completed and a result provided to 96.5% (n = 43,269) of the offers.

74.0% of the screens occurred in postpartum units and 9.4% of screens occurred in NICUs prior to infant discharge. 16.5% of infants were screened in community sites.

The following four measures describe screening participation, performance with respect to meeting the 1-month standard, and the breakdown of screening results including analysis of refer rate as a key performance indicator.

The EHDI Program collects screening data to track trends in participation that will identify areas where work to improve screening rates needs to occur. As part of ongoing operations, the EHDI Program provides this data to, and works closely with, AHS Zones to help them identify ways to improve their screening rates.



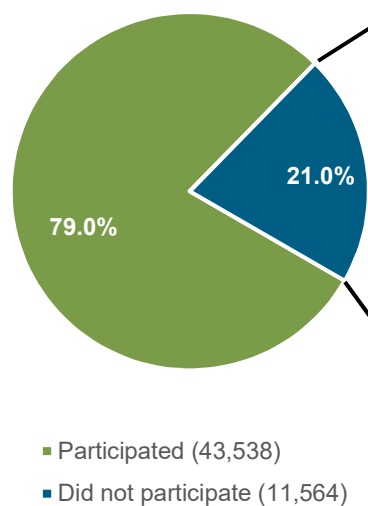
### Screening participation rate

The screening participation rate is defined as the percentage of the eligible infants who have completed hearing screening. This measure provides an indication of overall screening coverage and effectiveness of recruitment.

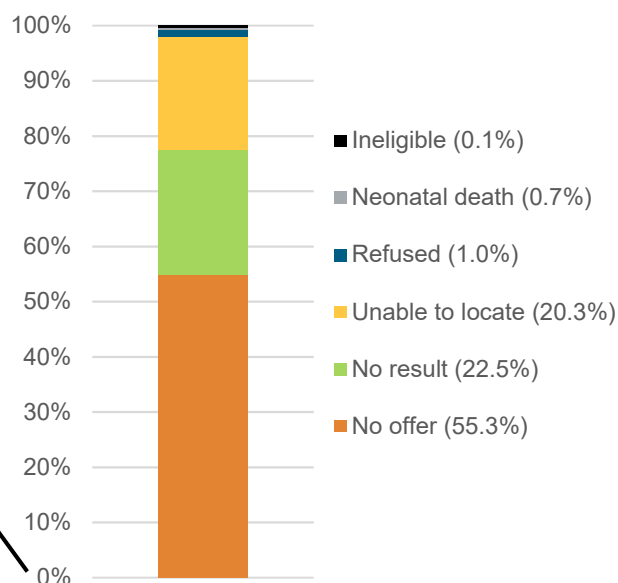
Figure 1 shows that of the 55,098 infants born in Alberta between April 1, 2019 and March 31, 2020, 79.0% have completed hearing screening and received a result. Infants that did not participate in the program (i.e., did not receive a hearing screening result) were due to one of the following reasons and are shown in Figure 2:

- No offer – infants for whom no screening report was received (n=6,400)
- No result – infants for whom no screening result was obtained; includes RNO and MISSED (n=2,601)
- Unable to locate – infants whose families relocated out of the province prior to completion of hearing screening or who are not eligible for health care coverage in Alberta (n=2,350)
- Refused – infants whose parents did not consent to hearing screening for their baby (n=113)
- Neonatal death – infants who died prior to completion of hearing screening (n=86)
- Ineligible – infants with bilateral aural atresia or meningitis (n=14)

**Figure 1. Screening Participation**



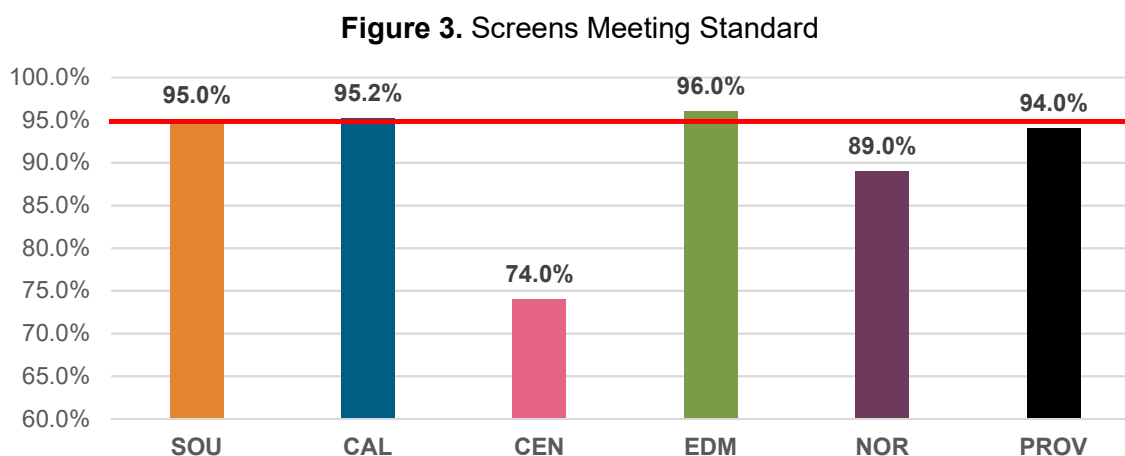
**Figure 2. Breakdown of Non-Participants**



### Completed screens meeting 1-month standard

This measure is a subset of the screening participation rate that provides an indication of how well the EHDI Program is meeting its goal of screening infants within one month<sup>1</sup>. That is, the number of screens completed within one month of birth out of the total number of screens completed for eligible infants (participants). Figure 3 shows the rates for meeting the 1-month standard across the AHS Zones and in comparison to the provincial rate. The target for this key performance indicator is > 95% and is indicated by the red line in Figure 3.

The range for AHS Zones meeting the 1-month screening standard during this reporting period was 74.0% to 96.0%. The provincial rate for meeting this standard was 94.0%, which is below the target set for this measure. The zone where screening was performed could not be identified for 1.9% of infants screened. These are shown in the “unknown” column in Table 1.



**Table 1.** Breakdown of screens meeting and not meeting standard, by zone.

	SOUTH	CALGARY	CENTRAL	EDMONTON	NORTH	UNKNOWN	PROVINCIAL
Meeting standard (n)	2,922	15,848	1,488	16,615	3,268	770	40,911
Not meeting standard (n)	155	805	522	693	404	48	2,627
<b>Total infants screened</b>	<b>3,077</b>	<b>16,653</b>	<b>2,010</b>	<b>17,308</b>	<b>3,672</b>	<b>818</b>	<b>43,538</b>

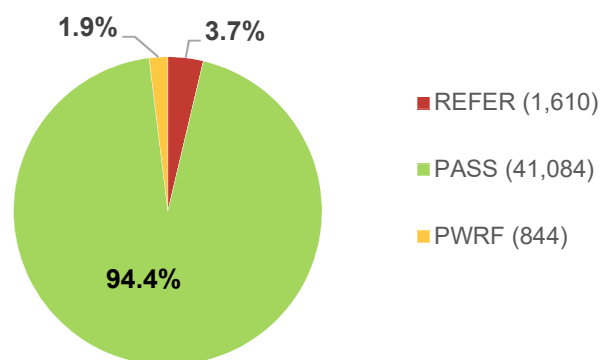
<sup>1</sup> For data extraction and calculation purposes, one month is defined as 30 days after date of birth.

### Breakdown of submitted screening reports and results

46,254 screening reports were received by the EHDI Program for infants born between April 1, 2019 and March 31, 2020. Of these, 43,538 (94.1%) had a final result. The breakdown of the provincial screening results is shown in Figure 4.

94.4% (41,084) of infants with a final screening result passed their screening test and required no further follow-up (PASS), while 1.9% (844) passed their screening test, but had risk factors that required follow-up to monitor for late onset hearing loss (PWRF).

Figure 4. Breakdown of Provincial Results



3.7% of infants received a REFER result. This means that 1,610 infants that had a final result did not pass their hearing screening test and were referred for diagnostic assessment.

5.9% of the total reports received did not have a final result or final recommendation and were therefore deemed incomplete.

A detailed breakdown of the screening reports by AHS Zone, and compared to the provincial rates, is shown in Table 2. The zone where screening was done could not be identified in 3.3% of screening reports. These are indicated in the table below as “unknown”.

Table 2. Breakdown of submitted screening reports by zone and compared to provincial rates.

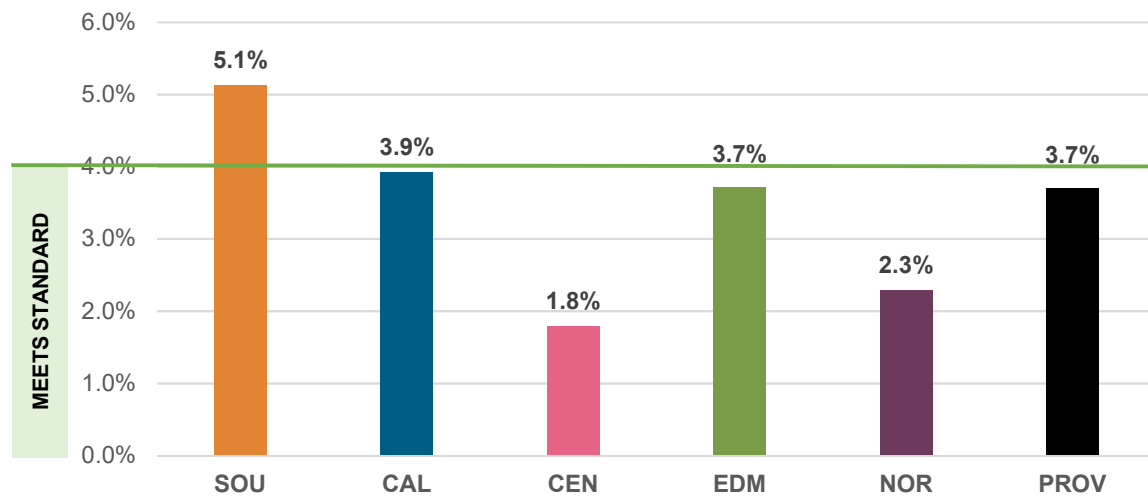
	REFER		PASS		PWRF		INCOMPLETE		TOTAL
<b>PROVINCIAL</b>	3.5%	1,610	88.8%	41,084	1.8%	844	5.9%	2,716	46,254
<b>SOUTH</b>	4.9%	158	88.4%	2,869	1.5%	50	5.2%	169	3,246
<b>CALGARY</b>	3.8%	654	91.5%	15,714	1.7%	285	3.0%	521	17,174
<b>CENTRAL</b>	1.5%	36	78.1%	1,927	1.9%	47	18.5%	457	2,467
<b>EDMONTON</b>	3.6%	644	91.6%	16,271	2.2%	393	2.6%	464	17,772
<b>NORTH</b>	2.1%	84	87.2%	3,532	1.4%	56	9.3%	378	4,050
<b>UNKNOWN</b>	2.2%	34	49.9%	771	0.8%	13	47.1%	727	1,545

## Refer rate

The refer rate is a key performance indicator (KPI) for the EHDI Program. It shows the percentage of eligible infants who were screened and then referred for a diagnostic audiological assessment. It provides an indication of the overall impact on downstream services. It may also help inform the performance of screeners and screening equipment. The target for this KPI is < 4%.

Figure 5 shows the refer rates across the AHS Zones and in comparison to the provincial rate. Unlike other performance measures, the EHDI Program strives not to exceed the target of 4%, which is indicated by the green line.

**Figure 5. Provincial and Zone Refer Rates**



The provincial refer rate during the reporting period was 3.7%, which meets the target. Refer rates across the province by AHS Zone varied from 1.8% to 5.1%.

## Diagnostic Assessment

Infants who do not pass their hearing screening require diagnostic assessment to confirm or rule out PCHL. The main test used for diagnostic assessment is the Auditory Brainstem Response (ABR).

There are nine sites in Alberta that perform pediatric ABRs for infants who have been referred from hearing screening. The average time from screening date to first diagnostic assessment date is 54 days.

During the reporting period, 2,945 diagnostic assessments were performed: 44.8% were performed in Edmonton Zone; 35.7% in Calgary Zone; 10.9% in South Zone; 7.5% in North Zone; and 1.1% in Central Zone.

Of the 1,610 infants who did not pass their hearing screening (i.e., had a REFER result), 61<sup>2</sup> were confirmed to have PCHL. This leads to the positive predictive value (PPV) of the screening test to be 3.8%.

66 infants who were born during the reporting year were confirmed to have PCHL. This leads to the incidence of PCHL in the birth cohort of 55,098 to be 0.12% or 1.20 per 1,000. It is worth noting that based on diagnostic results recorded as part of the ABR peer review process, an under-reporting of PCHL diagnoses to the EHDI Program was observed during the reporting year. Quality improvement measures were implemented to address this with the goal of more accurate PCHL identification and incidence reporting next year.

The following three measures describe diagnostic follow-up completion rate, performance with respect to meeting the 3-month standard and the incidence, or rate of occurrence, of PCHL in Alberta's birth population.

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<sup>2</sup> These 61 infants were screened during the reporting year, not necessarily born during the reporting year.

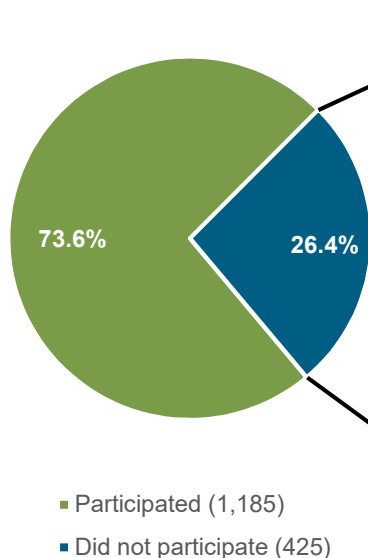
### Diagnostic follow-up completion rate

The diagnostic follow-up completion rate is defined as the percentage of infants who did not pass hearing screening (i.e., had a REFER result) and have received a final diagnostic result. This measure provides an indication of the effectiveness of the EHDI Program at providing diagnostic assessment after screening.

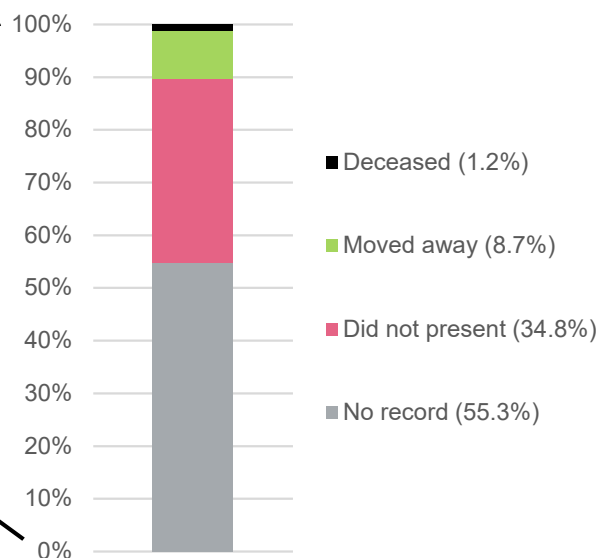
Figure 6 shows that of the 1,610 infants who received a REFER result from screening during the reporting period, 73.6% attended a diagnostic assessment and received a final diagnostic result. For the 425 infants (26.4%) who did not receive a final diagnostic result the rationale is provided below and shown in Figure 7.

- No record – infants for whom no Diagnostic Summary Report was received (n=235)
- Did not present – infants who did not attend their diagnostic appointment (n=148)
- Moved away – infants whose families relocated out of province before diagnostic assessment was completed (n=37)
- Deceased – infants who died prior to completion of diagnostic assessment (n=5)

**Figure 6.** Diagnostic Follow-up Completions



**Figure 7.** Breakdown of Incomplete Diagnostic Follow-up

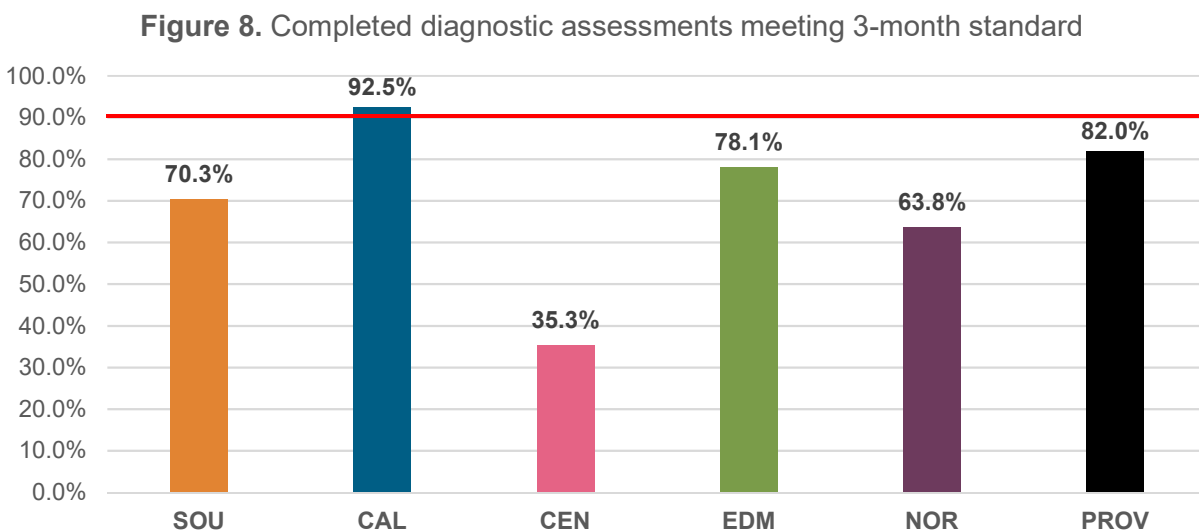


### Diagnostic assessments meeting 3-month standard

Having infants who 'REFER' on hearing screening and attend a diagnostic assessment by three months of age<sup>3</sup> is a goal of the EHDI Program. The target for this measure, as a key performance indicator, is to have > 90% of referred infants receive a diagnostic assessment by three months (90 days) of age.

During the reporting period, 1,486 diagnostic assessments were completed across nine diagnostic sites in Alberta. Provincially, 1,219 (82.0%) of them were completed within three months of age.

Figure 8 shows the rates for completed diagnostic assessments meeting the 3-month standard for each AHS Zone during the reporting period. The red line indicates the target of 90% for this measure.



<sup>3</sup> For data extraction and calculation purposes, three months is defined as 90 days after date of birth.

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The total number of diagnostic assessments performed in each AHS Zone and their breakdown for this measure (i.e., meeting or not meeting the 3-month standard) are detailed in Table 3. The data was calculated from the Diagnostic Summary Reports received by the program and entered into the EHDI Database.

**Table 3.** Breakdown of diagnostic assessments meeting and not meeting standard, by zone.

	SOUTH	CALGARY	CENTRAL	EDMONTON	NORTH	PROVINCIAL
Meeting standard (%)	70.3%	92.5%	35.3%	78.1%	63.8%	82.0%
Meeting standard (n)	121	567	6	474	51	1,219
Not meeting standard (n)	51	46	11	133	29	267
<b>Total diagnostic assessments</b>	<b>172</b>	<b>613</b>	<b>17</b>	<b>607</b>	<b>80</b>	<b>1,486</b>

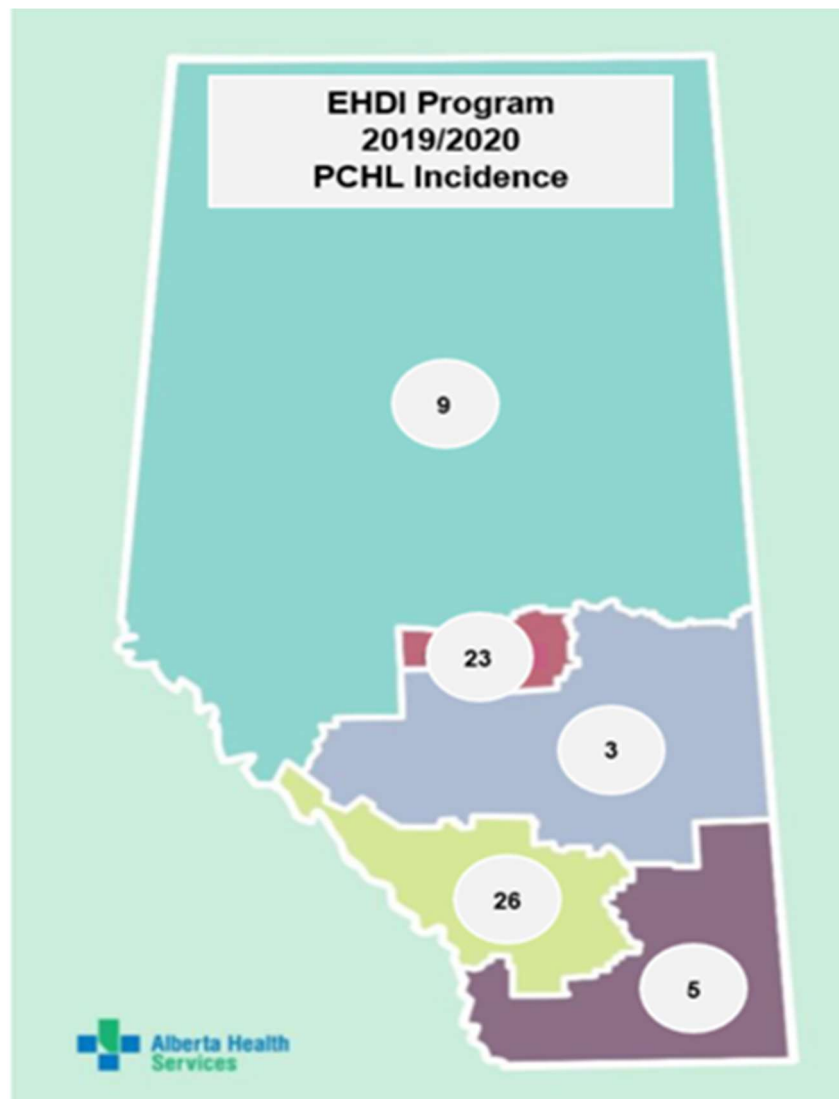


### *PCHL incidence*

Of the 55,098 infants born during the reporting period, 66<sup>4</sup> infants were reported to the EHDI Program as confirmed to have PCHL.

Based on these reported numbers, the incidence of PCHL is 0.12% or 1.20 per 1,000 infants born in Alberta during the reporting year.

**Figure 9.** Distribution of infants identified with PCHL, by zone of residence



<sup>4</sup> 67 infants were reported to the EHDI Program with confirmed PCHL, but one infant was from NWT therefore was excluded from incidence calculations.

## Intervention

The ability to provide intervention services to infants who are identified with PCHL is a critical part of the EHDI Program pathway. The screening and diagnostic steps identify the target population for intervention. The delivery of intervention services in an evidence-informed and standardized manner ensures optimal outcomes for children with permanent hearing loss in Alberta.

With the establishment of standardized screening and diagnostic services in Alberta, the EHDI Program has shifted its program development focus to identifying and standardizing core intervention services for infants newly diagnosed with PCHL and their families. This is a complex, large-scale initiative involving the collaboration of many partners and stakeholders within and external to AHS. Current projects underway in AHS related to the intervention portion of the EHDI pathway include:

- Development of a standardized resource for healthcare providers to guide their conversations with families of infants diagnosed with PCHL
- Development of standardized resources for families to support and guide them in the interventions available
- Provincial standardization of a pediatric amplification protocol for children birth through 6;0 years
- Provincial standardization of communication intervention for children with hearing loss

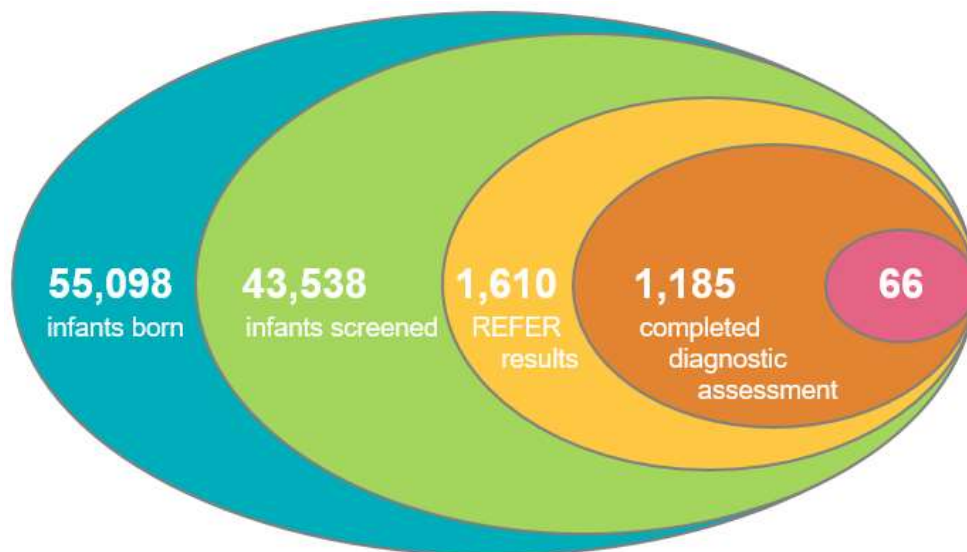
This important work will be ongoing for a number of years. The implementation of standardized intervention services will be phased-in across the province as is feasible to enable consistent, high quality, equitable care for children with PCHL and their families.

The EHDI Program's ability to track uptake of intervention services and intervention outcomes is not possible in the current data system. The EHDI Program is working to build the capture and reporting of intervention measures within Connect Care.

## Conclusion

Alberta's EHDI Program is a provincial population-based screening program that aims to identify PCHL as early as possible to help improve outcomes for children with this target condition.

During the 2019-2020 reporting year, 79.0% of infants born in Alberta were reported to the program as having completed hearing screening. Of those, 1,610 infants did not pass screening and were referred for diagnostic assessment. 1,185 infants completed their diagnostic assessment and of those, 66 infants were reported to the program as confirmed to have PCHL.



COVID-19 pandemic public health measures came into effect in March 2020, therefore the impact of the pandemic on EHDI Program performance during the reporting period was relatively small. The COVID-19 impact on hearing screening included service suspensions, deferrals due to staff isolation protocols, and a tripling of parent refusals (from 15 to 46) leading to a 5.4% decrease in screening participation in Q4.

The EHDI Program is looking to leverage the functionality of Connect Care to address its data limitations and reporting needs, including the data and reporting gaps identified in this report. As operations continue and more data is collected, reporting will improve and opportunities for quality improvement will be identified. This will enable targeted mitigation for improved overall program quality and success over time.

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## Appendix 1: EHDl Screening & Diagnostic Sites, by Zone

Zone	Live Sites	Environment			Diagnostic ABR Sites
		NICU (inpatient service)	Postpartum (inpatient service)	Community (outpatient by appointment)	
North	Barrhead Community Health Centre			X	
	Bonnyville Health Centre (Covenant Health)			X	
	Cold Lake Community Health Services			X	
	Edson Healthcare Centre			X	
	Grande Prairie Virene Building			X	X
	Hinton Healthcare Centre			X	
	Lac la Biche Community Health Services			X	
	Northern Lights Regional Health Centre (Fort McMurray)		X	X	X
	Northwest Healthcare Centre (High Level)		X	X	
	Peace River Community Health Centre			X	
	Whitecourt Healthcare Centre			X	
	Queen Elizabeth II Hospital (Grande Prairie)	X	X		
St. Therese - St. Paul Community Healthcare Centre			X		
Edmonton	Fort Saskatchewan Community Hospital			X	
	Glenrose Rehabilitation Hospital			X	X
	Grey Nuns Community Hospital (Covenant Health)	X	X		
	Misericordia Community Hospital (Covenant Health)	X	X		
	Royal Alexandra Hospital	X	X		
	St. Marguerite Health Services Centre (Grey Nuns/Covenant Health)			X	
	Stollery Children's Hospital	X			X
	Sturgeon Community Hospital	X	X		
Central	Camrose - Professional Centre			X	
	Drumheller Health Centre			X	
	Maskwacis Health Services			X	
	Olds Campus Community Health Centre			X	
	Provost Provincial Building			X	
	Red Deer Regional Hospital Centre	X	X		
	Red Deer 49th Street Community Health Centre			X	X
	Rocky Mountain House Health Centre			X	
	Stettler Community Health Centre			X	
	Vegreville Community Health Centre			X	
	Vermillion Community Health Centre			X	
	Wainwright Provincial Building			X	
Wetaskiwin Community Health Centre			X		
Calgary	Alberta Children's Hospital	X			
	Canmore General Hospital		X	X	
	Foothills Medical Centre	X	X		
	High River General Hospital		X	X	
	Peter Lougheed Centre	X	X		
	Richmond Road Diagnostic and Treatment Centre			X	X
	Rockyview General Hospital	X	X		
	South Health Campus	X	X		
South	Brooks Health Centre		X	X	
	Chinook Regional Hospital (Lethbridge)	X	X		
	Medicine Hat Regional Hospital	X	X	X	X
	Melcor Centre (Lethbridge)			X	X
<b>TOTALS:</b>		<b>14</b>	<b>17</b>	<b>33</b>	<b>8</b>

## Appendix 2: Glossary of terms

**Deceased** – infants who died prior to completion of diagnostic assessment

**Did not present** – infants who did not attend their diagnostic appointment

**Incidence** – the number of new cases identified in a population at risk in a given time period

**Incomplete** – for the purpose of this report, indicates that a screening report was received, but a final result was not obtained due to RNO, MISSED or the final recommendation was not indicated

**Ineligible** – infants with bilateral aural atresia or meningitis

**Missed** – infants for whom screening was not offered or attempted

**Moved away** – infants whose families relocated out of province before diagnostic assessment was completed

**Neonatal death** – infants who died prior to completion of hearing screening

**No offer** – for the purpose of this report, indicates that a screening report was not received for that infant

**No record** – infants for whom no Diagnostic Summary Report was received

**No result** – for the purpose of this report, indicates that a screening report was received, but either MISSED or RNO was indicated on the form, so a final result was not obtained

**PASS** – a screening result indicating that the infant was hearing well on the day of the screening test and likely does not have PCHL

**Pass with risk factors (PWRF)** – a screening result indicating that the infant was hearing well on the day of the screening test and does not have PCHL, however the infant does have factors that put it at risk for developing late onset hearing loss and therefore should be assessed by an audiologist at a later date

**Permanent Congenital Hearing Loss (PCHL)** – hearing loss in one or both ears that is confirmed to be permanent (not temporary or transient) and congenital (present at birth); this is the target condition for the EHDI Program

**Positive Predictive Value (PPV)** – the probability that individuals with a positive screening test truly have the condition; demonstrated as the percentage of infants who do not pass the screening test (i.e., have a REFER result) who are then confirmed to have PCHL

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**Prevalence** – the measure of the proportion of persons with a condition in a population at a given point in time

**REFER** – a screening result indicating that the infant did not pass the screening test and must be referred for audiological assessment to confirm or rule out permanent hearing loss

**Refused** – infants whose parents did not consent to hearing screening for their baby

**Results not obtained (RNO)** – infants for whom screening is attempted and conclusive results are not obtained

**Unable to locate** – infants whose families relocated out of the province prior to completion of hearing screening or who are not eligible for health care coverage in Alberta

**Unknown zone** – the AHS Zone that the data pertains to is not indicated or on the screening report or could not be determined from the information provided, often due to missing or illegible documentation

## Appendix 3: EHDI Program Key Performance Indicators

- Percentage of parents and guardians who refuse hearing screening
- Percentage of eligible infants who complete hearing screening by one month of age (target >95%)
- Percentage of eligible infants who are screened and “REFER” for diagnostic audiological assessment (target <4%)
- Percentage of infants lost to follow-up (hearing screening)
- Percentage of infants who receive diagnostic assessment by three months of age (target >90%)
- Number of calendar days between referral and diagnostic ABR assessment
- Percentage of infants with confirmed PCHL by three months of age
- Percentage of infants lost to follow-up (diagnostic assessment)
- Percentage infants with screen detected PCHL receive intervention within six months of age (target >90%)



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