Demystifying iEHDI

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Disclaimer

The opinions expressed in this presentation are solely those of the presenter and do not necessarily represent the official position of the Centers for Disease Control and Prevention. The data presented here are provisional and have not been published.

Learning Objectives

iEHDI = Individualized Early Hearing Detection and Intervention

- Participants will be able to explain the purpose of iEHDI data collection
- Participants will identify opportunities for use of iEHDI to reduce disparities and promote health equity
- Participants will be able to identify how jurisdictions can compile a complete and accurate iEHDI dataset

iEHDI 101

What is iEHDI?

- Deidentified, individualized data that is submitted biannually to the CDC EHDI program
    - Required activity under the current CDC Cooperative Agreement DD20-2006 "Improving Timely Documentation, Reporting and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems“
    - 39 funded jurisdictions
    - Up to 179 variables reported on each child

iEHDI Variable Examples

Infant	Maternal/ Paternal	Screening	Diagnosis	Intervention	Outcome
DOB	DOB	Screening Date(s)	Date of Test(s)	Referral Date	Other Referrals
Gender	Race & Ethnicity	Result L/R	Test(s) Completed	Part C Eligibility	Hearing Aid (Y/N)
Birth Weight	Location (Zip Code)	Method	Overall Result	Enrollment Status	Hearing Aid Fitting Date
Location (Zip Code)	Education Level	Location & Provider	Degree & Severity (L/R)	Enrollment Date	CI (Y/N)
CHIP (Y/N)	WIC (Y/N)		Location (Zip Code)	Exit Date	CI Surgery
Risk Factors	Marital Status		Disposition	Exit Reason	Communication Used

Individualized versus Aggregated Data: Benefits

Individualized

- Explore factors influencing timeliness of receipt of service or examine which populations are more at risk for not seeking follow-up
- Can use the data to guide efforts to promote health equity
- Identify disparities within iEHDI data quality

Aggregated

- Generate routine reports and indicators, and allow estimates of for large areas (e.g., state, city)
- Allows for multiple comparisons (e.g., percent screened in each birthing facility in a state)

Individualized vs. Aggregated Data: Limitations

Individualized

- Variations in data definitions and standards

Aggregated

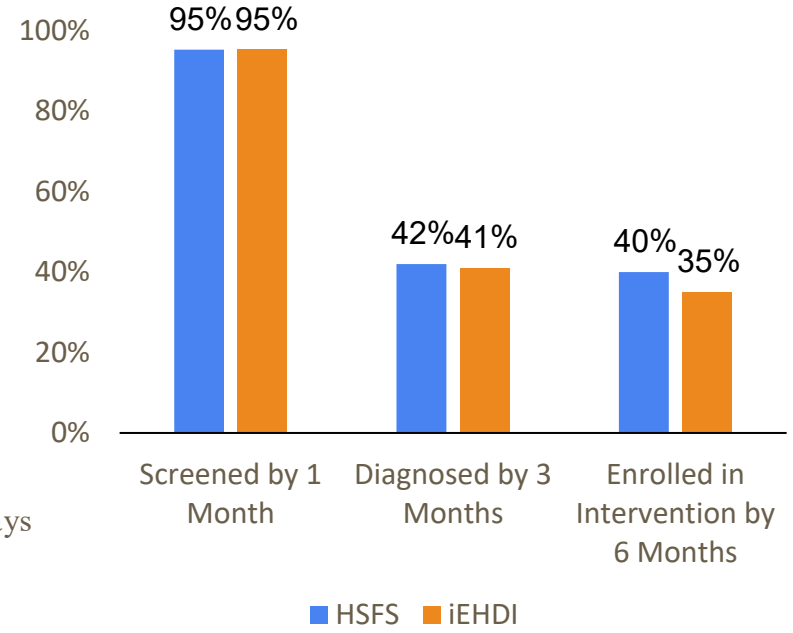
- Inflexibility to examine relationships among variables, answer specific questions, identify data quality issues, and to re-aggregate data if reporting needs change

1-3-6

How well does iEHDI align with HSFS?

1-3-6 Comparison: 2021 Birth Cohort

- **May of 2023 iEHDI submission versus 2021 HSFS submitted in January of 2023**
  - Removed 3 due to data quality concerns



Screened by 1 month: Number of infants with final screening by 30 days of age ÷ total births x 100
Diagnosed by 3 months: Number of infants receiving diagnosis by 90 days of age ÷ total not pass final hearing screen x 100
Enrolled in Intervention by 6 months: Number of infants enrolled in intervention by 6 months of age ÷ total with permanent hearing loss x 100

1-3-6 Comparison: 2021 Birth Cohort

	Screen by 1 Month		Diagnosis by 3 Months		Enrolled in Intervention by 6 Months	
	HSFS	iEHDI	HSFS	iEHDI	HSFS	iEHDI
Numerator	2,413,483	2,410,224	19,390	18,072	1,726	1,391
Denominator	2,532,201	2,527,923	46,432	44,412	4,351	3,973
%	95.31%	95.34%	41.76%	40.69%	39.67%	35.01%

Screened by 1 month: Number of infants with final screening by 30 days of age ÷ total births x 100
Diagnosed by 3 months: Number of infants receiving diagnosis by 90 days of age ÷ total not pass final hearing screen x 100
Enrolled in Intervention by 6 months: Number of infants enrolled in intervention by 6 months of age ÷ total with permanent hearing loss x 100

How Complete are the Data?

Why Data Completeness Matters

- To conduct in-depth analysis exploring demographic and geographic factors impact on 1-3-6 and loss to follow-up, missing data limits the ability to generalize findings

iEHDI Variables continued…

Tier 1 vs Tier 2

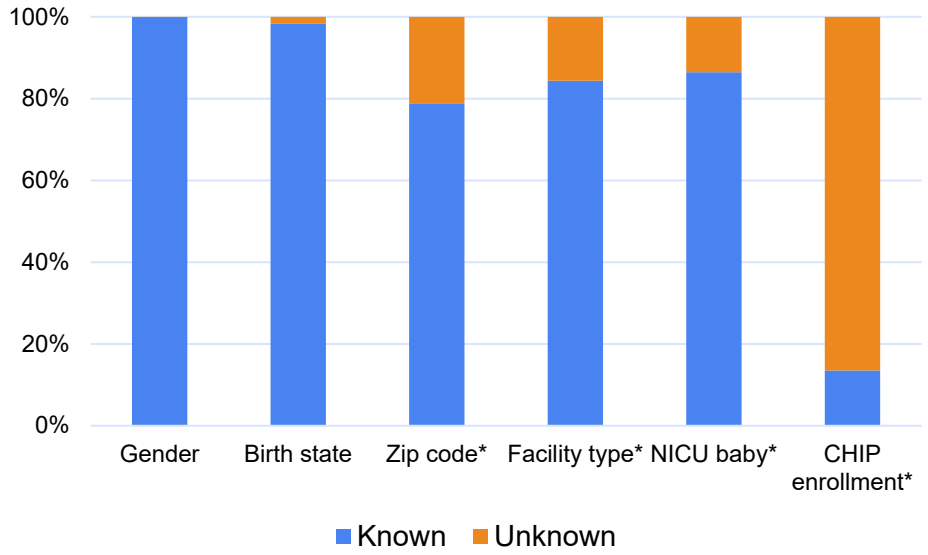
- Tier 1 = Required
- Tier 2 = Optional

Category	Tier 1 Items	Tier 2 Items
General > Infant	4	7
Risk Factors		11
General > Mother	20	5
General > Father		19
Hearing Screening	8	5
Diagnostic Testing	9	60
Early Intervention	3	11
Type/Severity	10	
Medical Intervention		7
Total	54	125

Infant Demographics

Variable	Known	Unknown
Gender	99.98%	0.02%
Birth state	98.39%	1.61%
Birth zip code*	78.73%	21.27%
Facility type*	84.37%	15.63%
NICU baby*	86.45%	13.55%
CHIP enrollment*	13.50%	86.50%

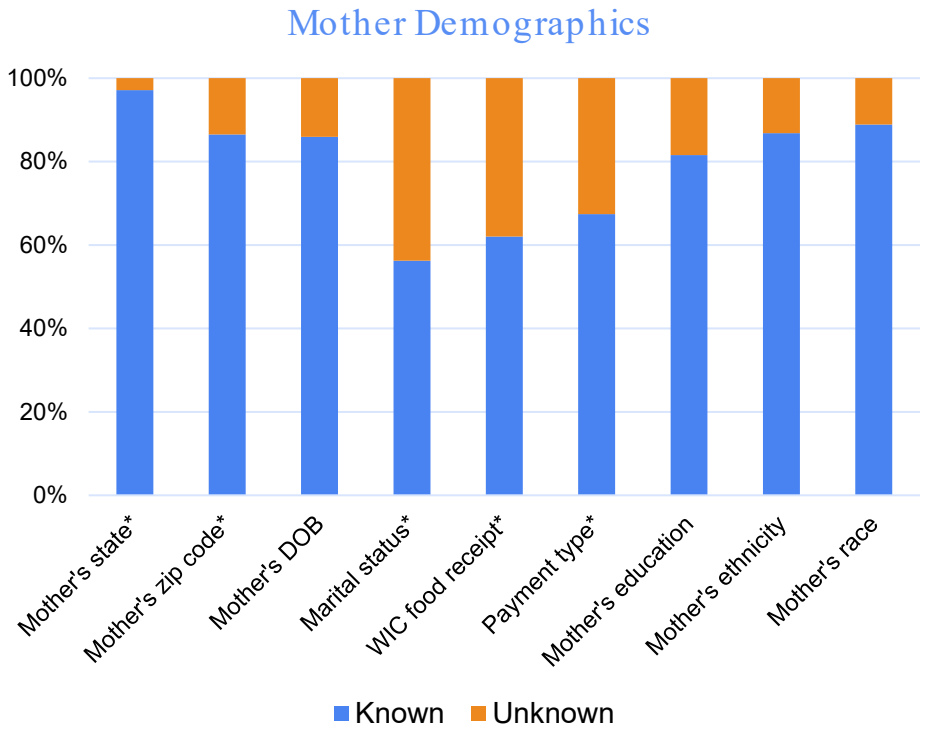
*Tier 2 variable



Mother Demographics

Variable	Known	Unknown
Mother's state*	97.15%	2.85%
Mother's zip code*	86.52%	13.48%
Mother's DOB	85.94%	14.06%
Marital status*	56.25%	43.75%
WIC food receipt*	62.06%	37.94%
Payment type*	67.41%	32.59%
Mother's education	81.57%	18.43%
Mother's ethnicity	86.83%	13.17%
Mother's race	88.87%	11.13%

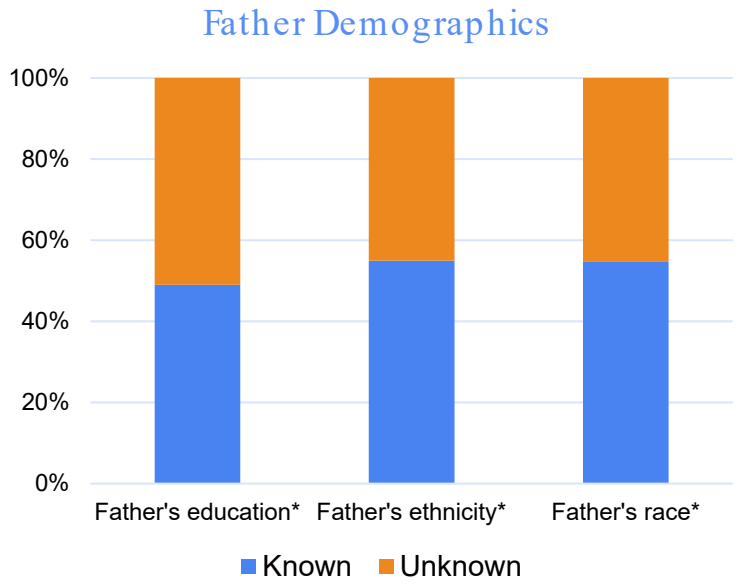
*Tier 2 variable



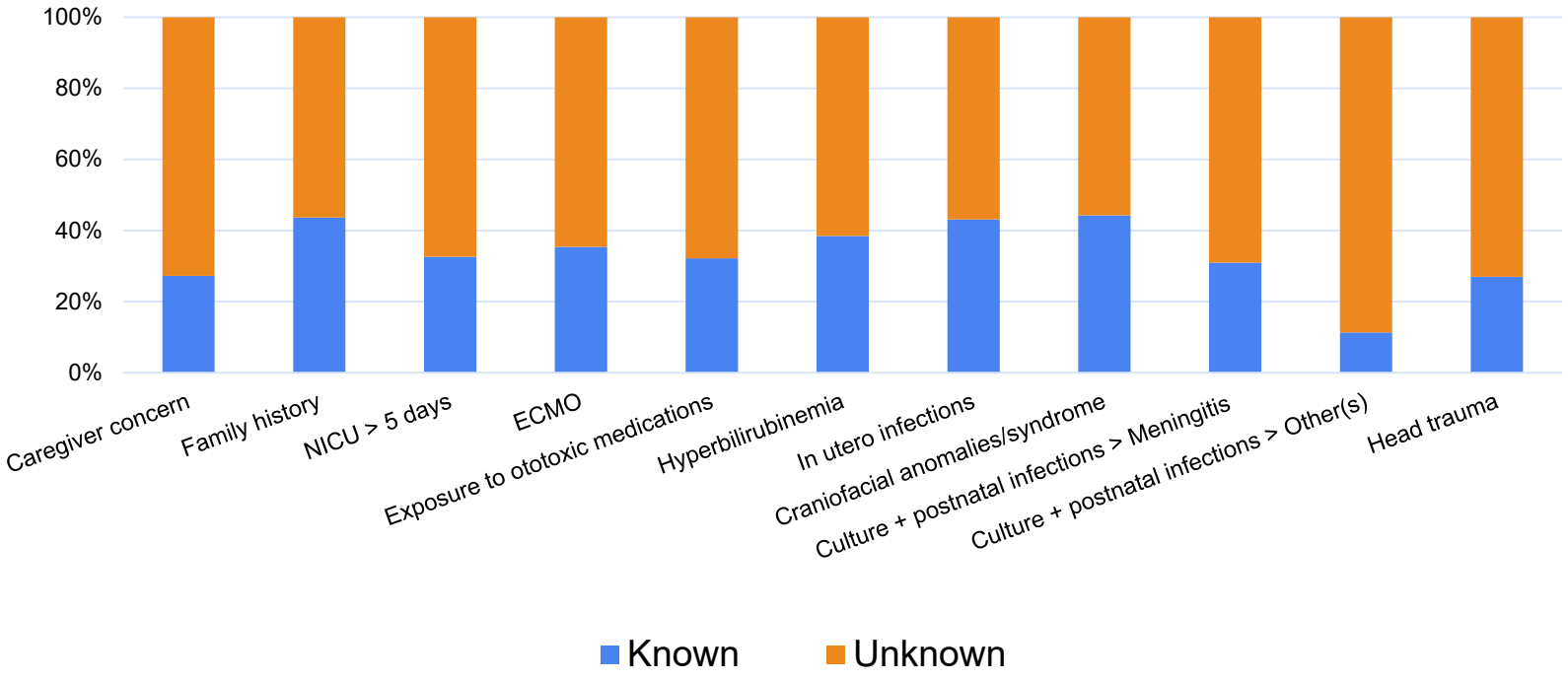
Father Demographics

Variable	Known	Unknown
Father's education*	49.02%	50.98%
Father's ethnicity*	54.94%	45.06%
Father's race*	54.63%	45.37%

*Tier 2 variable



Risk Factors*

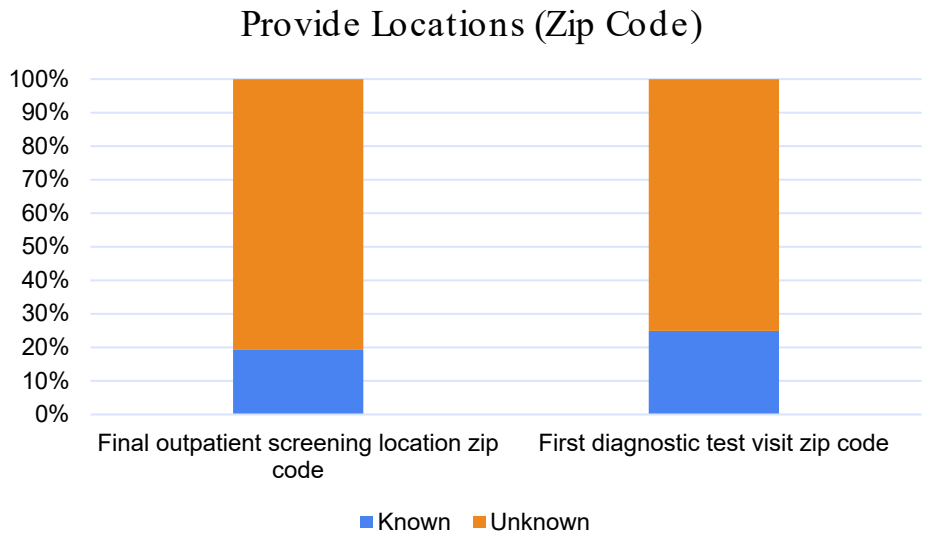


*Tier 2 variable

Provider Locations

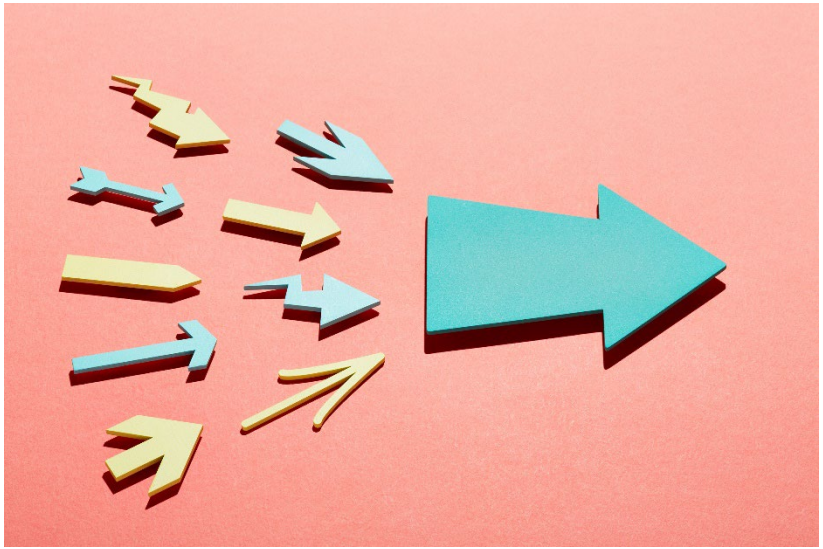
Variable	Known	Unknown
Final outpatient screening location zip code*	19.25%	80.75%
First diagnostic test visit zip code*	24.91%	75.09%

*Tier 2 variable



This population only includes infants who did not pass their hearing screening (N=47,140)

Preparation of iEHDI data



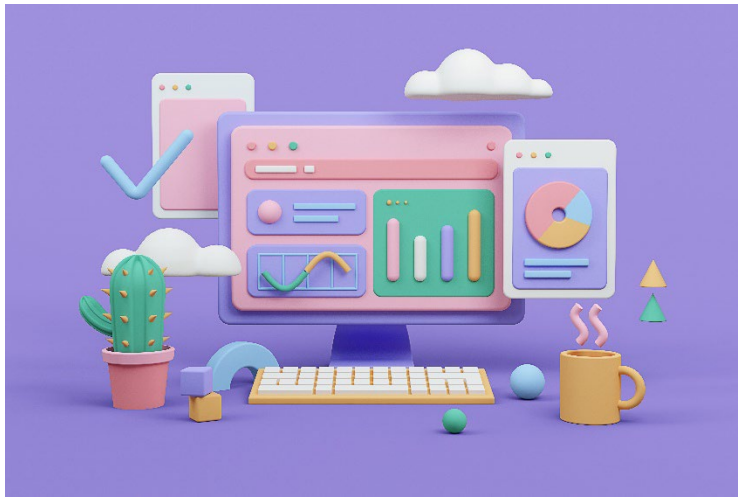
- Complete data needed from multiple sources
- Timing of complete data availability from sources
- Data quality

Preparation of iEHDI

- Variable present in data system vs known/unknown
- Knowing where your system is currently
- Increasing data variables
  - Of the 60 variables not present, 97% can be captured through other data sources
  - Combining data from multiple sources outside of the data system is challenging

Variable Category	Variable Present in MNScreen		Total
	Yes	No	
General Infant	8	3	11
General Mother	11	14	25
General Father	7	12	19
Risk Factors	11	0	11
Hearing Screening	11	2	13
Diagnostic Testing	62	17	79
Medical Intervention	5	2	7
Early Intervention	4	10	14
Grand Total	119	60	179
Percent	66%	34%	

iEHDI for QA



- Improving data quality
  - Free text
  - Frequently missing
  - identify different sources for the same data and examine which source may be more reliable
- Investigate differences between HSFS & iEHDI
- Review definitions
- Collaborations

Conclusion

- There are advantages to jurisdictions submitting individualized data to CDC EHDI, but:
  - Variations between HSFS and iEHDI at a jurisdictional level create opportunity for closer examination of data
    - For jurisdictions that don't use iEHDI dataset for preparing HSFS, there is a need to better understand how the data is prepared

Conclusions continued…

- There is work to be done to improve data completeness to improve ability to conduct analyses on demographic and geographic factors impact on 1-3-6 and loss to follow-up
  - Consider sources outside of Vital Records for demographic data that there are already existing data sharing agreements

Next Steps?

- Work collaboratively, CDC and jurisdictions, to improve alignment of iEHDI and HSFS measures and iEHDI data completeness
  - Developing and sharing universal formulas and coding calculating 1-3-6 using iEHDI dataset
  - Reports of known versus unknown on Tier 1 variables

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