



Audiology Outcomes and Follow-up Trends in Universal Newborn Congenital Cytomegalovirus Screening in Minnesota

Presenters: Amanda Pavan & Sara Lammert | Senior Epidemiologists

Authors: Lexie Barber, Kirsten Coverstone, Darcia Dierking, Sara Lammert, Gina Liverseed, Amanda Pavan, Annikka Strong, Melanie Wege

Learning Objectives

01

Summarize the statewide approach to universal CMV screening and the recommended audiology monitoring for infants/children with cCMV

02

Review hearing outcomes, follow-up timeliness, and the impact of targeted versus universal screening on the detection of infants with cCMV

03

Describe longitudinal follow-up of cCMV-positive infants diagnosed with a hearing loss, including intervention, and strategies to support long-term follow-up for children with cCMV

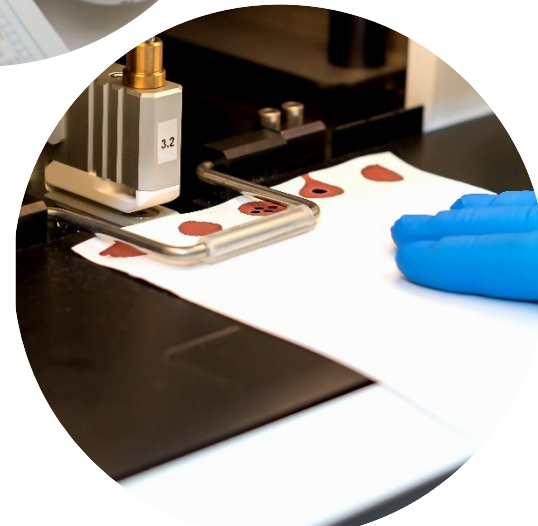
What is cytomegalovirus (CMV)?

- Cytomegalovirus (CMV) is a member of the herpes virus family
- Congenital CMV (cCMV) occurs when CMV is passed from a pregnant woman to the fetus
- cCMV presents in various ways:
 - Most infants are asymptomatic at birth and unlikely to develop long-term sequelae
 - Up to 20% may have permanent hearing loss, either at birth or later in childhood



Universal cCMV Screening in Minnesota



- Universal screening began February 6, 2023
- Screen for CMV through newborn dried blood spot
- If CMV detected, confirmatory testing recommended within first 21 days of life
 - Urine PCR recommended
- If PCR positive, recommend several follow up tests/examinations




Minnesota's Audiology Monitoring Guidelines (Dec. 2022)

- **Initial Diagnostic Audiology Assessment**
 - By 1 month of age or within 1 month of cCMV confirmed PCR test
- **Second Diagnostic Audiology Assessment**
 - By 4-5 months of age
- **Monitoring Audiology Visits up to age 2 years**
 - Every 3 months
- **Monitoring Audiology Visits age 2-6 years**
 - Every 6 months
- **Monitoring Audiology Visits age 6-10 years**
 - Every 12 months

NOTE: Decisions on timing and type of evaluations may need to be adjusted based on clinical judgement or to accommodate needs of individual families. These decisions should be made jointly between family and child's care teams.




Audiology Guidelines For Infants With
Congenital Cytomegalovirus



DEPARTMENT
OF HEALTH

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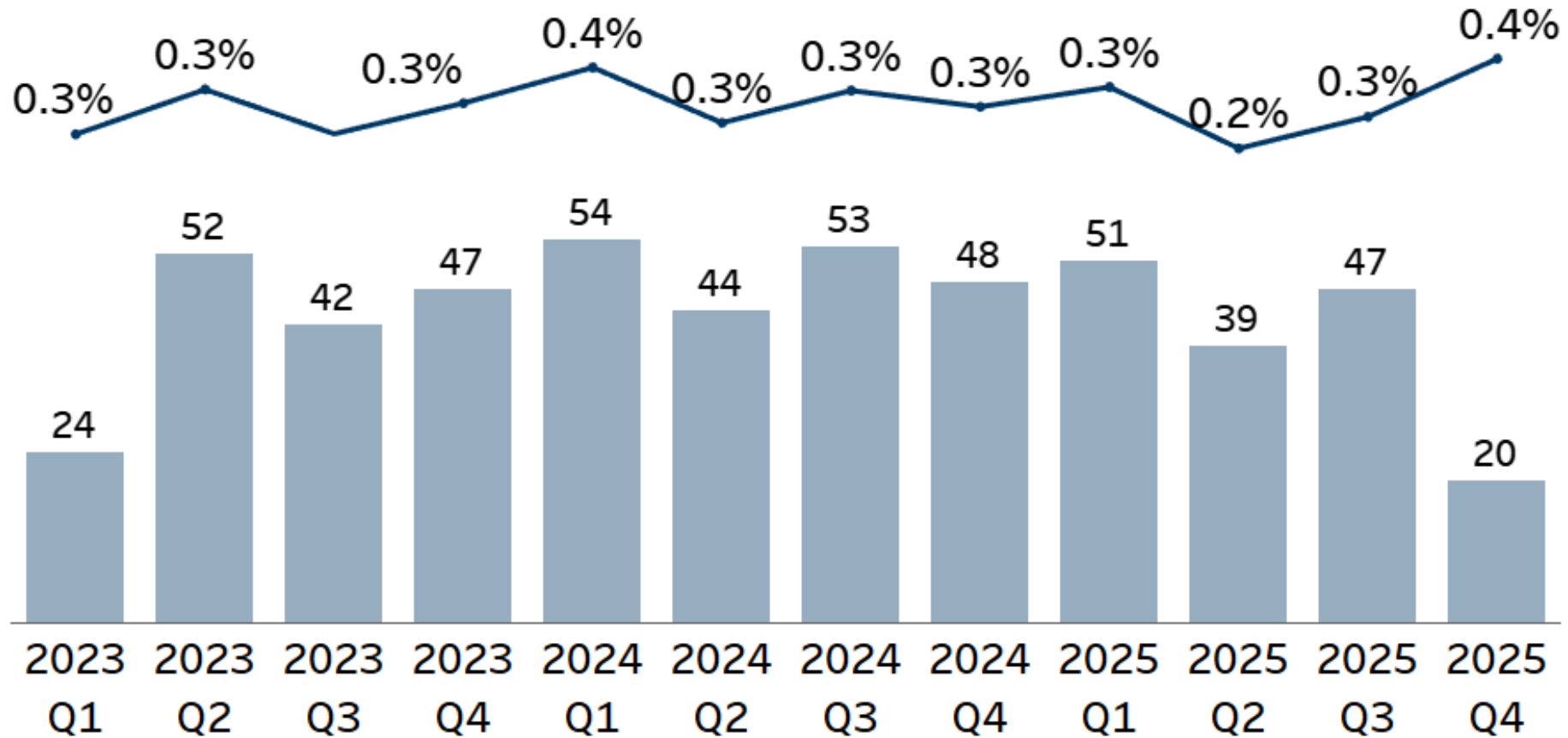


<https://www.health.state.mn.us/docs/people/childreneyouth/improveehdi/audiogdlnccmv.pdf>

Newborn Screening Results

infants born 2/6/23 – 10/31/25

166,556 infants screened
521 cases identified (0.3% of births)



Prevalence of cCMV in Minnesota

infants born 2/6/23 – 10/31/25

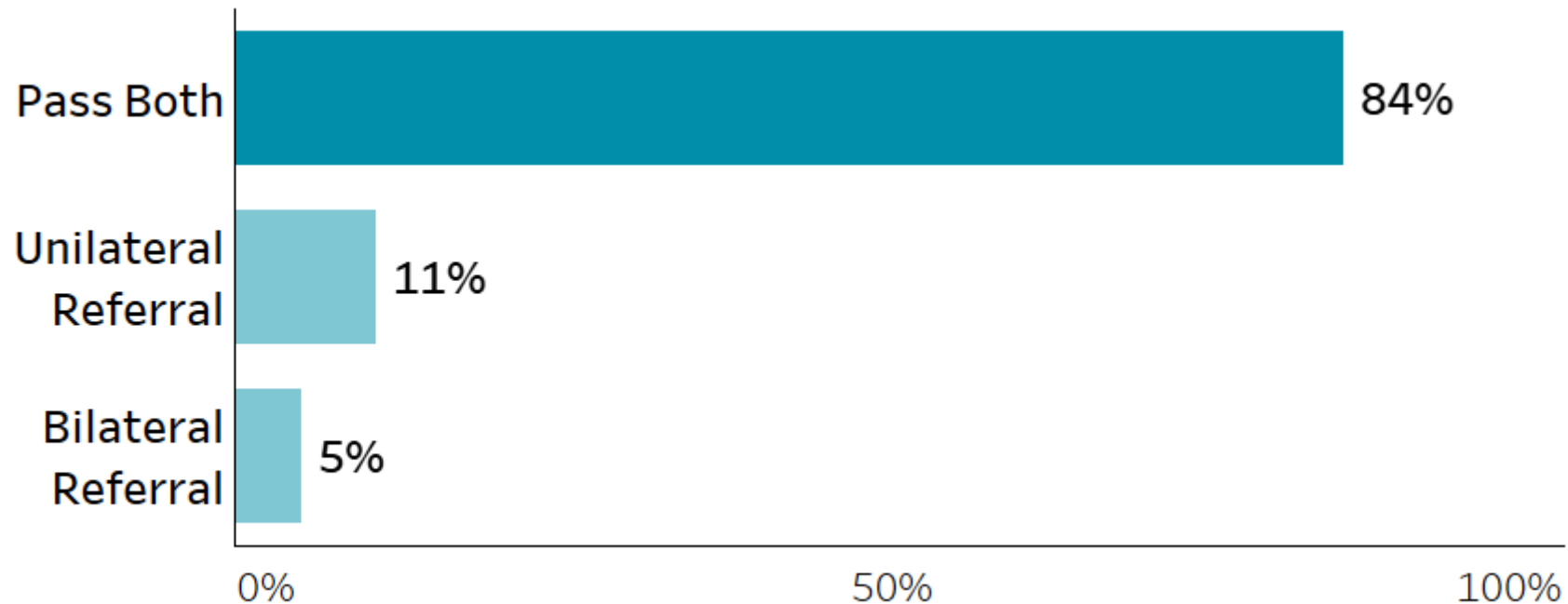
- **0.3% of births (3 per 1,000 or 1:320)**

- Lower than the estimated 0.64% average (1:200) prevalence reported in the literature
 - (*Kenneson & Cannon, 2007*)
- Lower than the 0.45% (1:220) in a population-based screening study in Minnesota
 - (*Dollard et al., 2021*)
- Higher than the 0.13% (1:800) reported by Ontario, Canada's newborn screening program
 - (*Dunn et al., 2025*)
- Higher than the 0.13% (1:754) reported in a population-based study in New York; isolated sensorineural hearing loss in cCMV was 4% (11/276)
 - (*Tavakoli, 2026*)

Newborn Hearing Screen Results

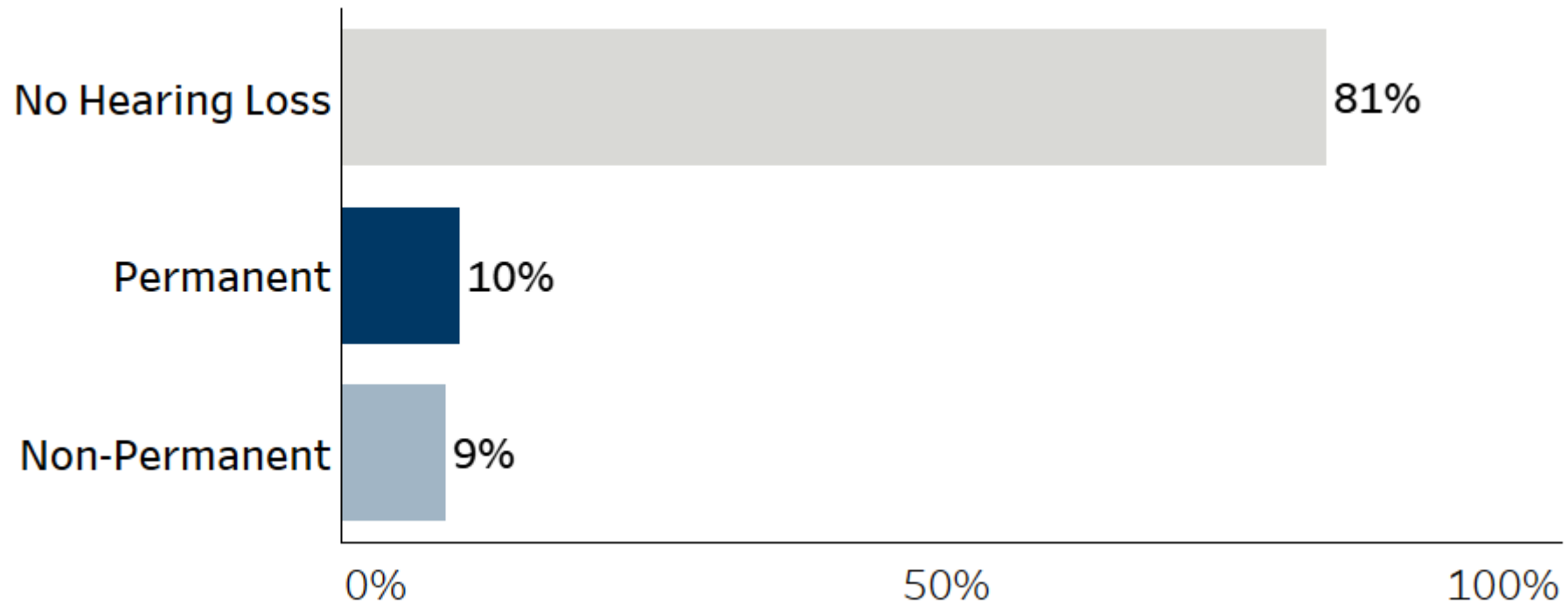
16% of infants had a refer result on their newborn hearing screen

(includes cCMV cases with a newborn hearing screen result, n=506)



Diagnostic Audiology Assessment Results

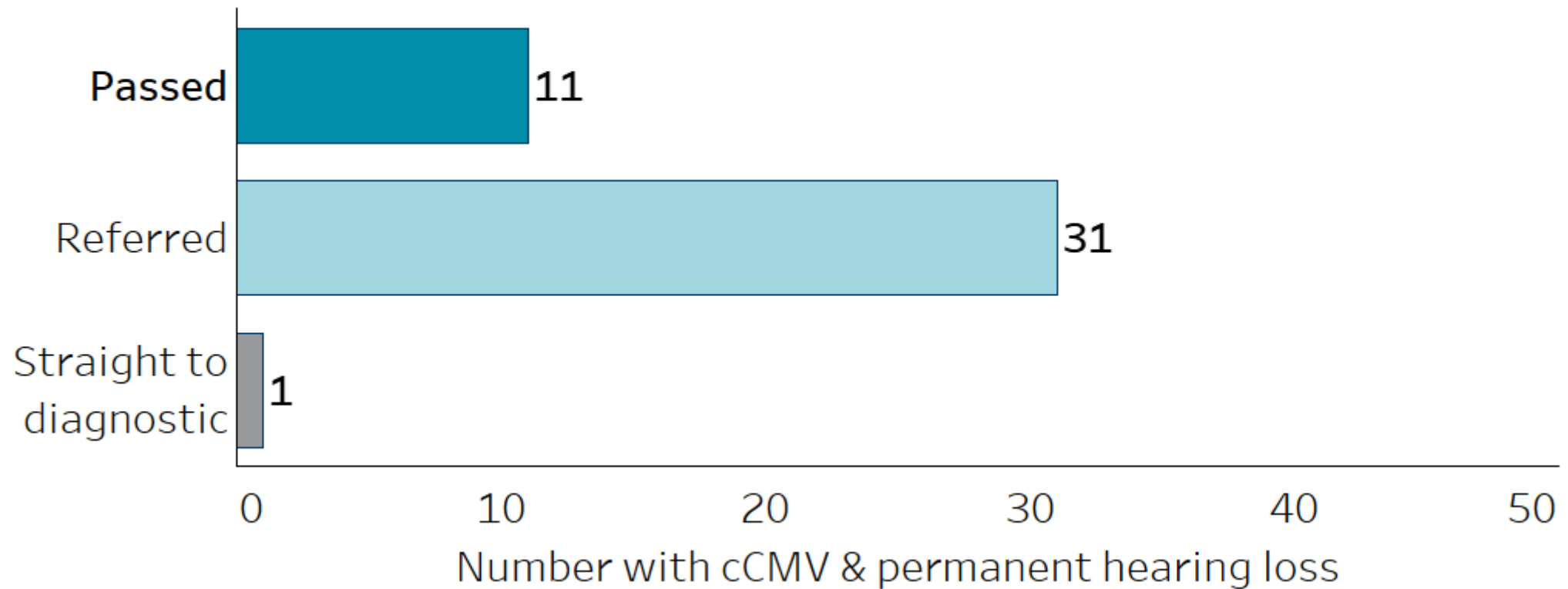
10% of infants were diagnosed with permanent hearing loss (n=43)
(among cCMV cases with a diagnostic audiology assessment)



Newborn Hearing Screen Results

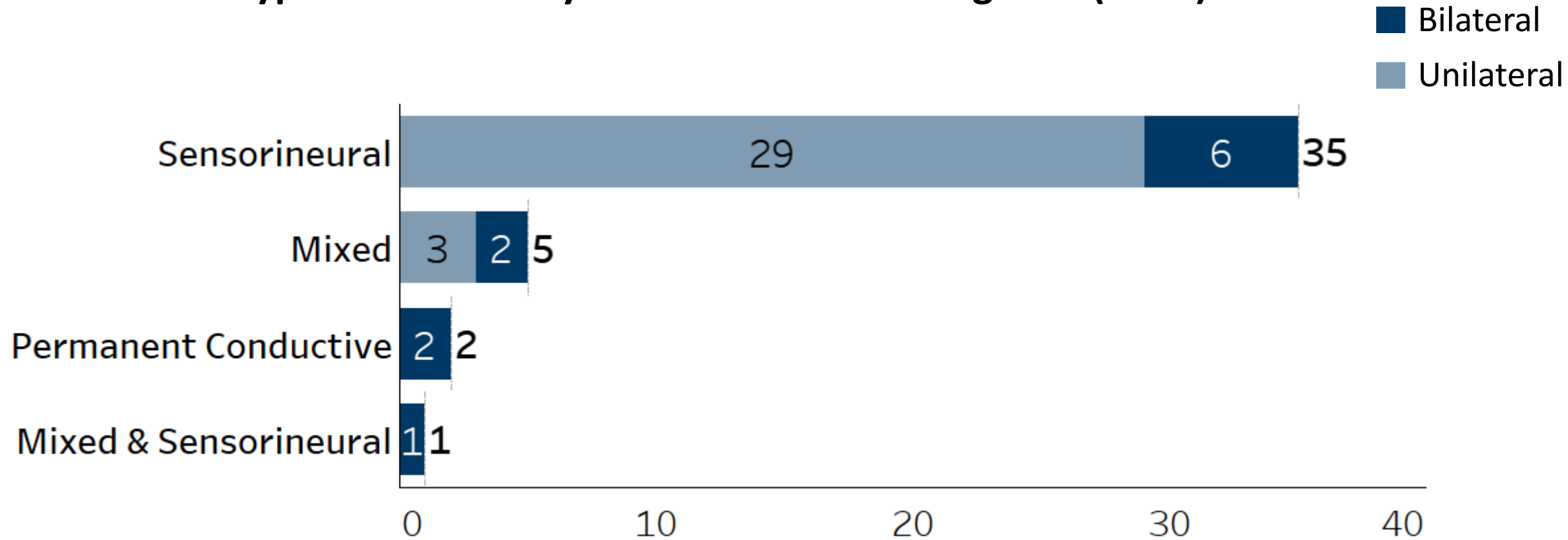
Newborn hearing screening results among infants with permanent hearing loss (n=43)

11 infants passed their newborn hearing screen



Diagnostic Audiology Assessment Results

Type and Laterality of Permanent Hearing Loss (n=43)*



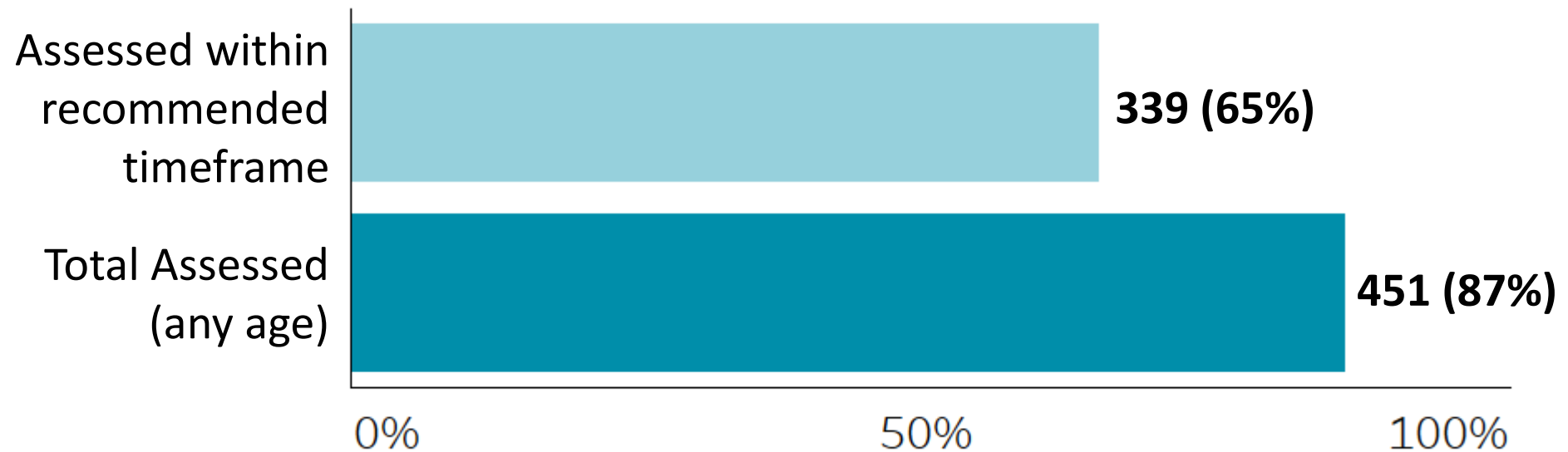
Timing of Diagnostic Audiology Care

Timeliness: First diagnostic audiology assessment

Recommendation:

Complete an initial diagnostic audiology evaluation within 1 month of PCR confirmation

65% met the recommended timing for diagnostic audiology*

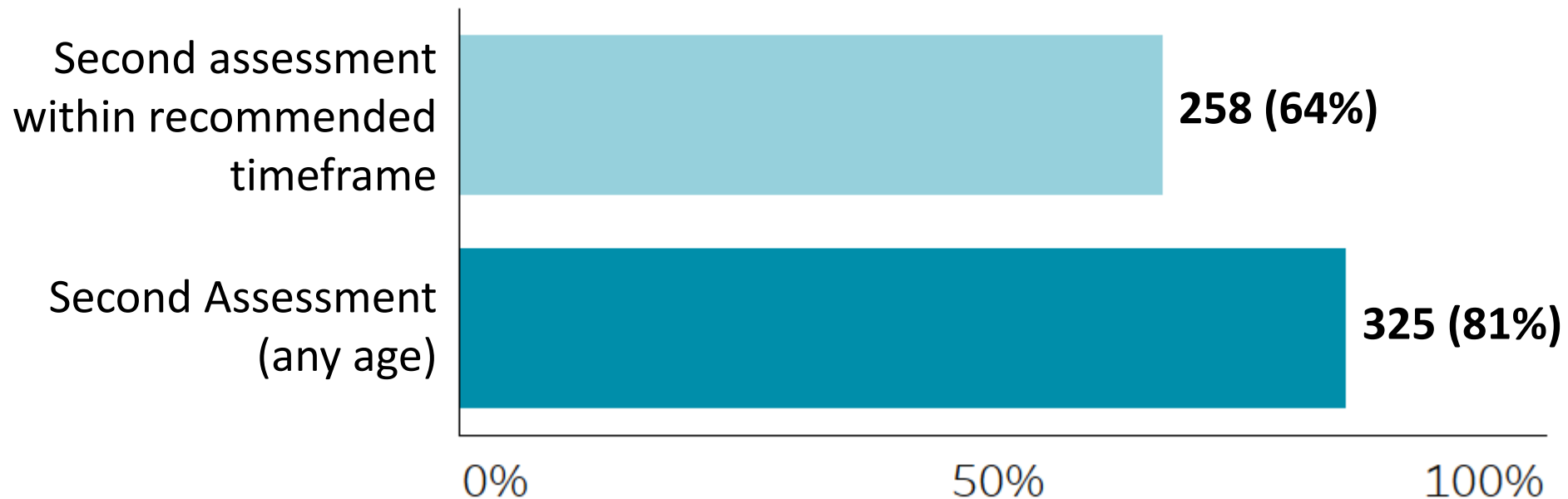


**As reported to MDH by 2/9/26*

Timeliness: Second diagnostic audiology assessment

*Recommendation:
Complete a second diagnostic audiology evaluation by 4-5 months of age*

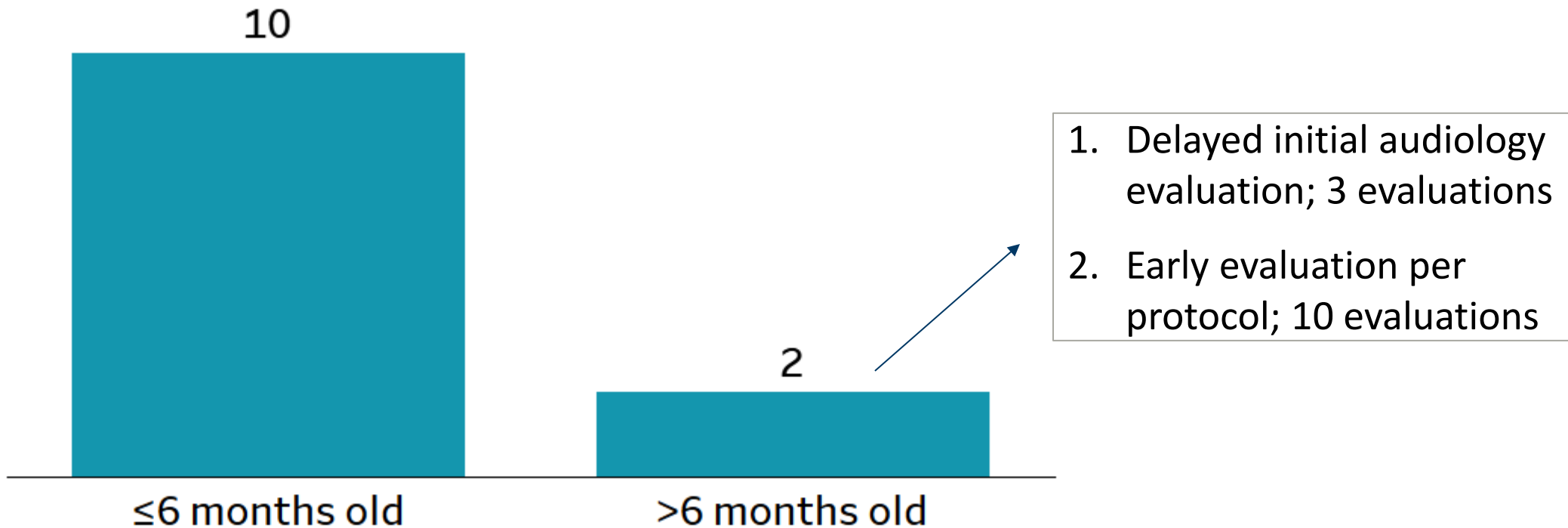
64% met the recommended timing for diagnostic audiology*



**As reported to MDH by 2/9/26*

Age at Diagnosis in Late Onset Hearing Loss

Late onset hearing loss among cCMV cases (n=12)

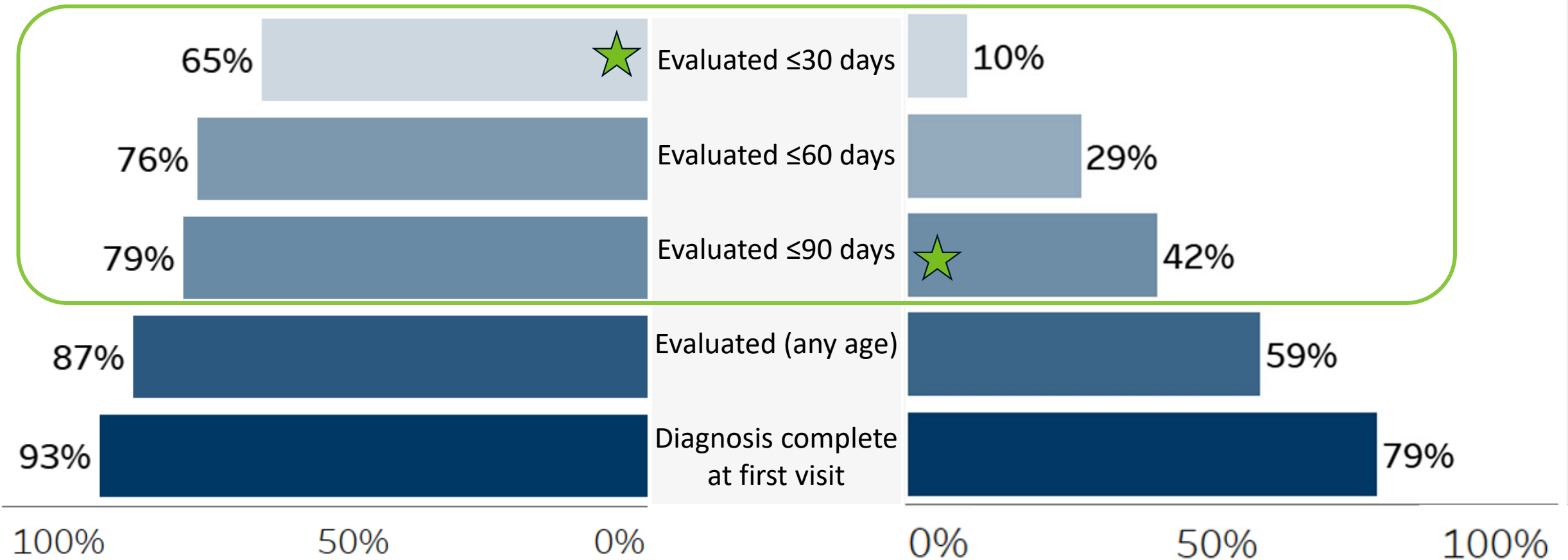


Time to Audiology: A Comparison

★ = Goal

cCMV Cases (n=517)

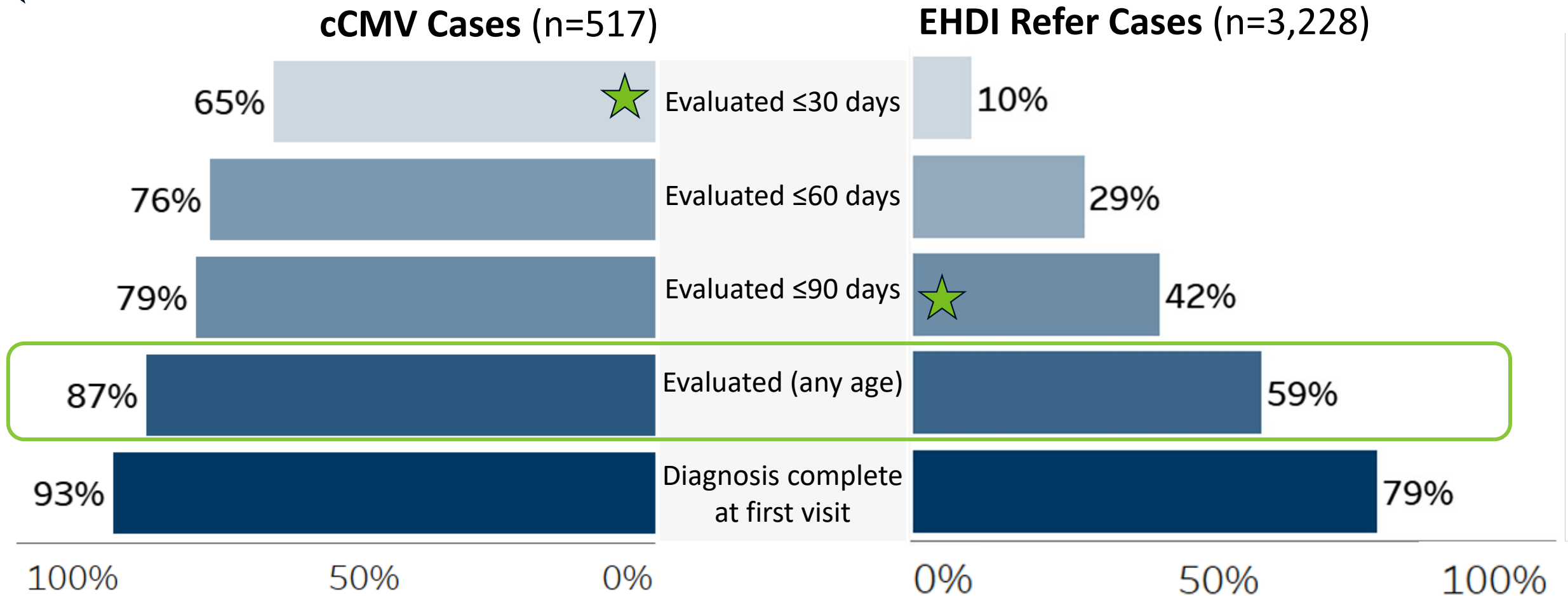
EHDI Refer Cases (n=3,228)



EHDI refer excludes cCMV cases

Time to Audiology: A Comparison

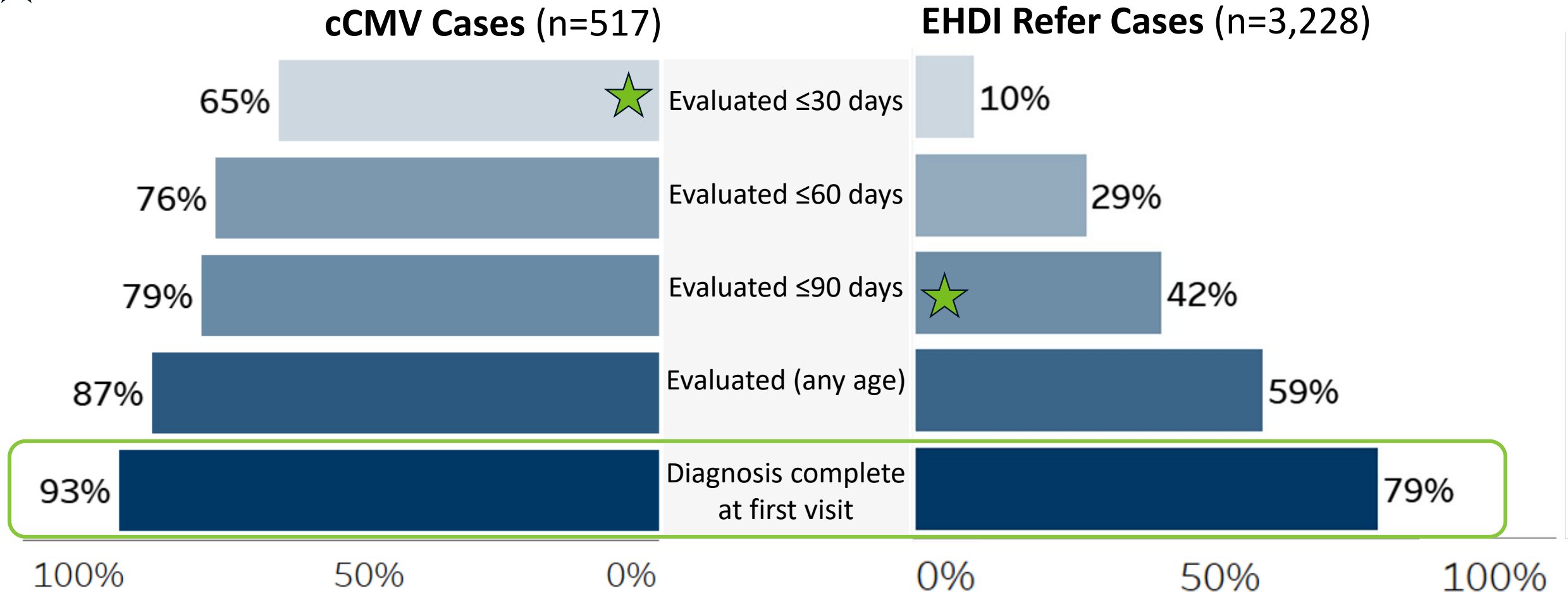
★ = Goal



EHDI refer excludes cCMV cases

Time to Audiology: A Comparison

★ = Goal



EHDI refer excludes cCMV cases

Hearing-Targeted Screening
VS
Universal Screening Approach

Key Differences Between Screening Approaches

Universal Screening

- All newborns for cCMV regardless of symptoms or hearing screen results
- Typically performed within the first 21 days of life

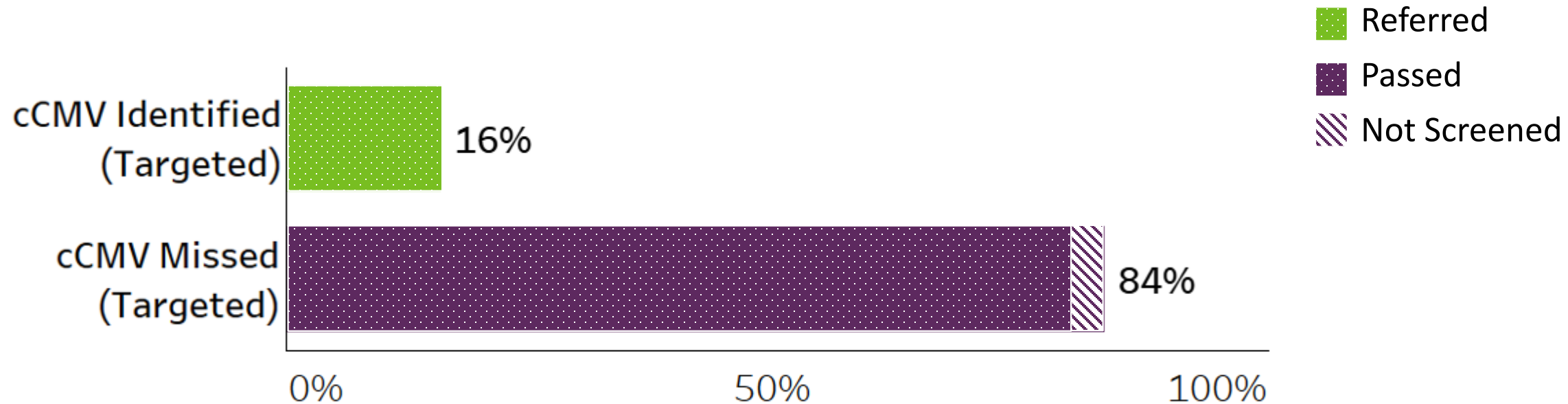
Hearing-Targeted Screening

- Only newborns who refer/do not pass the newborn hearing screen for cCMV
- Performed after a refer/did not pass newborn hearing result, ideally within 21 days of life

Infants would be Missed by a Hearing-Targeted Screening Approach

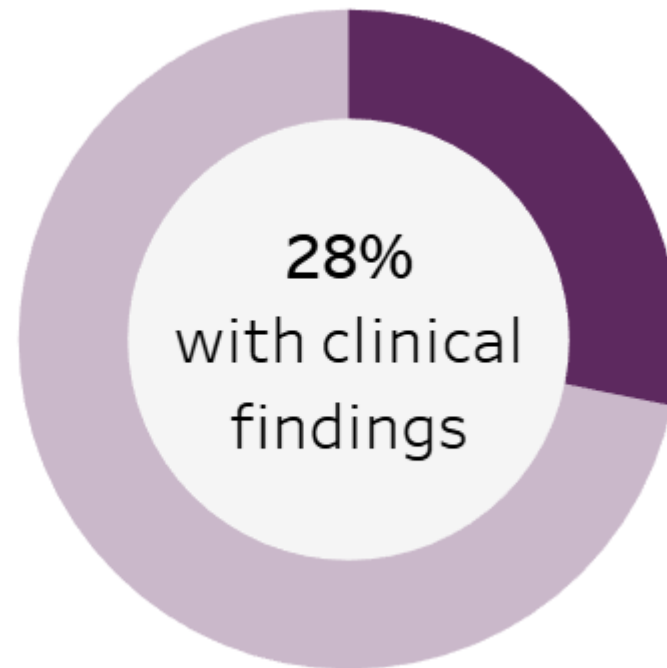
84% of infants with cCMV would be missed by hearing-targeted screening alone

Most infants passed their newborn hearing screen



Infants would be Missed by a Hearing-Targeted Screening Approach

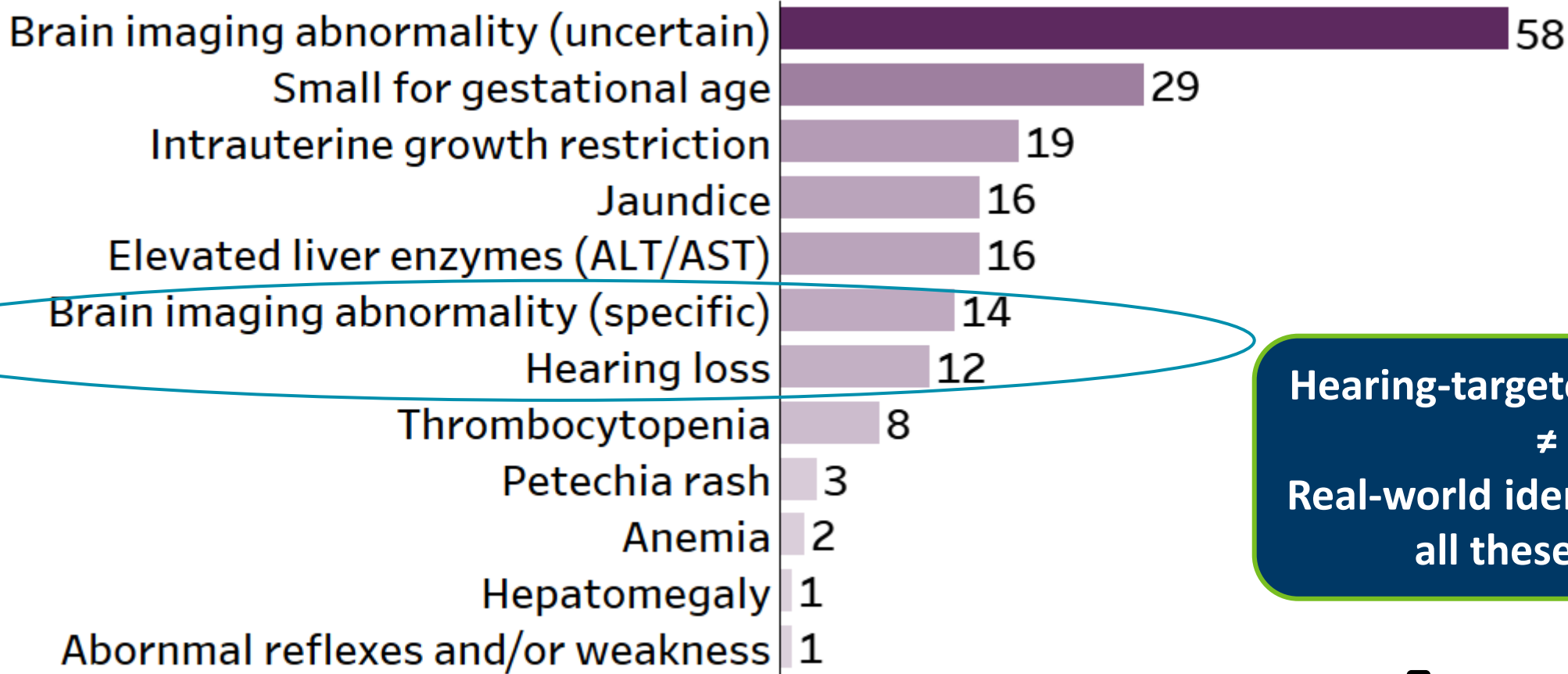
Among infants with cCMV who would have been missed by hearing-targeted screening: 28% had ≥ 1 sign or symptom



Cohort: infants missed by hearing-targeted screening

Infants would be Missed by a Hearing-Targeted Screening Approach

Signs and symptoms among cCMV infants missed by hearing-targeted screening



Hearing-targeted screening
≠
Real-world identification of
all these signs

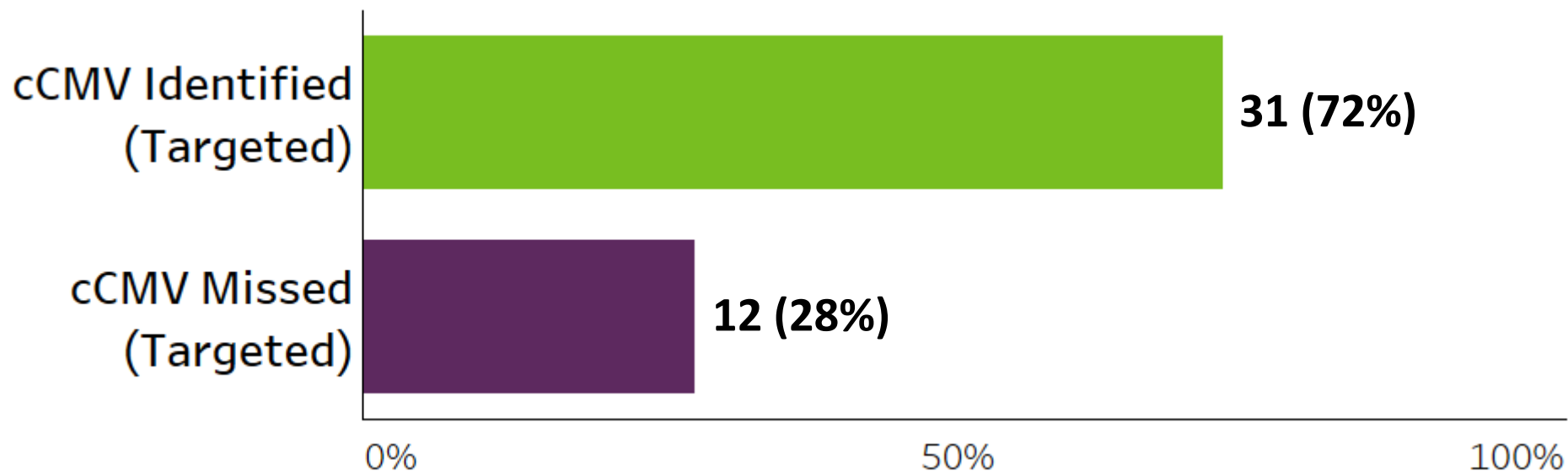
(n=123 infants with clinical findings)



Cohort: infants missed by
hearing-targeted screening

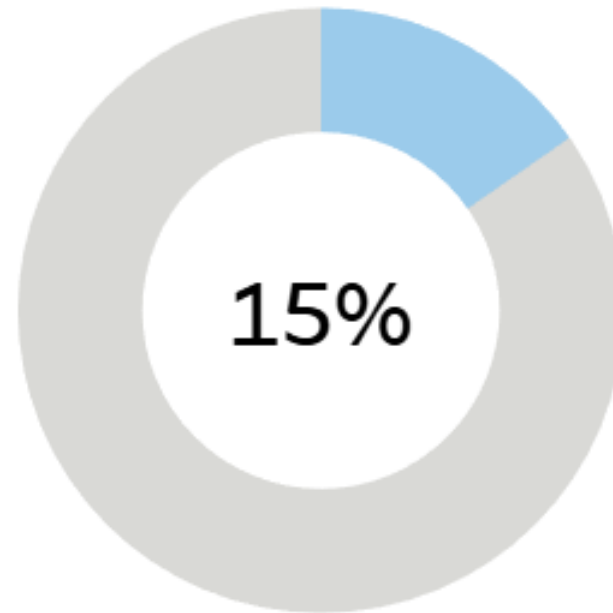
Infants would be Missed by a Hearing-Targeted Screening Approach

12 of 43 infants with cCMV + permanent hearing loss would have been missed by a hearing-targeted CMV screening approach

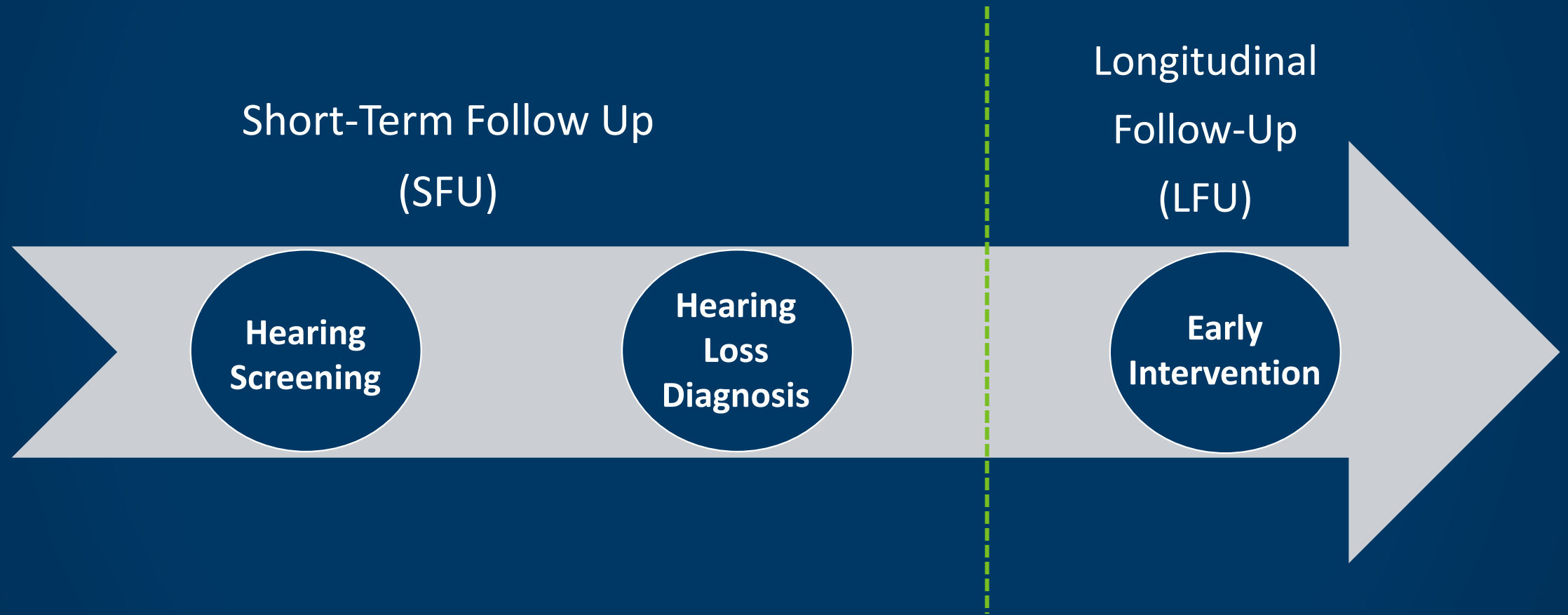


What Would a NICU-Based Testing Approach Capture?

Proportion of all cCMV Infants Admitted to the NICU



Coordinated System: Newborn Screening



Longitudinal Follow-Up Activities

What is longitudinal follow-up?

*“The **assurance** and provision of quality chronic disease management, condition-specific treatment, and age-appropriate preventive care throughout the lifespan of individuals identified with a condition included in newborn screening.”*

-Kemper et al. *Genet Med.* 2008:10(4): 259-261



Evidence-based
Treatment



Care Coordination
through a
Medical Home



Continuous Quality
Improvement

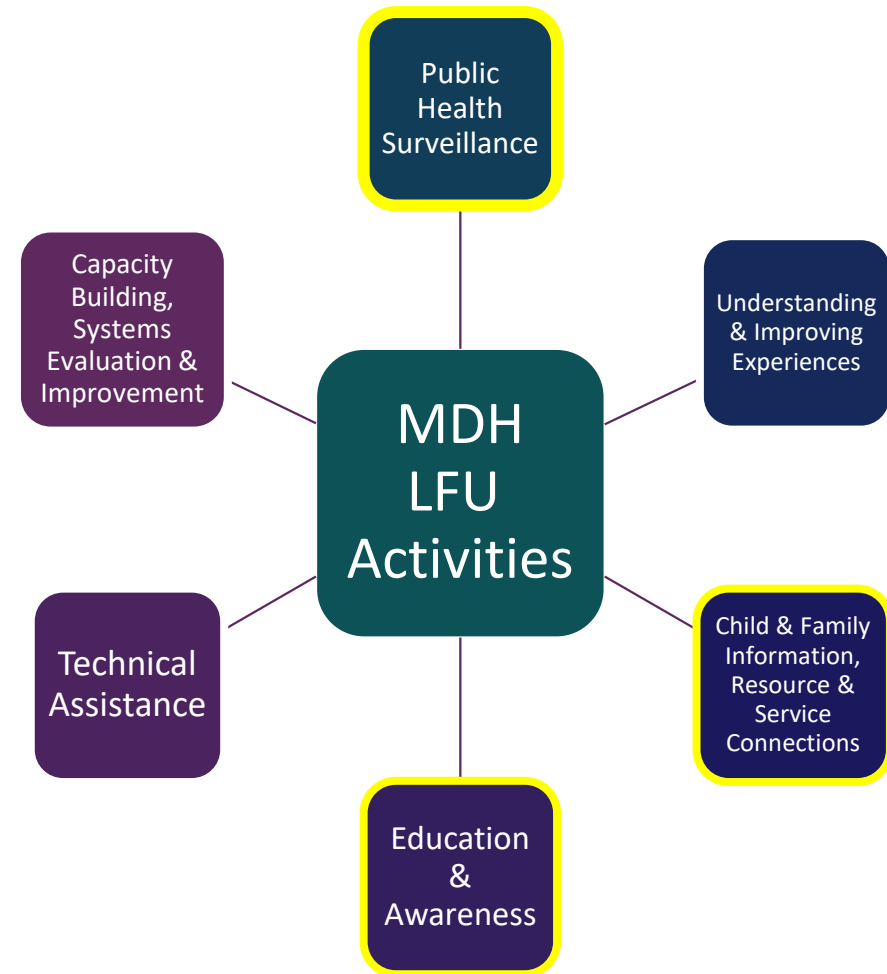


New Knowledge
Discovery

What are the activities longitudinal follow-up does?

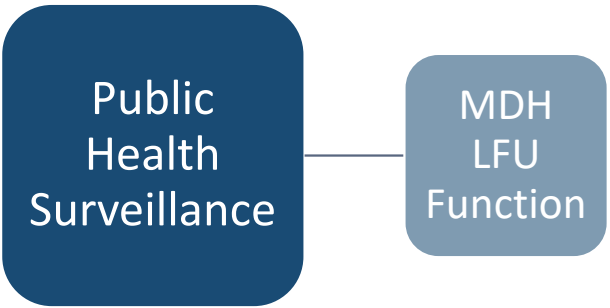
Systematic evaluation to determine how newborn screening is meeting its goal.

Focus: *after* diagnosis of a person with a condition included in newborn screening.



Surveillance

What information are we collecting?



Demographics



Survival



Development



Healthcare
Utilization

Where does our longitudinal follow-up information come from?

- Data on children with hearing loss and cCMV come from multiple clinical and public health data sources

Public Health Surveillance

MDH LFU Function



Electronic Medical Record Abstraction



Local Public Health Nursing Assessment



Newborn Screening Program



Audiology Reporting



Interagency Data Sharing Agreements



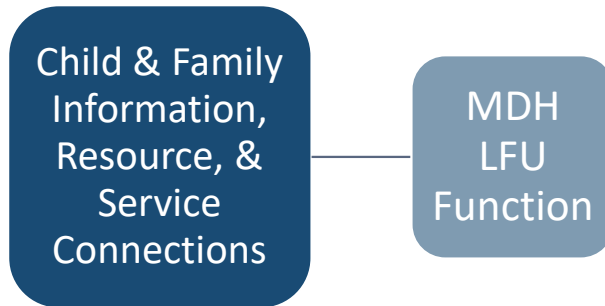
Vital Records

Child & Family Information, Resource, & Service Connections

What does Local Public Health do?

After notification of diagnosis and review by MDH CYSHN staff (audiologist, nurse, etc.), MDH refers a child to the Local Public Health (LPH) department serving their county of residence.

- LPH nurse contacts the family to complete a nursing assessment that includes up to 5 domains:
 - Income
 - Communication with community resources
 - Caretaking/parenting
 - Growth and development
 - Health care supervision
- May facilitate connections to primary and/or specialty health care
- Links to information, services, and support, including Early Intervention and Developmental Screening
- Communicates nursing assessment results, public health interventions and concerns back to MDH



Connection to MN Hands & Voices

- Children with hearing loss or cCMV can be referred to Minnesota Hands & Voices by audiologists or public health for parent-to-parent support.
- MN Hands & Voices provides families with the resources, networks, and information they need to improve communication access and educational outcomes for their children.
- MN Hands & Voices communicates enrollment and contact dates to MDH.

Child & Family
Information,
Resource, &
Service
Connections

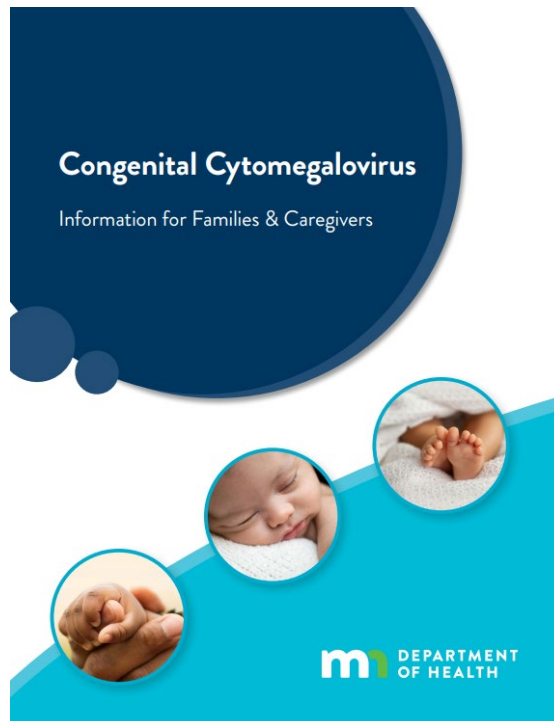
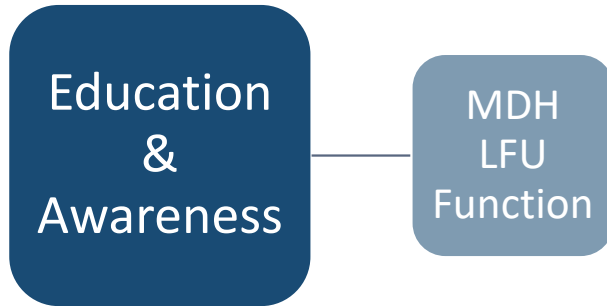
MDH
LFU
Function



Education & Awareness

What information does MDH share with families?

MDH mails a booklet (translated into multiple languages) containing resources to families in Minnesota with children recently identified with congenital CMV or hearing loss:



What information does MDH share with families?

MDH distributes a congenital CMV and EHDI roadmap as well as the Beginnings Book to children with hearing loss and cCMV. Families can use this brochure to make a care plan and discuss with their primary care provider the tests and supportive services their baby may receive.

Congenital Cytomegalovirus (CMV)

A roadmap for families and caregivers

What is congenital CMV?

CMV is a common virus that is spread through contact with bodily fluids like urine and saliva. If a pregnant person gets CMV, the virus can pass through the placenta to the growing fetus. When a baby is born with CMV, the infection is called congenital CMV.

Congenital CMV affects each baby differently. Most babies will never show any signs or symptoms. Around one in five babies with congenital CMV will be born with or develop long-term health challenges. All babies with congenital CMV should have close monitoring of their health, development, and hearing throughout childhood so that any concerns can be found as early as possible.

In this brochure, you will learn about

- Next steps to take after your child is diagnosed with congenital CMV.
- Follow-up testing that helps to guide your baby's treatment and monitoring plan.
- Resources and programs available to you.
- Medical and educational professionals you might involve in your child's care.

Use this brochure as a guide to discuss the tests and supportive services your baby may receive with their primary care provider.



Coordinate with your child's health care providers

Primary Care Provider: Manages and coordinates your child's medical care. They might connect you with medical specialists who work with young children.

Location: 

Phone: _____

Audiologist: Performs specialized hearing tests and manages and treats hearing loss.

Location: 


Phone: _____

Ophthalmologist: Provides specialized medical care for eyes and vision.

Location: 

Phone: _____

Pediatric Infectious Disease Specialist: Provides specialized medical care for children with infections.


Location: 

Phone: _____



EARLY HEARING DETECTION & INTERVENTION

A step-by-step road map for families and caregivers








DEPARTMENT OF HEALTH

Hearing Evaluation






Audiologist:
Date of Identification: _____

YOUR CHILD'S HEARING LEVELS:

Left Ear

 typical
 slight
 moderate
 severe
 profound

Right Ear

 typical
 slight
 moderate
 severe
 profound

Your audiologist will:

- Review the different choices in hearing technology and ways to communicate.
- Inform your child's primary care provider and the Minnesota Department of Health about your child's hearing levels.
- Connect your family to resources.

The next step...

Your child needs to return to the audiologist/physician for further care.

Appointment Date:
Time: _____
Location: _____

Respect for Identities

We respect the terms people use to identify themselves. People may self-identify as deaf, hard of hearing, a person with hearing loss, a person with a hearing difference, etc.

You might see the phrase "deaf and hard of hearing (DHH)" used in an all-inclusive manner. You might also see the words "hearing loss" when talking about a medical diagnosis.


Your child's hearing test shows hearing levels outside the typical range.

With early care and connections to interventions, your family will find support while your child is developing language and communication skills. Connect with these programs while you are making these early decisions for your child and for your family, ensuring your child's good health and development.

In this brochure you will learn the...

- Resources and programs available to you
- Medical and Educational professionals you can involve in your child's care, and
- Steps to take in the next year to ensure your child's development.

Let's get started.




The first step is to connect with programs to help your child


Programs are voluntary. Both local and statewide programs work together to ensure the needs of your child are met.

- **Your Local Public Health (LPH) Agency**
LPH agencies offer newborn and child follow-up services to help navigate and guide you through the process. MDH will link you with the agency in your area that provides the services you may need. When LPH calls you, they will be able to answer your questions about and connect you to:
 - Financial Resources
 - Insurance Resources
 - Identifying Health Care Specialists
 - Family-to-Family Networking
 - Early Childhood Intervention
 - Medical Condition Information
 - Community Resources
- **Minnesota Department of Health (MDH)**
Early Hearing Detection and Intervention (EHDI), 1.800.728.5420, health.mn.gov/ehdi

MDH's EHDI Program will send you a package of written information that will outline resources available to you.



This resource is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under the HRSA award number 5U49CE000434. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement by HRSA, HHS, or the U.S. Government. For more information, please visit www.hrsa.gov.









**Understanding Your Child's Hearing Loss:
A Guide for Parents**

EARLY HEARING DETECTION & INTERVENTION

A step-by-step road map for families and caregivers



Hearing Evaluation

Audiologist:

Date of Identification:

YOUR CHILD'S HEARING LEVELS:

Left Ear



- typical
- slight
- mild
- moderate
- severe
- profound

Right Ear



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This resource is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$369,000 with 0% financed with non-governmental sources. The contents are those of the author(s) and do

Minnesota Hands & Voices

1-651-265-2435 Voice Only;
Email: MNHV@lssmn.org;
www.mnhandsandvoices.org

Minnesota Hands & Voices (MNH&V) is staffed by parents of children who are deaf and hard of hearing (DHH). A Parent Guide By Your Side™ in your region will contact your family to provide information and support.

Minnesota Department of Human Services

Deaf and Hard of Hearing Services
651-964-1514 (Videophone)
1-800-657-3663 (Voice or relay)
mn.gov/deaf-hard-of-hearing

The Minnesota Deaf and Hard of Hearing Services Division (DHHSD) is responsible for creating and delivering a wide range of innovative programs and services to help children and adults who are deaf and hard of hearing.

Early Childhood Special Education

1-866-693-GROW (4769)
www.helpmegrowmn.org

Connect with your local school district through Help Me Grow. Children who are DHH may be eligible to receive free early intervention through early childhood special education services in their local public school district. A provider from your local district program will contact you and work with you to make a plan. Children older than 5 can be connected through your elementary school.





Your audiologist will inform your child's primary care provider of the test results.

Primary Care Clinic/Contact:

In the next few weeks, discuss your child's hearing loss with your child's primary care provider. Your provider may connect you with specialists who work with young children in each of the following care areas:

ENT Doctor

(Ear, Nose and Throat Specialist)

Provides specialized medical care for ears and can provide the medical clearance for hearing devices (if chosen).

Doctor:

Location:

Phone:

Ophthalmologist (Eye Specialist)

Provides specialized care for eyes and vision, which is very important for a child who is deaf and hard of hearing.

Doctor:

Location:

Phone:

Geneticist (Heredity and Gene Specialist)

A geneticist can advise if your child's hearing difference is related to other health issues.

Doctor:

Location:

Phone:

Work on these steps by the **1ST MONTH**

Child's Primary Doctor

Discuss your child's hearing evaluation. Get referrals for the doctors/specialists listed on reverse side.

Appointment Date & Time:

ENT Doctor

Schedule an exam that includes the medical clearance for hearing devices (if chosen).

Appointment Date & Time:

Audiologist

Return for monitoring and hearing device fitting (if chosen). Ask about options for loaner hearing devices, if desired.

Appointment Date & Time:

Help Me Grow (HMG)

Through Help Me Grow, connect with your school district to talk about next steps for early intervention services and identify your child and your family's strengths and needs.

Phone:

Family Supports

Connect with other families of children who are deaf and hard of hearing (DHH) (i.e. Minnesota Hands & Voices) and connect with adult mentors/role models who are DHH.

Work on these steps by the **2ND MONTH**

Child's Primary Doctor

Review your child's progress at the well child appointment (or sooner).

Appointment Date & Time:

Audiologist

Follow-up and test your child's hearing devices (if chosen). Discuss a plan in case your child's hearing devices are lost or stop working.

Appointment Date & Time:

Local School District

With your local school district's early childhood special education staff, develop and review the Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP).

Start Date:

Work on these steps by the **6TH MONTH**

Child's Primary Doctor

Review your child's progress at check-ups.

Appointment Date & Time:

Ophthalmologist (Eye Specialist)

Have your child evaluated.

Appointment Date & Time:

Audiologist

Continue check-ups and follow-up care. Evaluations will include play-based audiological testing as your child gets older.

Appointment Date & Time:

Any additional notes:

Work on these steps by the **12TH MONTH**

Child's Primary Doctor

Review your child's progress at check-ups.

Appointment Date & Time:

Geneticist

Have your child evaluated.

Appointment Date & Time:

Audiologist

Continue audiology care as recommended for evaluation and hearing aid testing (if applicable).

School IFSP or IEP Team

Review programs and services as described in your child's IFSP or IEP with the team.

Gather & Share Information

Continue to learn about and discuss communication considerations and choices in hearing technology for your child.

TO LEARN MORE AT ANY TIME

Learn more about **Communication Opportunities**
mnlowincidenceprojects.org/Projects/ehdi/ehdiCommunicationOpp.html



Learn more about **Deaf Mentor Family Services and American Sign Language**
lssmn.org/services/families/deaf-hard-of-hearing/mentor-services



Learn more about **Minnesota Hands & Voices Parent to Parent and Deaf and Hard of Hearing Guide programs**
lssmn.org/mnhandsandvoices



Longitudinal Follow-Up (LFU) Data



LFU follows 40 MN children who are deaf and hard of hearing with cCMV



60% Males
40% Females



80% born to mothers
with other living
children

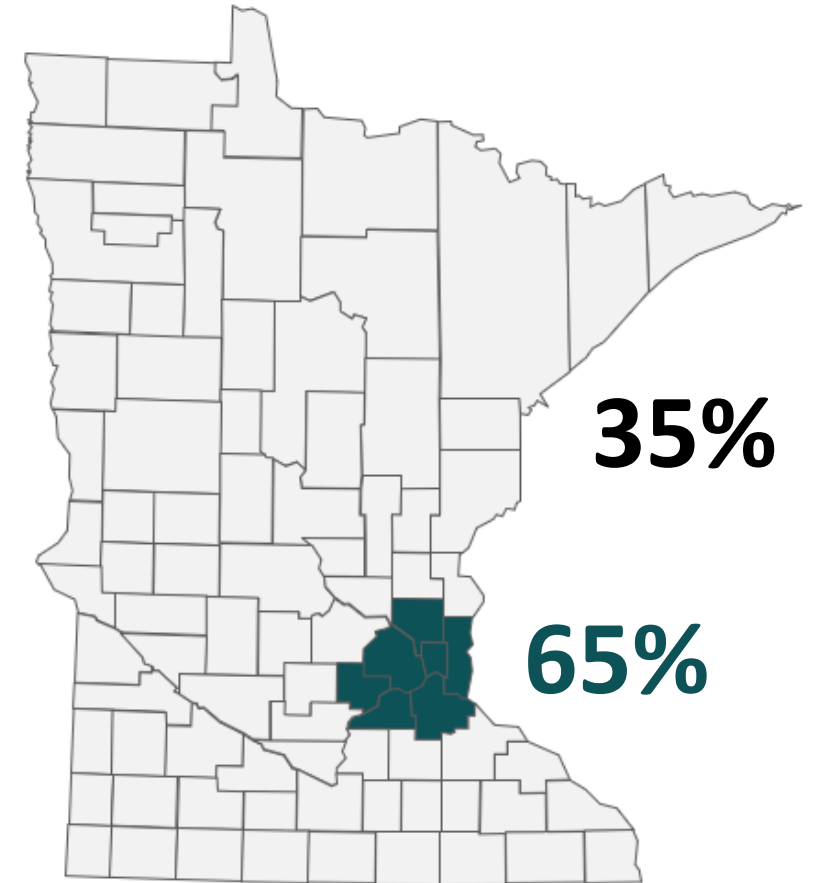


Mothers Race:

77% White
13% Asian
5% Black or African American
5% Missing



23% MN Public Insurance
45% Private Insurance
32% Missing or Unknown



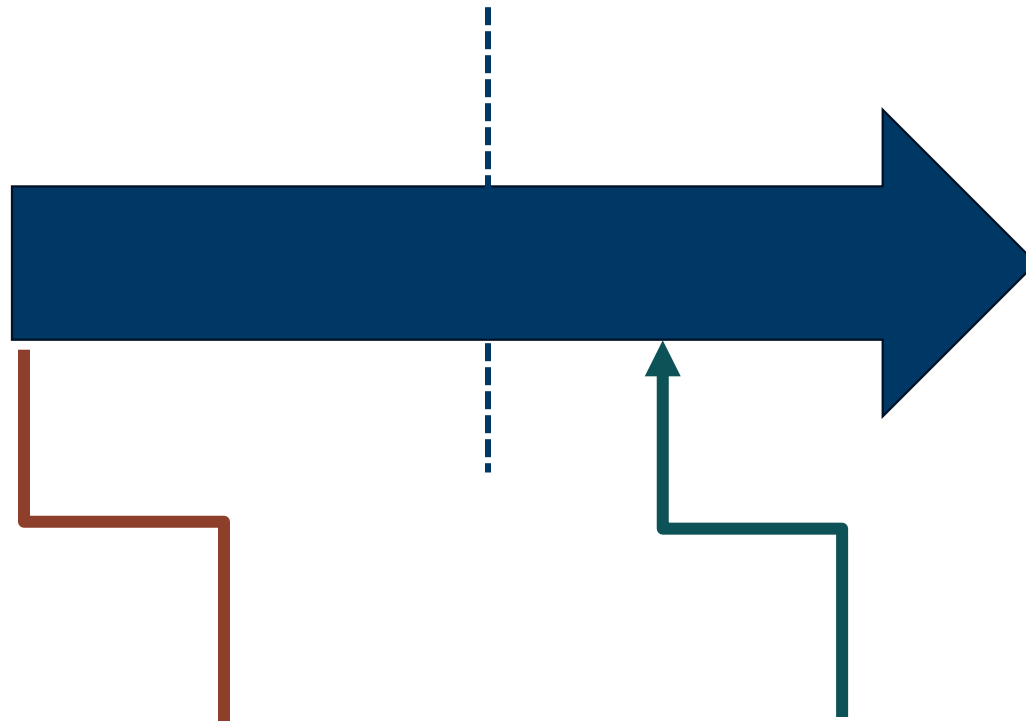
Why are the numbers between SFU & LFU slightly different?

Short Term Follow Up

Longitudinal Follow-Up

43

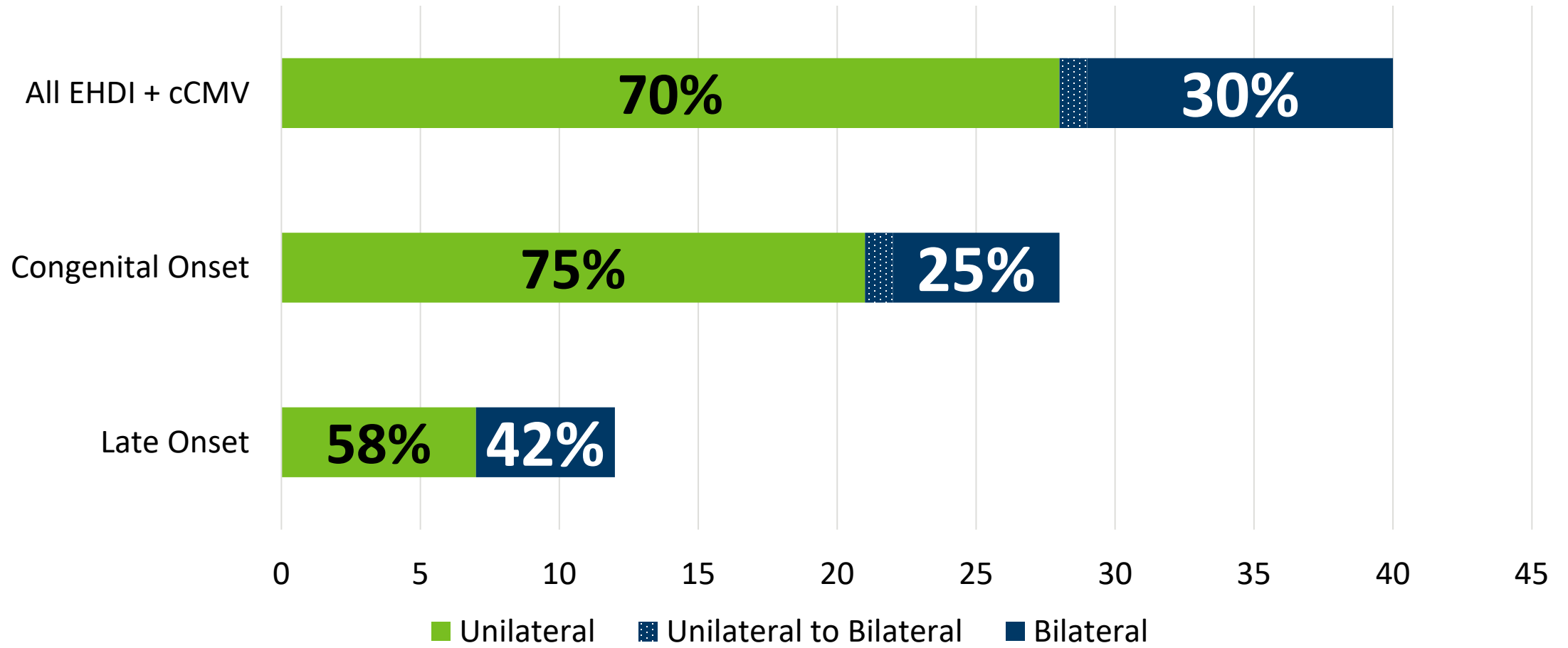
40



1 child moved out of state;
3 are not yet or no longer followed*

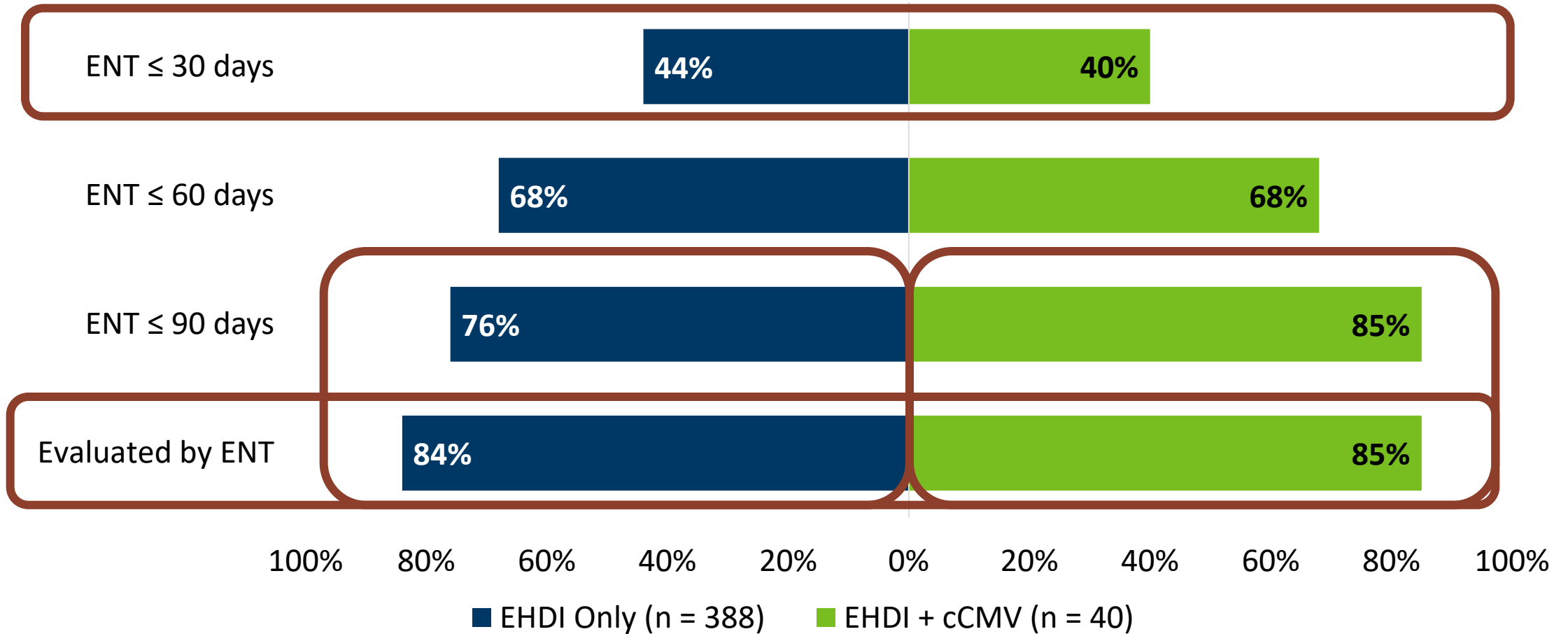
1 child born out of state

70% of children with HL & cCMV have congenital onset of hearing loss; 30% have bilateral hearing loss

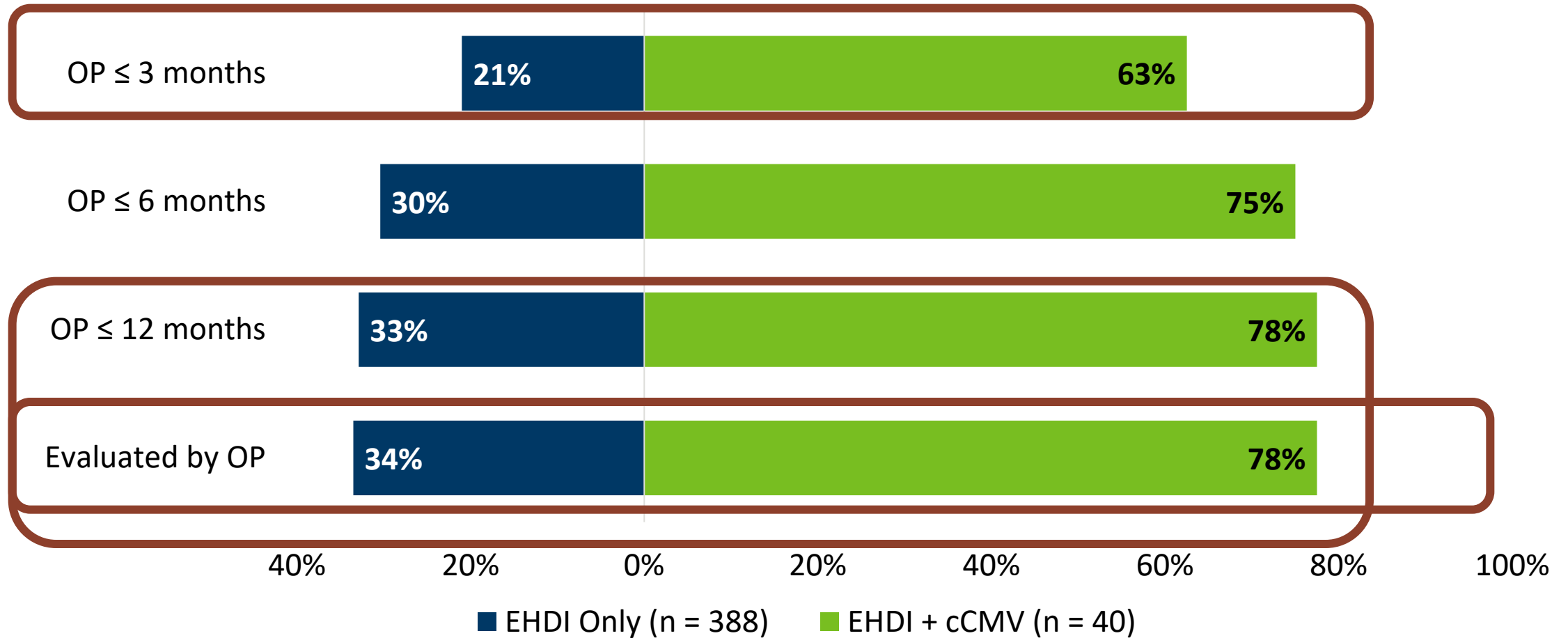


Are children being evaluated by recommended medical care?

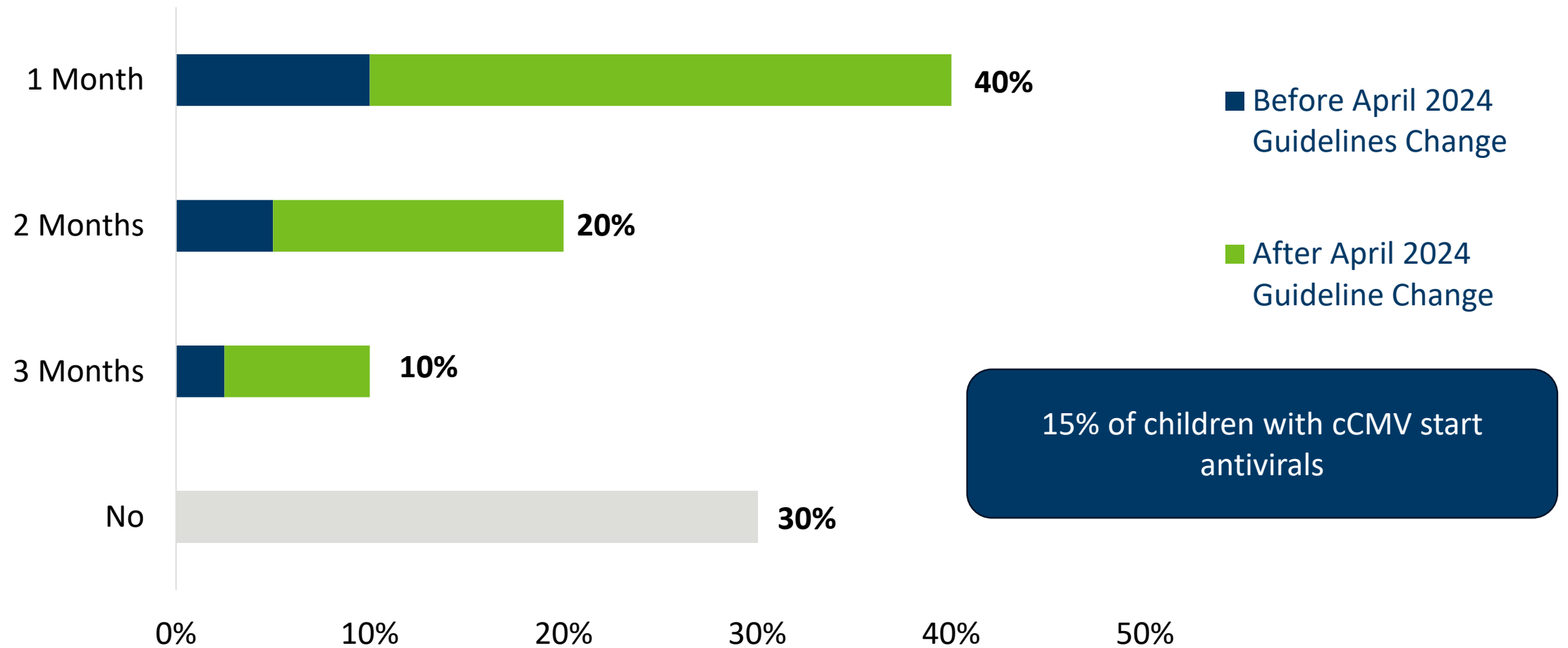
40% of children with cCMV & HL were evaluated by ENT within 30 days of permanent HL diagnosis



More than 75% of children with cCMV & HL were evaluated by ophthalmology; 63% within 3 months of permanent HL diagnosis



70% of children with cCMV & HL received antiviral therapy. 40% started treatment within 1 month of birth



Council of State and Territorial Epidemiologist (CSTE) Case Definitions

- CSTE has a criteria to determine how public health agencies should classify a case of cCMV infection or disease. These specific definitions allow for reporting consistency across state health agencies.
- A wide spectrum of severity exists, from clinically inapparent infection to severe disease that is clinically apparent at birth or manifests as sequelae. The guidelines are intended to be used for the purposes of **cCMV surveillance** and not intended to be used as a guide to clinical management of cCMV infection or disease.

CSTE classifies both laboratory and clinical criteria for
cCMV infection and cCMV disease

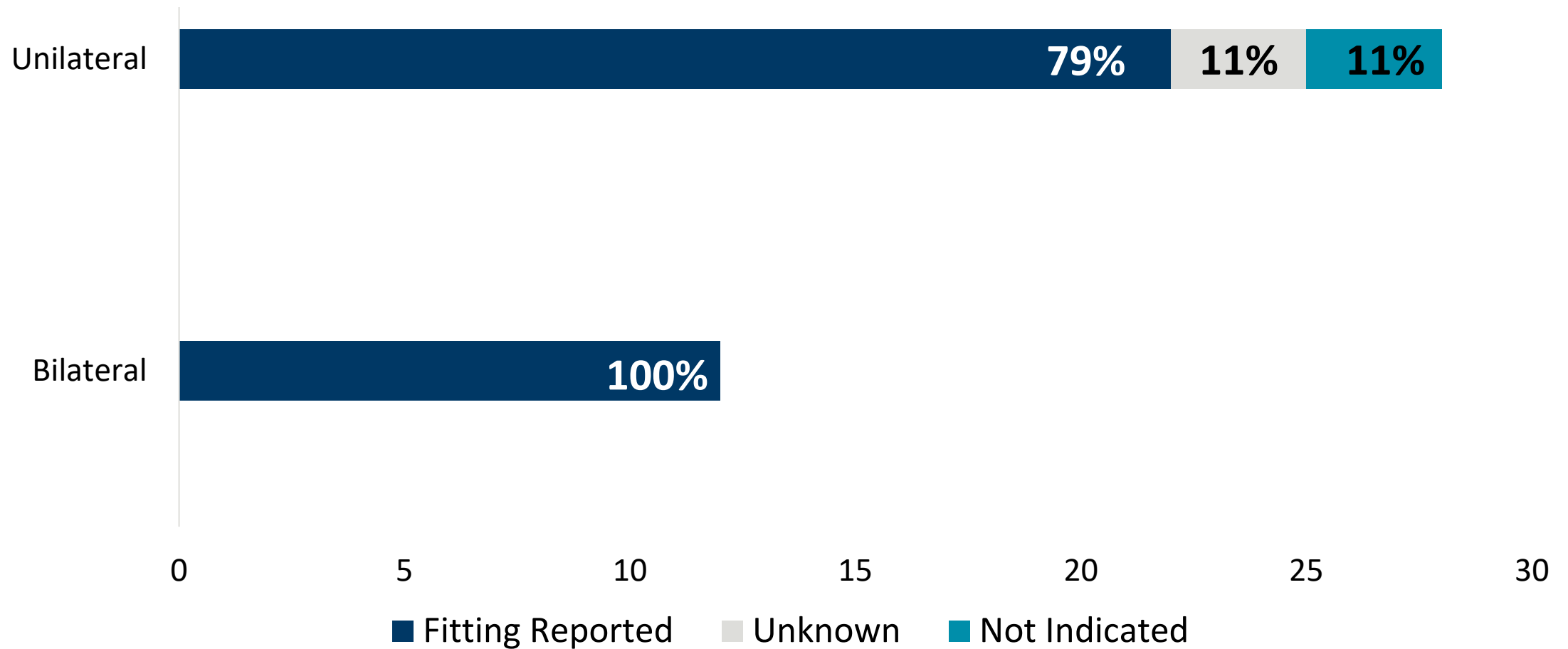
Laboratory Criteria

**Laboratory Criteria + Clinical Criteria
= cCMV Disease**

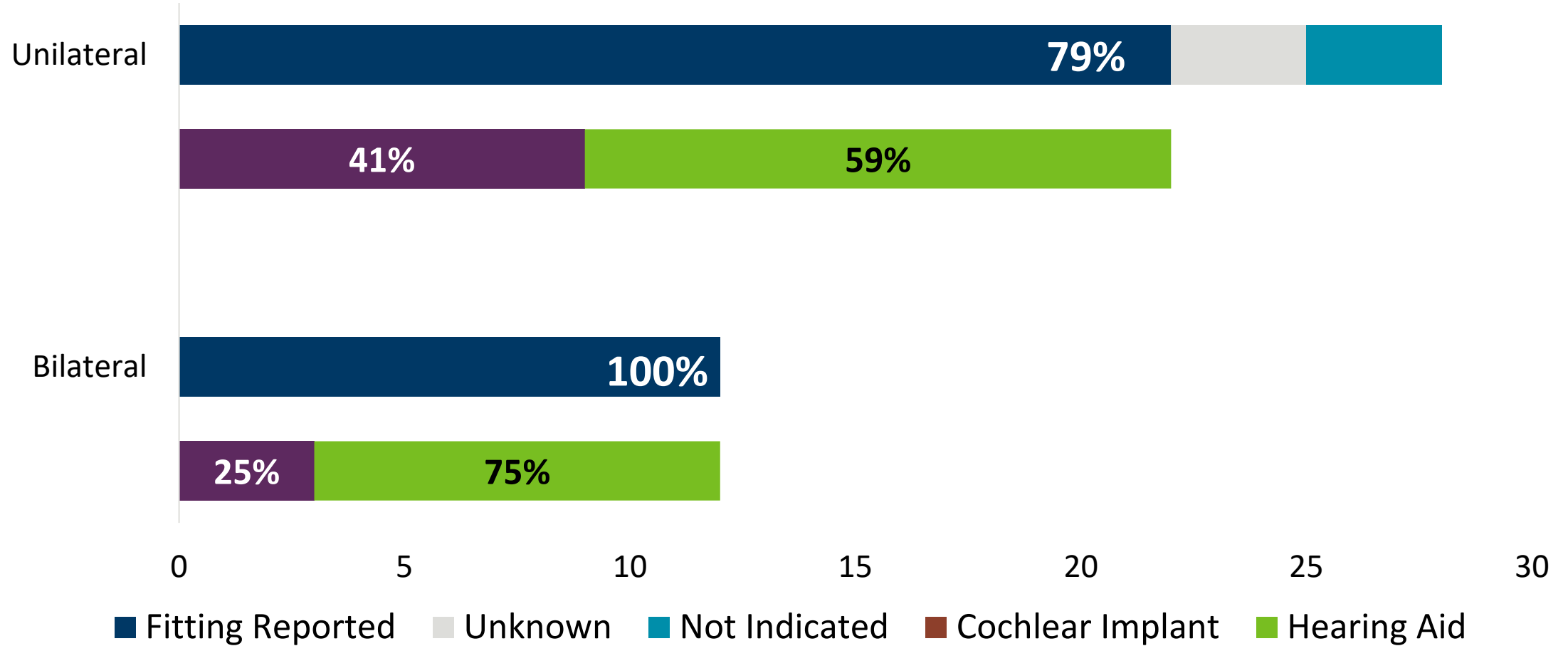
What additional signs or conditions did these children have?

- All children with **sensorineural hearing loss** meet the CSTE case definition for cCMV disease.
- 33% of children with hearing loss and cCMV had additional signs or conditions that would have classified them with cCMV disease based on the CSTE case definitions, such as microcephaly, brain imaging abnormalities consistent with cCMV, etc
- 25% of children with hearing loss and cCMV were admitted to the NICU (Unrelated to CSTE case definitions)

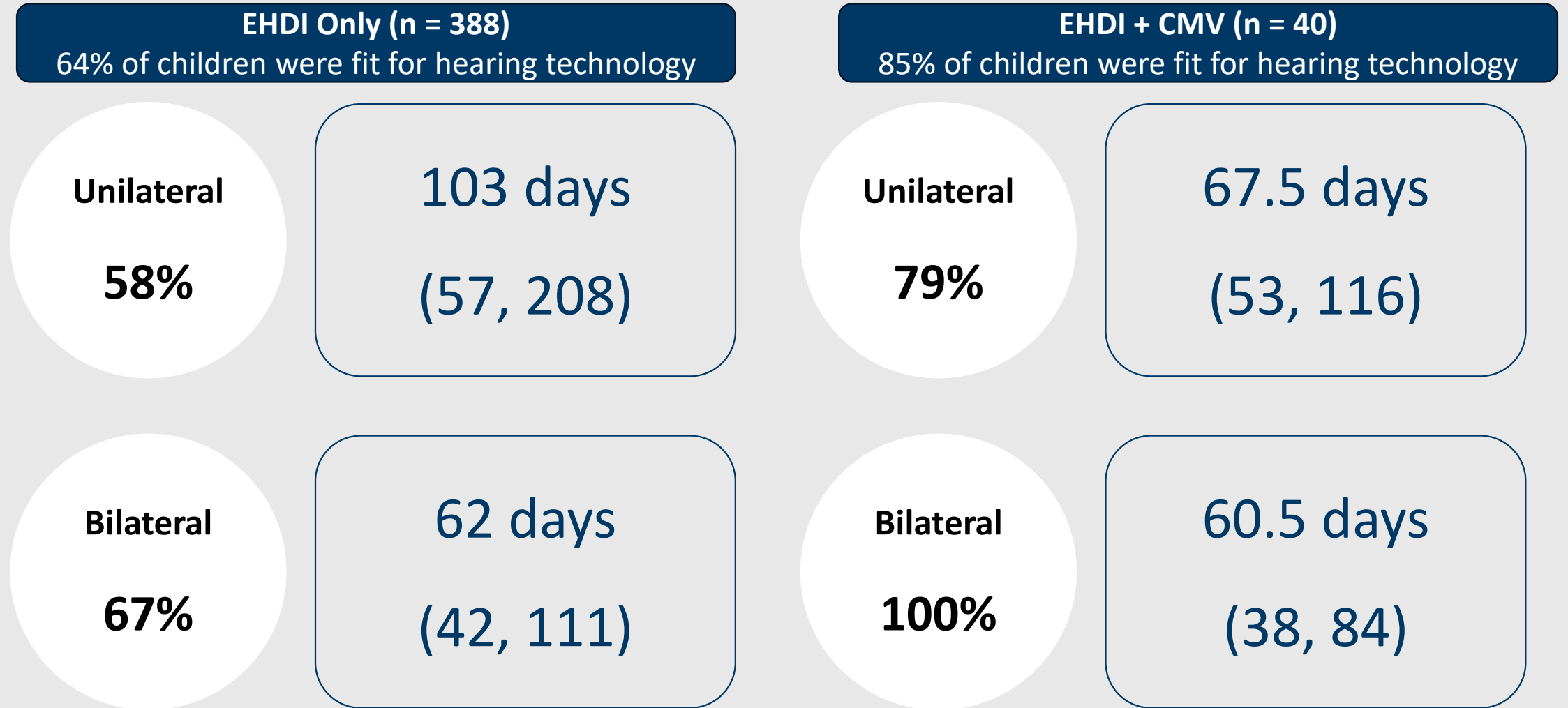
100% of children with bilateral hearing loss and 79% of children with unilateral hearing loss have been fit for amplification.



100% of children with bilateral hearing loss and 79% of children with unilateral hearing loss have been fit for amplification.



Children with unilateral hearing loss & cCMV are being fit with hearing technology sooner than children with unilateral HL



Median time (IQR) between permanent diagnosis of hearing loss & amplification

Children with HL & cCMV are being evaluated by medical providers quickly

- Children with HL & cCMV tend to be evaluated by medical providers more quickly than those with hearing loss alone. This is likely due to the recommended work-up at the time of diagnosis and the potential medical treatment for CMV.
 - Children with HL & cCMV were eventually evaluated by ENT at similar rates as those with HL, but are being seen sooner. All were seen within 90 days of permanent HL diagnosis.
 - More children with HL & cCMV were evaluated by ophthalmology compared to those with HL only. Nearly two-thirds with HL & cCMV are evaluated within 3 months of permanent diagnosis of HL compared to 20% of those with HL only.
 - 85% of families of children with HL & cCMV chose amplification for their children. Children with unilateral HL & cCMV are being fit with amplification more than one month sooner than those with HL only.

Are children and their families
connecting with local and statewide
EHDI services?

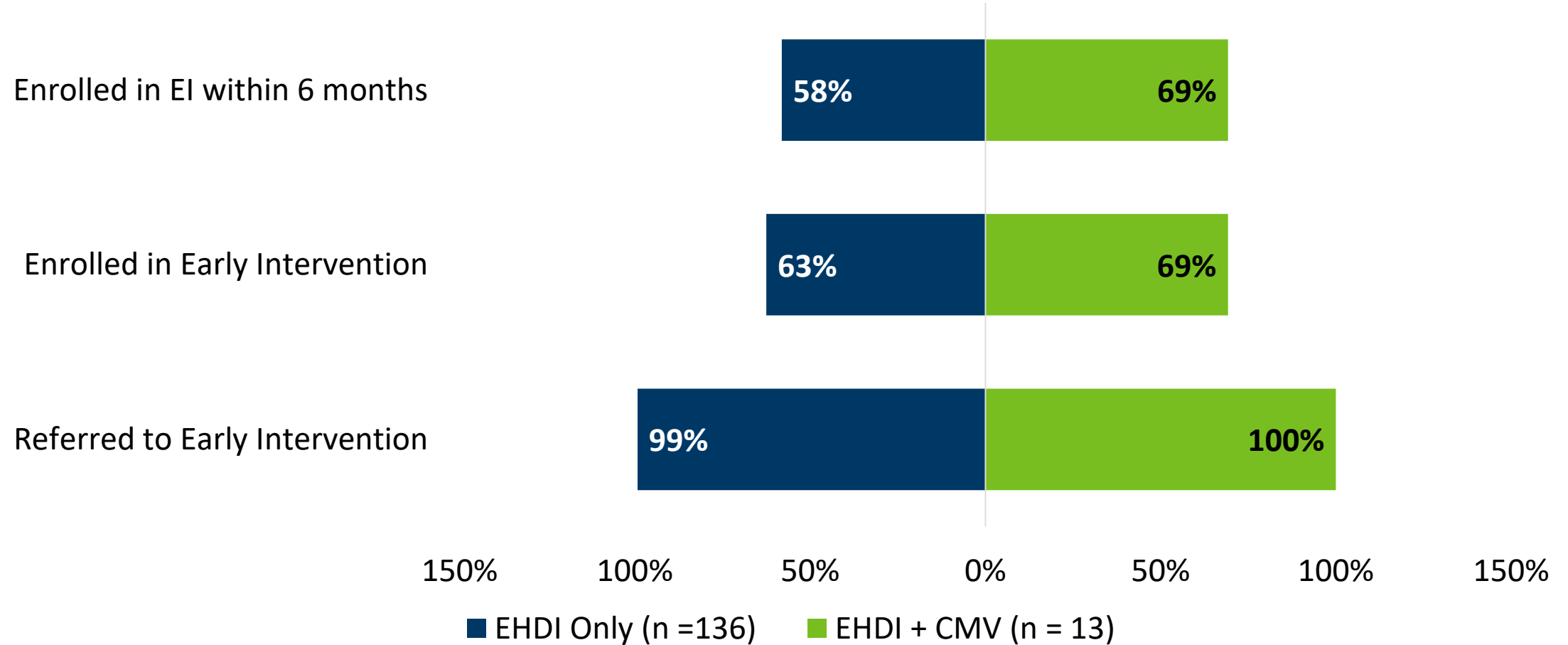
All families were referred to Local Public Health and 75% completed a public health nursing assessment.

- All families that were residents of MN were referred to LPH for a nursing assessment & 75% of families completed a nursing assessment.
- During the nursing assessment, LPH nurses can assess problems areas including income, communication with community resources, caretaking & parenting, growth & development, and healthcare supervision
 - Document assessment findings related to each problem area
 - Provide resources/interventions to families
- Nurses are required to complete questions about insurance, language, and referrals to family home visiting and early intervention.

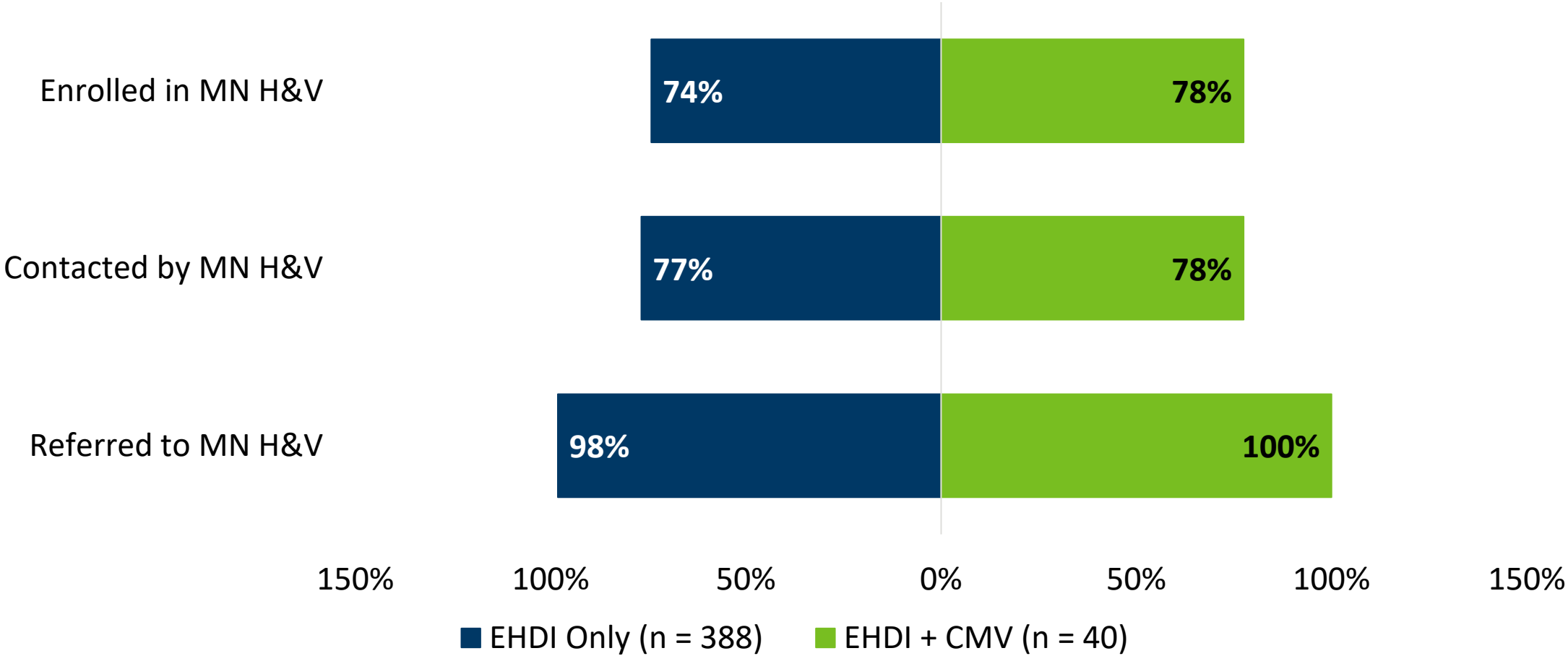
How many children who are deaf and hard of hearing with cCMV are enrolled in early intervention?

- MDH maintains a data sharing agreement (DSA) with the Minnesota Department of Education for Part C enrollment data
- Data reported annually is from approximately 1.5 - 2 years prior
- The most recent year of early intervention data is from 2023.

Among children born in 2023, nearly 70% were enrolled in early intervention





More than three-quarters of families were enrolled in parent-to-parent support




Children with hearing loss and cCMV and their families are connecting to EHDI services across the state

- Nearly 100% of children with HL & cCMV and their families are being referred to services across the state
- Many families are connecting with these resources.
 - Approximately 75% of families were connected with local public health and completed a nursing assessment.
 - More than 75% enrolled in Minnesota Hands & Voices for parent-to-parent support.
- Nearly 70% of children born in 2023 were enrolled in early intervention. All were enrolled within 6 months of age.








Audiology Guidelines For Infants With
Congenital Cytomegalovirus


DEPARTMENT
OF HEALTH

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Thank you!

Questions?

amanda.pavan@state.mn.us

sara.lammert@state.mn.us