

CENTERS FOR DISEASE CONTROL AND PREVENTION
National Center on Birth Defects and
Developmental Disabilities

Baby Flow through the EHDI System:

An Examination of Data
and Performance
Measures

Erika Odom, PhD, MS, LMSW

Corey Lipton, MPH



Disclaimer: The opinions expressed in this presentation are solely those of the presenters and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Learning Objectives

- Participants will be able to describe the differences in the denominators being used at the 1-3-6 benchmarks.
- Participants will be able to interpret the calculations generated with the different denominators.
- Participants will be able to analyze their infants LTD/LFU at each stage of the EHDI process.

Agenda

- Why is this important?
- Baby Flow through 1-3-6
- Screening by 1 month
- Diagnosis by 3 months
- Early Intervention by 6 months
- LTD/LFU
- Case Study

Why is this important?

- **These aren't just numbers, they represent the lives of babies.**
- **There are many ways to analyze data, and we can slice it in different ways to gain insights.**
- **The CDC EHDI team is focusing on surveillance efforts, specifically around the 1-3-6 benchmarks, to understand who is eligible and how many within eligible population receive recommended services on time.**
- **iEHDI uniquely allows for analyses of health disparities. We can use LTD/LFU to help us better understand these disparities.**

Baby Flow through 1-3-6



1-3-6 Benchmarks

- All infants should have their hearing screened by **1 month of age**
- All infants who do not pass their hearing screening should receive a diagnostic evaluation by **3 months of age**
- All infants diagnosed with permanent hearing loss should be enrolled in early intervention by **6 months of age**

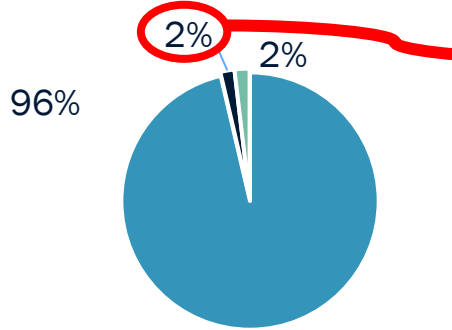
Eligible vs Served

- **Eligible Population** includes all infants that are eligible to move to the next part of the EHDI process.
- **Served Population** includes all infants that received the recommended services during each stage of the EHDI process. This is a sub-population of the Eligible Population.



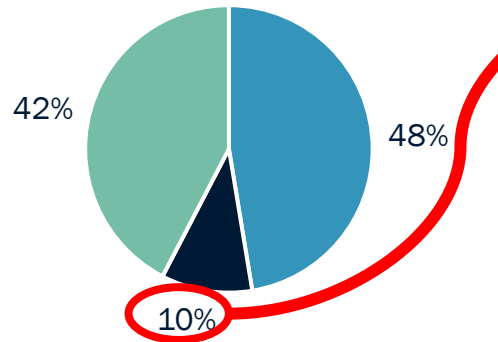
Who's in the Denominator: Not just data flow, but "Baby Flow"

Hearing Screening (n = 3,578,511)



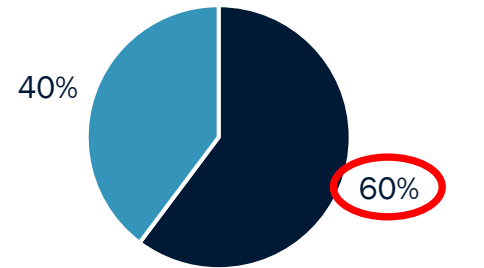
- Passed
- Not Pass + Referred to Diagnostic Evaluation
- Not Screened/Undetermined

Diagnostic Evaluation (n = 63,570)



- Normal Hearing (including transient cases)
- Permanent Hearing Loss
- No Documented Diagnosis/Undetermined

EI Enrollment (Part C & Non-Part C)
n = 6,518



- Enrolled in EI (Part C & Non-Part C)
- No Documented EI Services/Undetermined

Screening by 1 month

Definition: Screening by 1 month

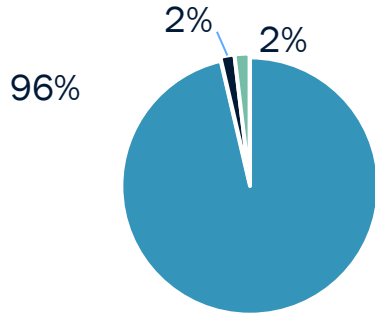
Numerator and Denominator

	Eligible Population (CDC Recommended)	Served Population
*Numerator	# screened by 1 month	# screened by 1 month
Denominator	# births reported by EHDI x 100	# screened x 100

* #screened before 1 month = # pass screen before 1 month + # not pass screen before 1 month

Who's in the Denominator: Not just data flow, but "Baby Flow"

Hearing Screening (n = 3,578,511)



- Passed
- Not Pass + Referred to Diagnostic Evaluation
- Not Screened/Undetermined

*Reported by 55 jurisdictions via 2021 HSFS

2021 Births: 1-Month Benchmark

Numerator: Infants Screened by 1 Month of Age = **3,418,241**

3,578,511



Eligible Population:
infants born reported by
EHDI systems



70,118

"Eligible"
includes infants
that did not
receive a
screening

Eligible Formula: **95.5 %**
($3,418,241 / 3,578,511 \times 100 = 95.5\%$)

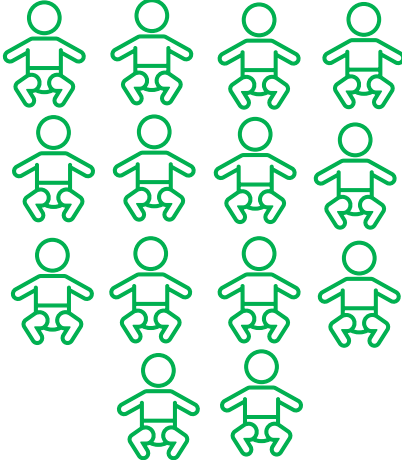
-  Infants born and screened
-  Infants born that did not receive a screening

2021 Births: 1-Month Benchmark


Numerator: Infants Screened by 1 Month of Age = **3,418,241**

3,508,393

Served Population:
infants that were
screened



Served Formula: **97.4 %**
($3,418,241 / 3,508,393 \times 100 = 97.4\%$)

 Infants born and screened

 Infants born that did not receive a screening

2021 Births: 1-Month Benchmark

Numerator: Infants Screened by 1 Month of Age = **3,418,241**

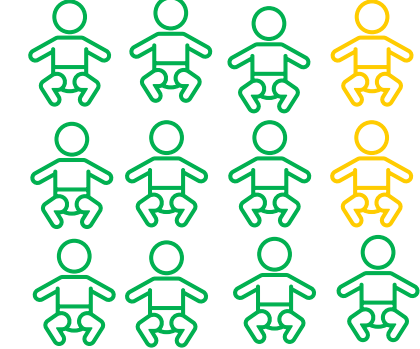
3,578,511

Eligible Population:
infants born reported by
EHDI systems



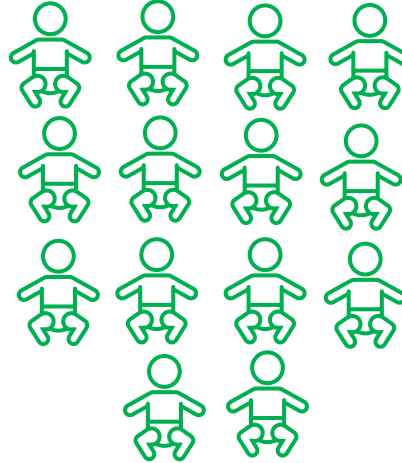
70,118

"Eligible"
infants that did
not receive a
screening





3,508,393

Served Population:
infants that were
screened



Eligible Formula: **95.5 %**
($3,418,241 / 3,578,511 \times 100 = 95.5\%$)

Served Formula: **97.4 %**
($3,418,241 / 3,508,393 \times 100 = 97.4\%$)

-  Infants born and screened
-  Infants born that did not receive a screening

Diagnosis by 3 months

Definition: Diagnosis by 3 months

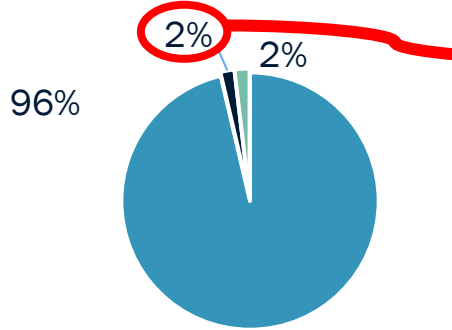
Numerator and Denominator

	Eligible Population (CDC Recommended)	Served Population
*Numerator	# diagnosed by 3 months	# diagnosed by 3 months
Denominator	# (infants not pass screening + infants referred straight to diagnostic evaluation) x 100	# w. documented diagnostic evaluation x 100

* # diagnosed by 3 months = # diagnosed with no hearing loss before 3 months + # with permanent hearing loss before 3 months

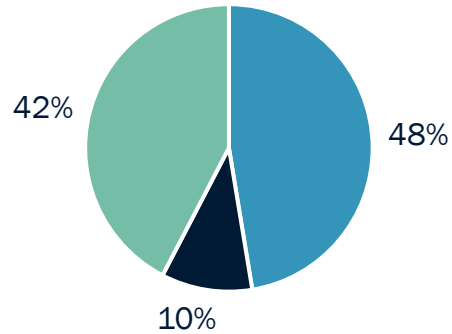
Who's in the Denominator: Not just data flow, but "Baby Flow"

Hearing Screening (n = 3,578,511)



- Passed
- Not Pass + Referred to Diagnostic Evaluation
- Not Screened/Undetermined

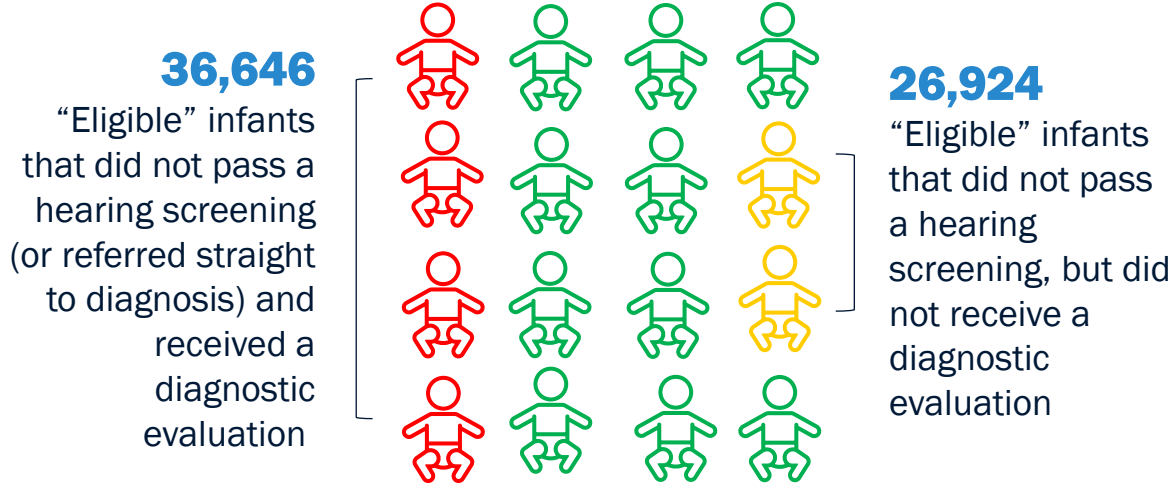
Diagnostic Evaluation (n = 63,570)



- Normal Hearing (including transient cases)
- Permanent Hearing Loss
- No Documented Diagnosis/Undetermined

2021 Births: 3-Month Benchmark

Numerator: Infants Diagnosed by 3 Months of Age = **27,137**



 Infants that passed hearing screening

 Infants that did not pass hearing screening and did receive a diagnostic evaluation, regardless of if the 3-month benchmark was met

 Infants that did not pass hearing screening and did not receive a diagnostic evaluation

N= 3,508,723 infants screened

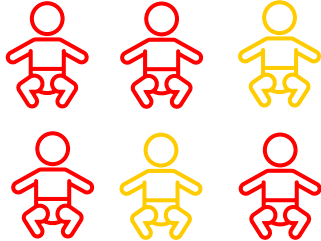
N= 63,570 infants diagnosed

2021 Births: 3-Month Benchmark

Numerator: Infants Diagnosed by 3 Months of Age = **27,137**

63,570

Eligible Population:
infants that did not pass screening



Eligible Formula: **42.7 %**
 $(27,137/63,570 \times 100 = 42.7\%)$



Infants that passed hearing screening



Infants that did not pass hearing screening and did receive a diagnostic evaluation, regardless of if the 3-month benchmark was met



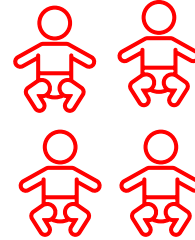
Infants that did not pass hearing screening and did not receive a diagnostic evaluation

2021 Births: 3-Month Benchmark

Numerator: Infants Diagnosed by 3 Months of Age = **27,137**

36,646

Served Population:
infants that received a
diagnostic evaluation



Served Formula: **74.1 %**
($27,137/36,646 \times 100 = 74.1\%$)



Infants that passed hearing screening



Infants that did not pass hearing screening and did receive a diagnostic evaluation, regardless of if the 3-month benchmark was met



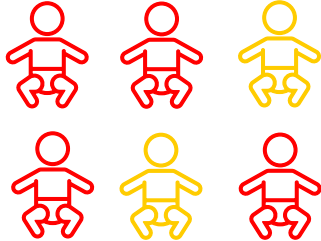
Infants that did not pass hearing screening and did not receive a diagnostic evaluation

2021 Births: 3-Month Benchmark

Numerator: Infants Diagnosed by 3 Months of Age = **27,137**

63,570

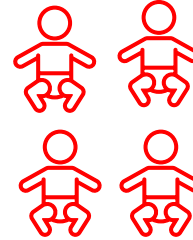
Eligible Population:
infants that did not pass screening



Eligible Formula: **42.7 %**
 $(27,137/63,570 \times 100 = 42.7\%)$

36,646

Served Population:
infants that received a
diagnostic evaluation



Served Formula: **74.1 %**
 $(27,137/36,646 \times 100 = 74.1\%)$



Infants that passed hearing screening



Infants that did not pass hearing screening and did receive a diagnostic evaluation, regardless of if the 3-month benchmark was met



Infants that did not pass hearing screening and did not receive a diagnostic evaluation

Early Intervention by 6 months

Definition: Early Intervention by 6 months

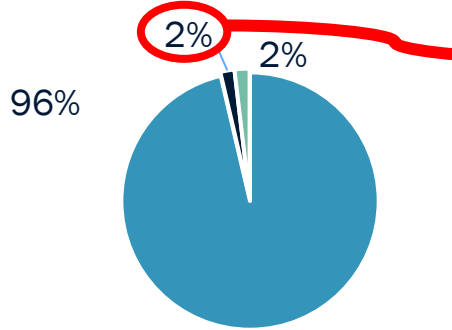
Numerator and Denominator

	Eligible Population (CDC Recommended)	Served Population
*Numerator	# enrolled in early intervention by 6 months	# enrolled in early intervention by 6 months
Denominator	# with permanent hearing loss x 100	# enrolled in Part C + # in non-Part C EI x 100

* # enrolled in Part C EI before 6 months + # in Non-Part C EI before 6 Months

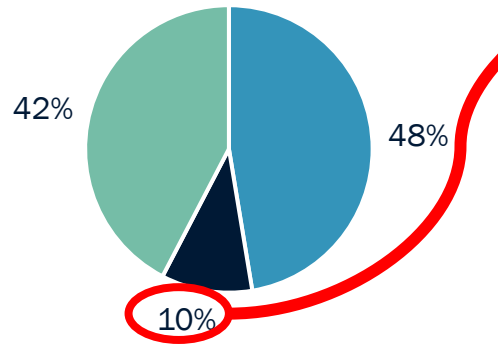
Who's in the Denominator: Not just data flow, but "Baby Flow"

Hearing Screening (n = 3,578,511)



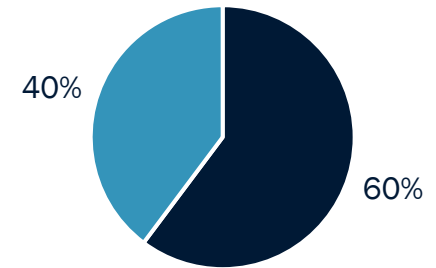
- Passed
- Not Pass + Referred to Diagnostic Evaluation
- Not Screened/Undetermined

Diagnostic Evaluation (n = 63,570)



- Normal Hearing (including transient cases)
- Permanent Hearing Loss
- No Documented Diagnosis/Undetermined

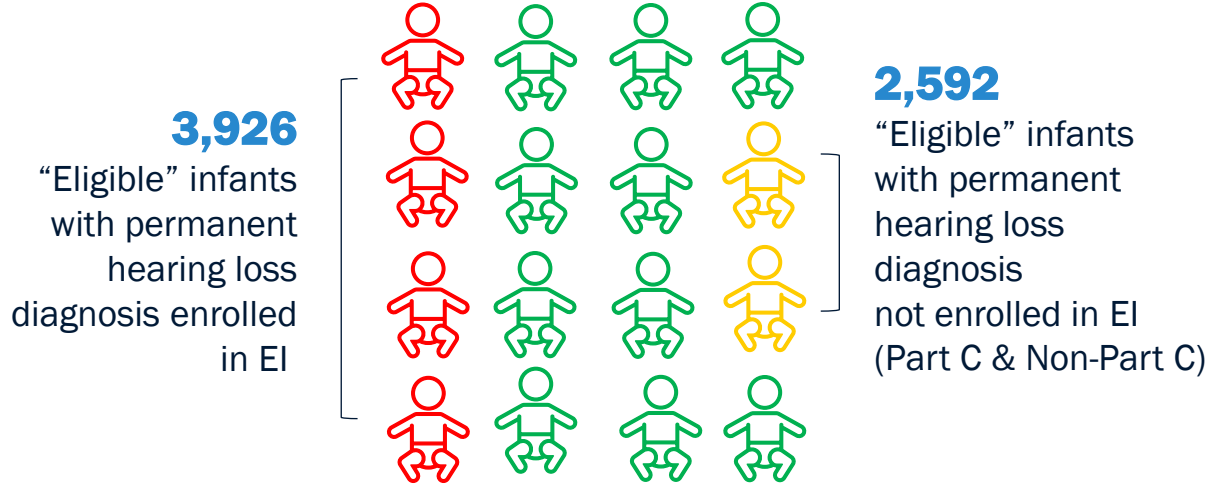
EI Enrollment (Part C & Non-Part C)
n = 6,518



- Enrolled in EI (Part C & Non-Part C)
- No Documented EI Services/Undetermined

2021 Births: 6-Month Benchmark

Numerator: Infants Enrolled by 6 Months of Age = **2,750**



Infants that received a diagnostic evaluation and diagnosed with normal hearing



Infants that received a diagnostic evaluation, were diagnosed with permanent hearing loss and enrolled into early intervention services, regardless of if the 6-month benchmark was met



Infants that received a diagnostic evaluation, were diagnosed with permanent hearing loss and not enrolled into early intervention services

N= 63,570 infants diagnosed

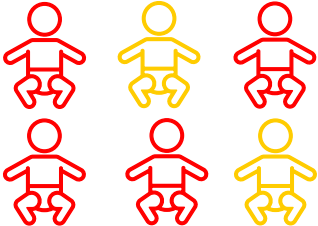
N= 6,518 infants diagnosed with permanent hearing loss

2021 Births: 6-Month Benchmark

Numerator: Infants Enrolled by 6 Months of Age = **2,750**

6,518

Eligible Population:
infants diagnosed with
permanent hearing loss



Eligible Formula: **42.2%**
 $(2,750/6,518 \times 100 = 42.2\%)$



Infants that received a diagnostic evaluation and diagnosed with normal hearing



Infants that received a diagnostic evaluation, were diagnosed with permanent hearing loss and enrolled into early intervention services, regardless of if the 6-month benchmark was met



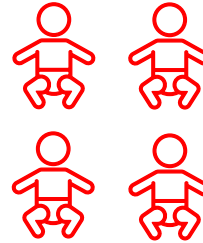
Infants that received a diagnostic evaluation, were diagnosed with permanent hearing loss and not enrolled into early intervention services

2021 Births: 6-Month Benchmark

Numerator: Infants Enrolled by 6 Months of Age = **2,750**

3,926

Served Population:
infants enrolled in EI



Served Formula: **70.0%**

$(2,750/3,926 \times 100 = 70.0\%)$



Infants that received a diagnostic evaluation and diagnosed with normal hearing



Infants that received a diagnostic evaluation, were diagnosed with permanent hearing loss and enrolled into early intervention services, regardless of if the 6-month benchmark was met



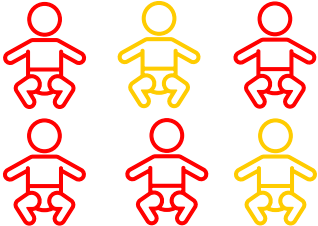
Infants that received a diagnostic evaluation, were diagnosed with permanent hearing loss and not enrolled into early intervention services

2021 Births: 6-Month Benchmark

Numerator: Infants Enrolled by 6 Months of Age = **2,750**

6,518

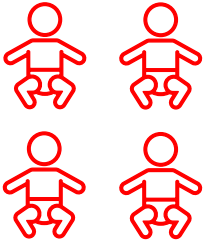
Eligible Population:
infants diagnosed with
permanent hearing loss



Eligible Formula: **42.2%**
($2,750/6,518 \times 100 = 42.2\%$)

3,926

Served Population:
infants enrolled in EI



Served Formula: **70.0%**
($2,750/3,926 \times 100 = 70.0\%$)



Infants that received a diagnostic evaluation and diagnosed with normal hearing



Infants that received a diagnostic evaluation, were diagnosed with permanent hearing loss and enrolled into early intervention services, regardless of if the 6-month benchmark was met



Infants that received a diagnostic evaluation, were diagnosed with permanent hearing loss and not enrolled into early intervention services

LTD/LFU

LTD/LFU

Lost to Documentation / Lost to Follow-Up

Categories

- Unable to contact
- Family contacted, but unresponsive
- Unknown

Data Collected by CDC

Hearing Screening and Follow-Up Survey (HSFS)

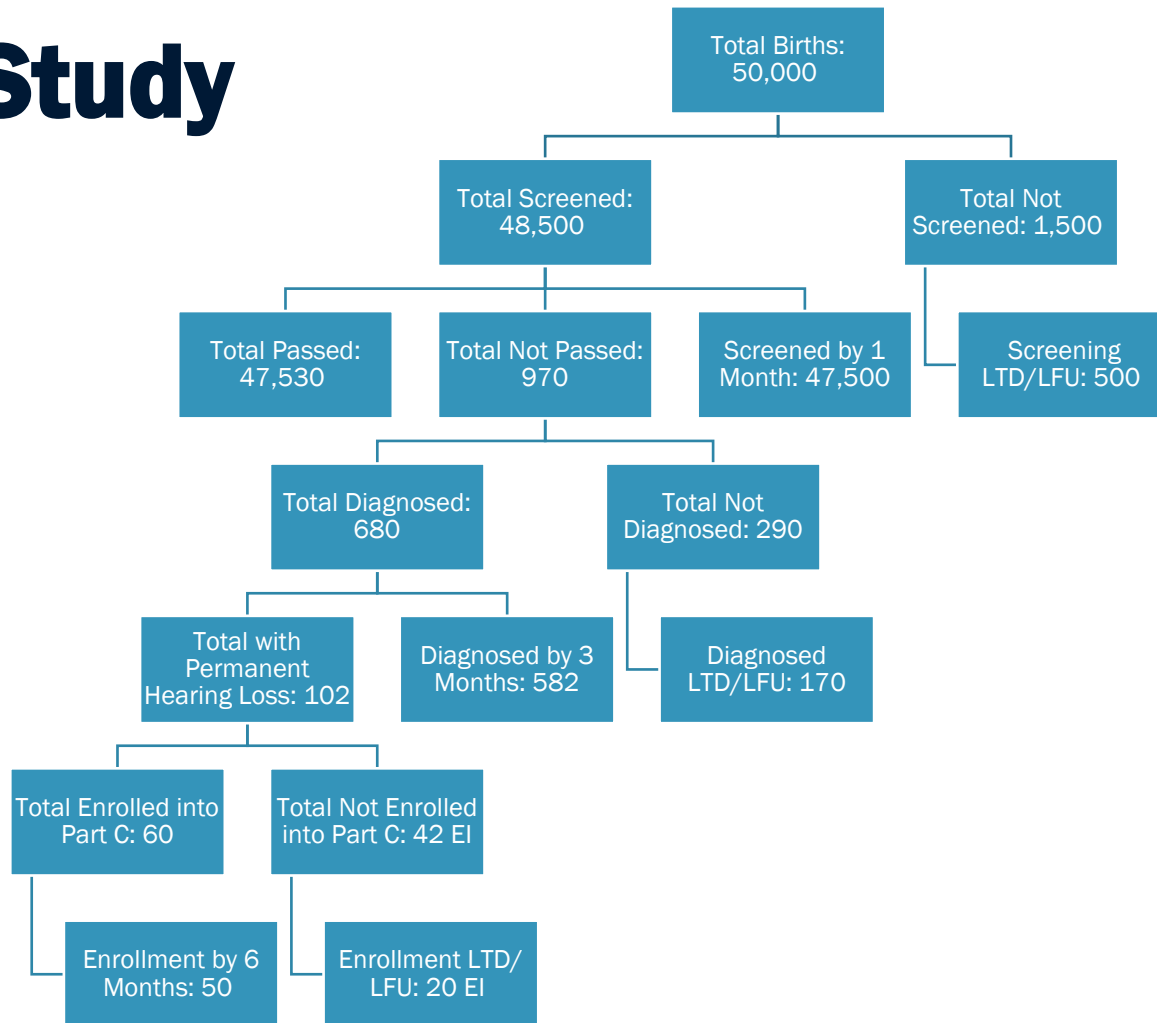
- Aggregate data
- Can provide LTD/LFU counts, but not specific sociodemographic characteristics

iEHDI

- Patient level data
- Can provide specific sociodemographic characteristics

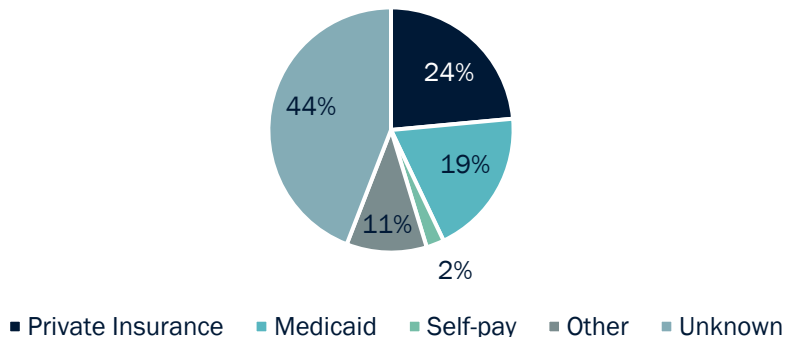
Case Study

Case Study

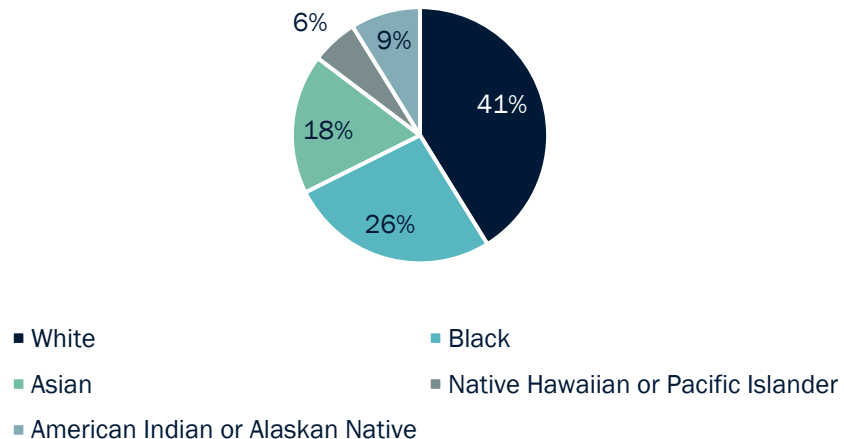


Case Study

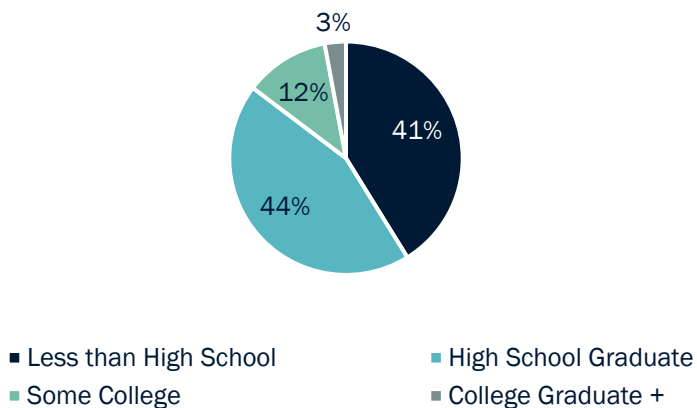
Mother's Primary Method of Payment



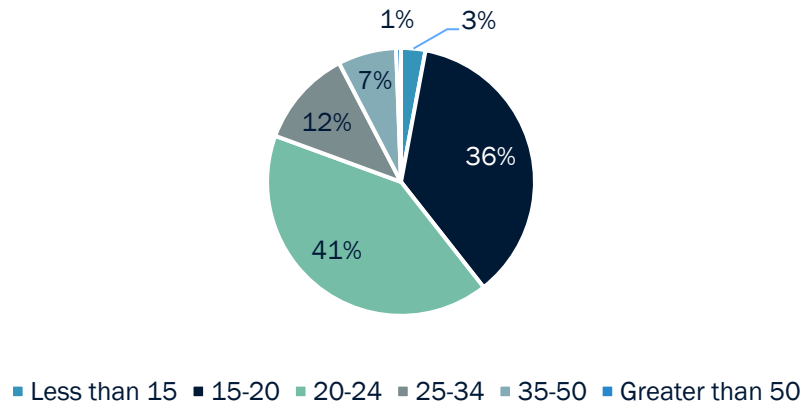
Mother's Race



Mother's Education Level



Mother's Age Group





Key Takeaways

- These aren't just data points, these are babies!
- Different denominators yield different metrics
 - Eligible vs served populations
- All formulas discussed provide important information
- iEHDI allows EHDI programs to examine the sociodemographic characteristics of their LTD/LFU
- Understanding the LTD/LFU population can help improve and strengthen follow-up efforts



Thank You

 Ecodom@cdc.gov

 [Clipton@cdc.gov](tel:Clipton@cdc.gov)