



Progress in EHDI-IS

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EHDI Conference

Overview

- Introduction
- Overview of EHDI-IS Functional Standards
- Overview of ESSET
- ESSET 2017 Results
- Future updates

EHDI-IS Functional Standards

- The EHDI-IS Functional Standards defines: A “Complete” EHDI-IS
 - Specifies the programmatic, operational, and technical functional requirements
 - Guides system development and evaluation activities
- Is
 - Intended to be used by ALL EHDI jurisdictions
 - A living document and will be reviewed and revised on periodical basis
- Is NOT
 - An implementation guide of EHDI-IS
 - An information system technical manual

Understanding the Functional Standards

- Programmatic Goals
- Functional Standards by Programmatic Goals
 - EHDI-IS Data Item List
- Appendices:
 - Data Definition
 - Data Quality Worksheet
- <https://www.cdc.gov/ncbddd/hearingloss/ehdi-is-functional-standards.html>

Programmatic Goals

Care and Service Delivery

1. Document unduplicated, individually identifiable data on the delivery of newborn hearing screening services for all infants born in the jurisdiction.
2. Support tracking and documentation of the delivery of follow-up services for every infant/child who did not receive, complete, or pass newborn hearing screening.
3. Document all cases of hearing loss, including congenital, late-onset, progressive, and acquired cases for infants and children < 3 years old.
4. Document the enrollment status, delivery and outcome of early intervention services for infants and children < 3 years old with hearing loss.

Data Management, Analysis, and Reporting

1. Maintain data quality (accurate, complete, timely data) of individual newborn hearing screening, follow-up screening and diagnosis, early intervention and demographic information in the EHDI-IS.
2. Preserve the integrity, security, availability and privacy of all personally-identifiable health and demographic data in the EHDI-IS.
3. Enable evaluation and data analysis activities.
4. Support dissemination of EHDI information to authorized stakeholders.

ESSET Overview

- Assess the progress of EHDI-IS in meeting the Functional Standards
- The ESSET is intended to help you identify the strengths and weaknesses of your EHDI-IS
- Can inform activities in the work plan
- This tool is NOT intended to be used as a road map in that it does not tell you where to start or what to do next, rather can be used to inform the activities of your work plan
 - *Note: Program Logic model can serve as a roadmap*

ESSET

Microsoft Excel interface showing the ESSET spreadsheet. The ribbon includes File, Home, Insert, Page Layout, Formulas, Data, Review, and View. The spreadsheet displays a table with columns for Quality Indicators, Goal Statements, and related work plans. The 'Summary' tab is active, showing a table with columns for Rating (1-4) and Related Work Plan.

Quality Indicator	Met Y/N
Goal Statement 1	
1.1 The EHDI-IS SHALL provide a unique patient record for each newborn child born in the jurisdiction	Yes
1.2 The EHDI-IS SHALL receive and document information about patient's birth encounter and newborn admission information in a timely manner in accordance with scope of practice.	Yes
1.3 The EHDI-IS SHALL receive and document patient's maternal demographic information, in accordance with scope of practice, organizational policy and jurisdictional law.	Yes
1.4 The EHDI-IS SHALL receive and document all individual newborn hearing screening procedures and results, in a timely manner in accordance with scope of practice, organizational policy and jurisdictional law.	Yes
1.5 The EHDI-IS SHOULD receive and document information about risk factors of infant hearing loss at the time of newborn hearing screening.	Yes
1.6 The EHDI-IS SHALL review incoming and existing patient records and document the most recent newborn hearing screening status and outcome (Pass, refer, not screened).	Yes
1.7 The EHDI-IS SHALL receive and document information on the reason why an infant hearing screening is not performed or completed.	Yes
1.8 The EHDI-IS SHALL provide the ability to capture and document information about an infant's NICU stay and transfer status.	Yes
1.9 The EHDI-IS MAY receive submissions of newborn hearing screening information in accordance with interoperability standards endorsed by CDC for message content, format, and transport.	Yes
Goal Statement 2	
2.1 The EHDI-IS SHOULD provide a unique patient record for each infant/child born out of the jurisdiction but currently reside within the jurisdiction and is in need of hearing screening or diagnostic follow-up services.	1
2.2 The EHDI-IS SHALL provide the ability to generate and present a list of infants who did not pass newborn hearing screening (including initial screening and any follow-up rescreening) and are in need of follow-up rescreening and/or diagnostic evaluation services.	4
2.3 The EHDI-IS SHALL provide the ability to generate and present a list of infants who did not receive or complete newborn hearing screening and are in need of recommended screening and/or diagnostic evaluation services.	4
2.4 The EHDI-IS MAY provide the ability to make referrals for recommended follow-up services.	4
2.5 The EHDI-IS SHALL document referrals made.	4
2.6 The EHDI-IS SHALL receive and document information on rescreening procedures and results in a timely manner in accordance with scope of practice, organizational policy and jurisdictional law.	3
2.7 The EHDI-IS SHALL receive and document information on procedures and results of ALL follow-up audiological diagnostic	

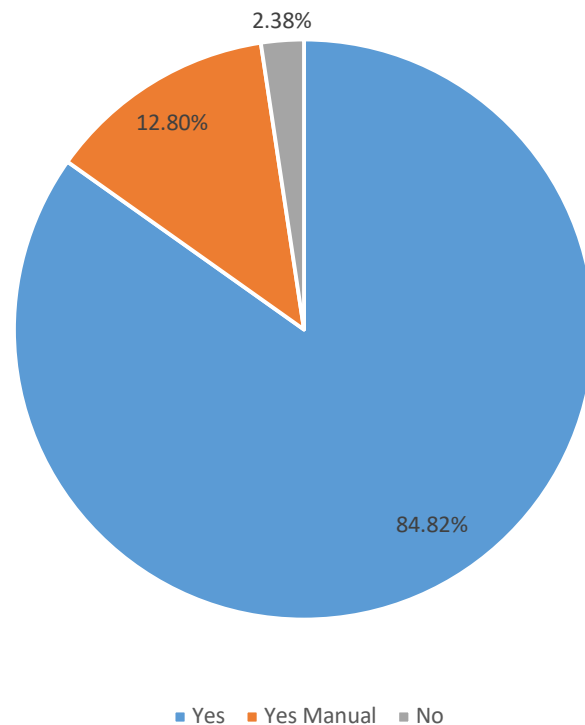
Additional Comment: ...

This Tab does not require any selection or additions from you. Rather, this is an overall summary of the standard ratings you assigned in Tabs 4 - 11. All of your assigned standard ratings and location of standards in your current work plan are pre-populated into this tab.

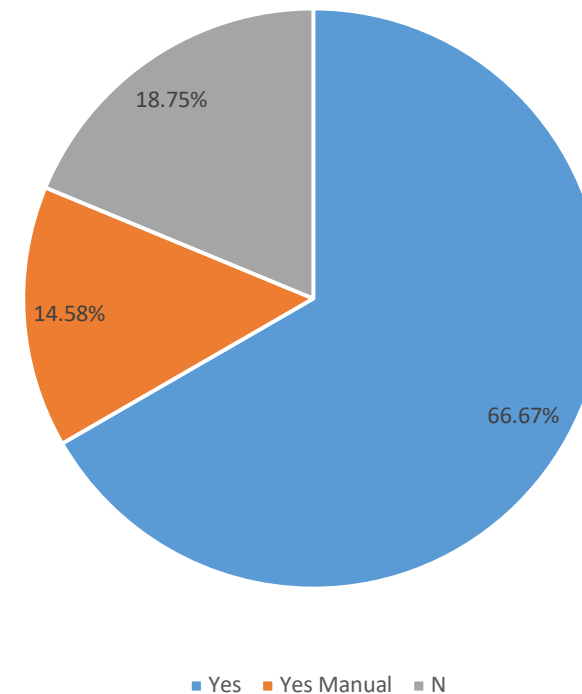
Goal #1: Document unduplicated individually identifiable data on the delivery of newborn hearing screening services for all infants born in the jurisdiction

- 7 SHALLs, 1 SHOULD, 1 May
- Response Categories: Yes/Yes Manual/No
- All jurisdictions combined (48)

Percentage of standards met - SHALL (N = 48X7 = 336)



Percentage of standards met - SHOULD (N=48)



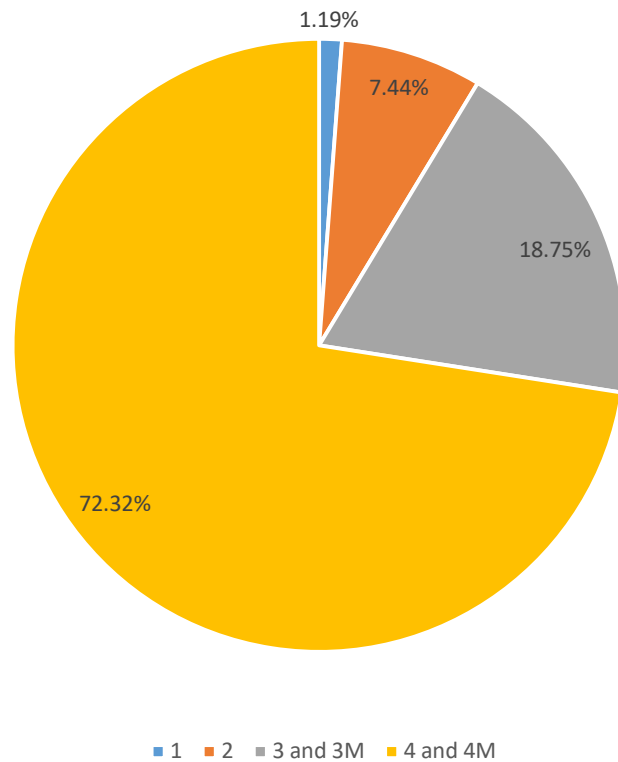
Goal #1 – By Individual Standard

- 1.1 The EHDI-IS SHALL provide a unique patient record for each newborn child born in the jurisdiction. - 100% (48/48)
- 1.2 The EHDI-IS SHALL receive and document information about patient's birth encounter and newborn admission information in a timely manner in accordance with scope of practice, organizational policy and jurisdictional law. - 100% (48/48)
- 1.3 The EHDI-IS SHALL receive and document patient's maternal demographic information, in accordance with scope of practice, organizational policy and jurisdictional law. -- (46/48)
- 1.4 The EHDI-IS SHALL receive and document all individual newborn hearing screening procedures and results, in a timely manner in accordance with scope of practice, organizational policy and jurisdictional law. 100% (48/48)
- 1.5 The EHDI-IS SHOULD receive and document information about risk factors of infant hearing loss at the time of newborn hearing screening. (39/48)
- 1.6 The EHDI-IS SHALL review incoming and existing patient records and document the most recent newborn hearing screening status and outcome (pass, refer, not screened) of the patient. 100% (48/48)
- 1.7 The EHDI-IS SHALL receive and document information on the reason why an infant hearing screening is not performed or completed. (45/48)
- 1.8 The EHDI-IS SHALL provide the ability to capture and document information about an infant's NICU stay and transfer status. (45/48)

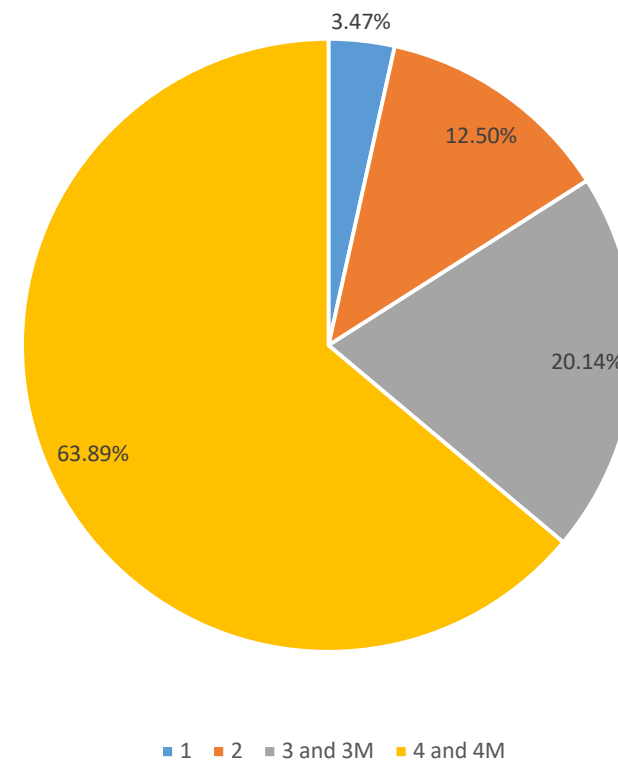
Goal #2: Support tracking and documentation of the delivery of follow-up services for every infant/child who did not receive, complete or pass newborn hearing screening

- 7 SHALLs, 3 SHOULDs, 2 Mays
- Response Categories: 1, 2, 3, 3M, 4, 4M
- All states combined (48)

Percentage of standards met -- SHALL (N = 48X7=336)

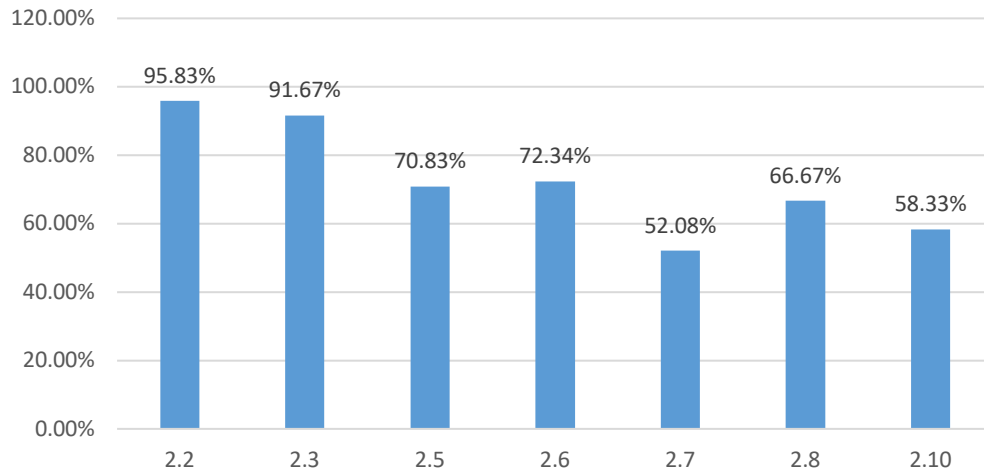


Percentage of standards met -- SHOULD (N=48X3=144)



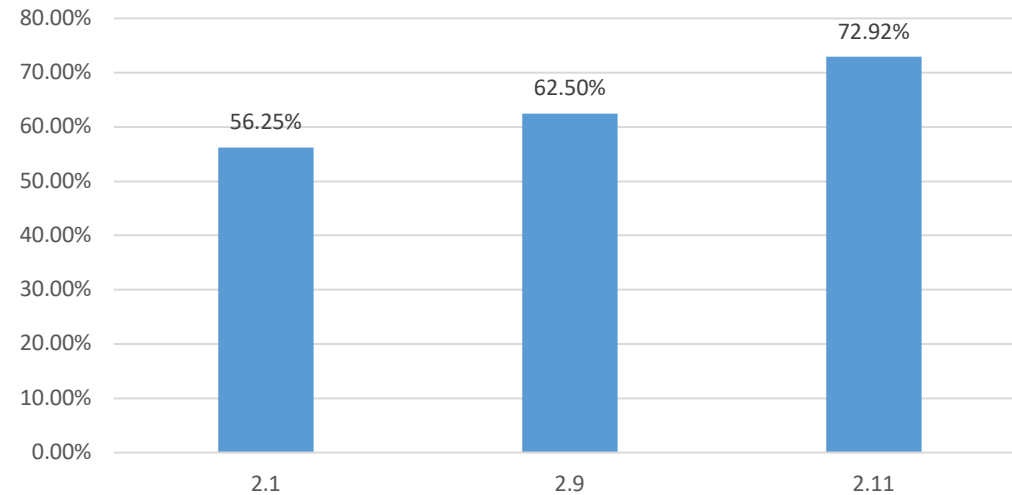
Goal #2 – By individual standard

Percentage of states meeting the standards - SHALL
(N=48)



- 2.7 The EHDI-IS SHALL receive and document information on procedures and results of ALL follow-up audiological diagnostic evaluation services in a timely manner in accordance with scope of practice, organizational policy and jurisdictional law.
- 2.10 The EHDI-IS SHALL receive and document information on the reason why an infant did not receive recommended follow-up services

Percentage of states meeting the standard -- SHOULD
(N =48)

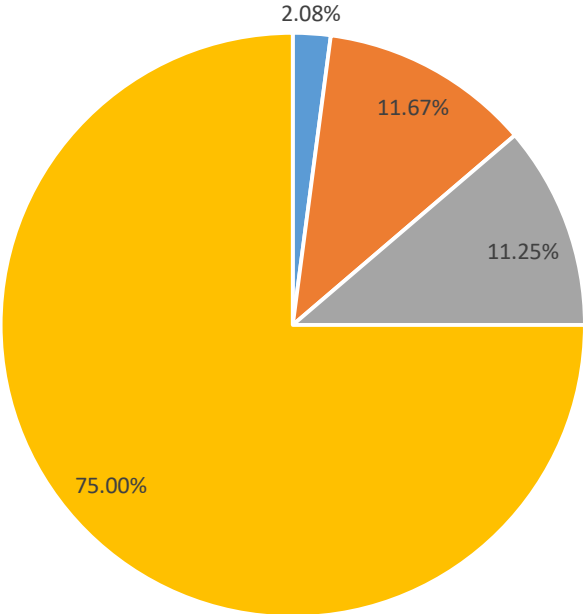


- 2.1 The EHDI-IS SHOULD provide a unique patient record for each infant/child born out of the jurisdiction but currently reside within the jurisdiction and is in need of hearing screening or diagnostic follow-up services.
- 2.9 The EHDI-IS SHOULD receive and document information about referrals and/or recommendations made following an audiological diagnostic evaluation.
- 2.11 The EHDI-IS SHOULD provide the ability to notify parents and healthcare providers of infants who are in need of follow-up services.

Goal #3: Document ALL cases of permanent hearing loss, including congenital, late-onset, progressive, and acquired cases for infants/children < 3 years old

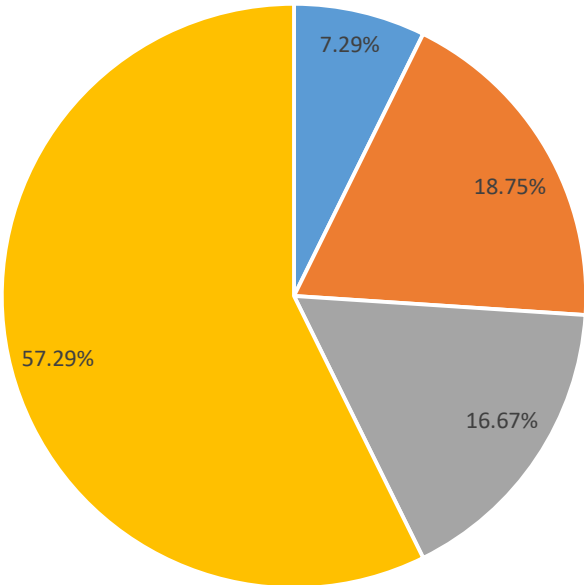
- 5 SHALLs, 2 SHOULDs
- Response Categories: 1, 2, 3, 3M, 4, 4M
- All states combined (48)

Percentage of standards met - SHALL (N=48X5 = 240)



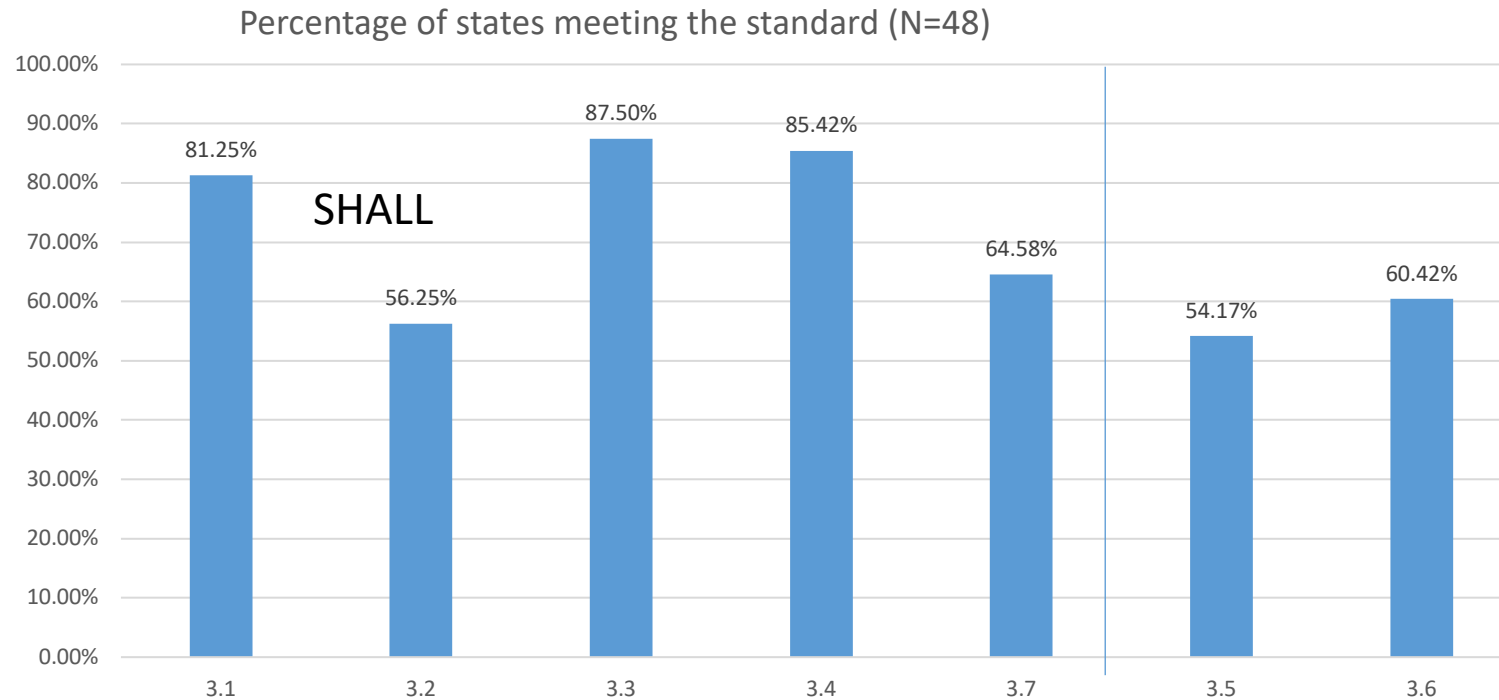
■ 1 ■ 2 ■ 3 and 3M ■ 4 and 4M

Percentage of standards met -- SHOULD (N=48 X 2 = 96)



■ 1 ■ 2 ■ 3 and 3M ■ 4 and 4M

Goal #3: By individual standard

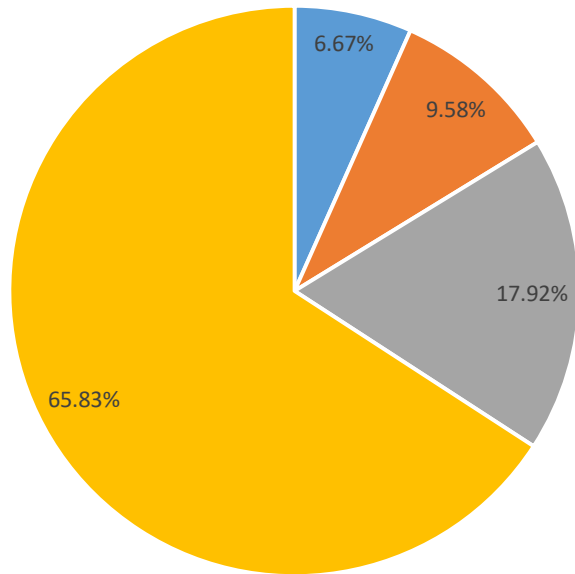


- 3.2 The EHDI-IS **SHALL** provide the ability to receive and document information on additional infants/children hearing loss that are not identified through the newborn hearing screening follow-up process, e.g. reported from primary care provider, or through data exchange with the early intervention systems, and other public health information systems and/or registries, in accordance with scope of practice, organizational policy and jurisdictional law.
- 3.7 The EHDI-IS **SHALL** provide the ability to generate and present separate lists of infants/children with presumed congenital (referred on newborn hearing screening) and late-onset/progressive/acquired hearing loss.

Goal #4: Document the enrollment status, delivery and outcome of early intervention services for infants and children with hearing loss < 3 years old

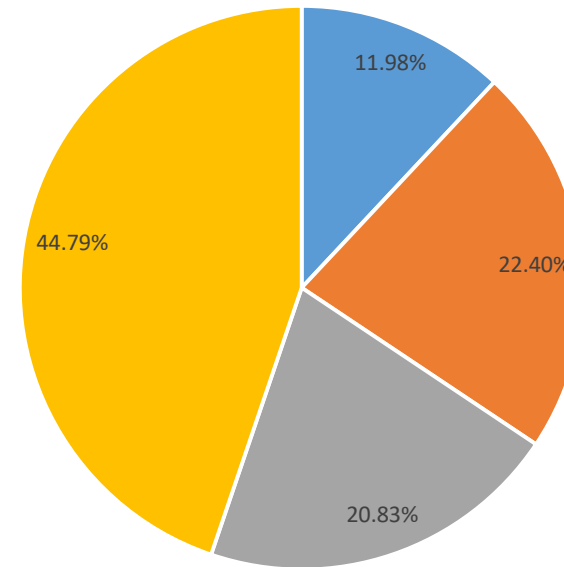
- 5 SHALLs, 4 SHOULDs
- Response Categories: 1, 2, 3, 3M, 4, 4M
- All states combined (48)

Percentage of standards met - SHALL (N=48x5 = 240)



■ 1 ■ 2 ■ 3 and 3M ■ 4 and 4M

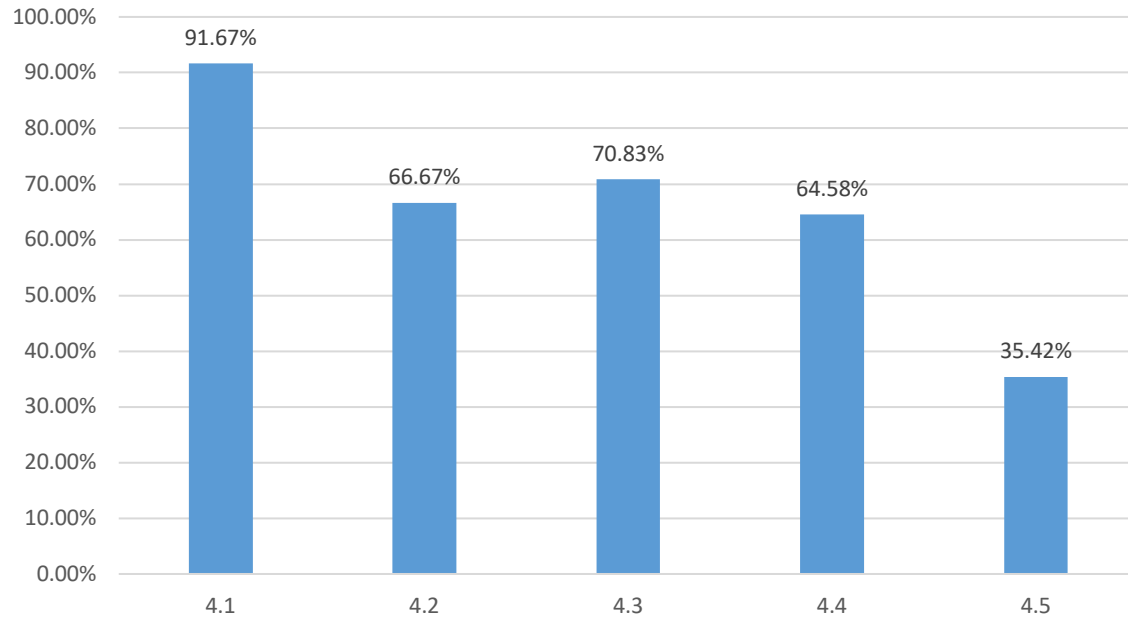
Percentage of standards met - SHOULD (N = 48 X 4 = 192)



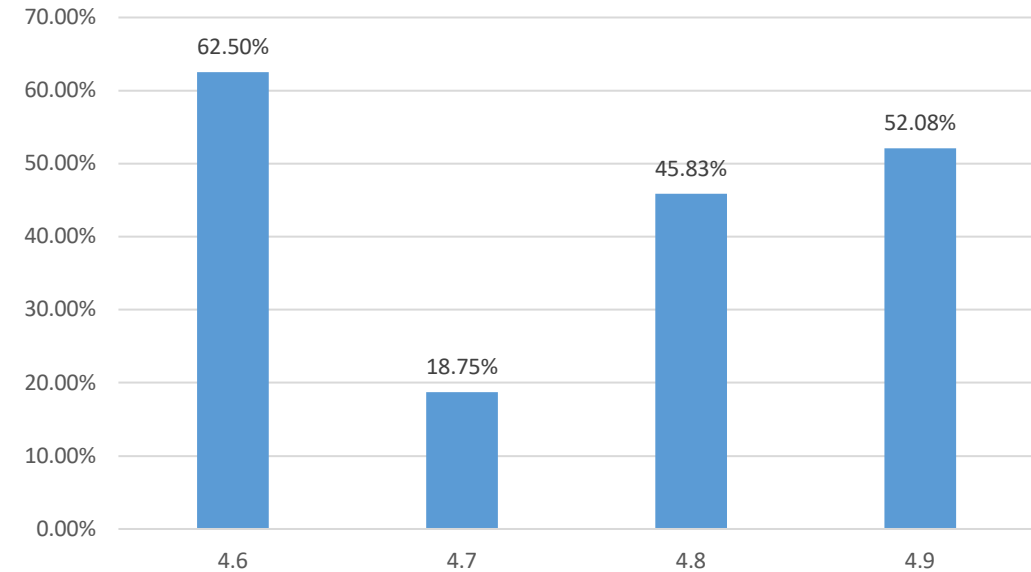
■ 1 ■ 2 ■ 3 and 3M ■ 4 and 4M

Goal #4 – By individual standard

Percentage of states meeting the standard – SHALL (N=48)

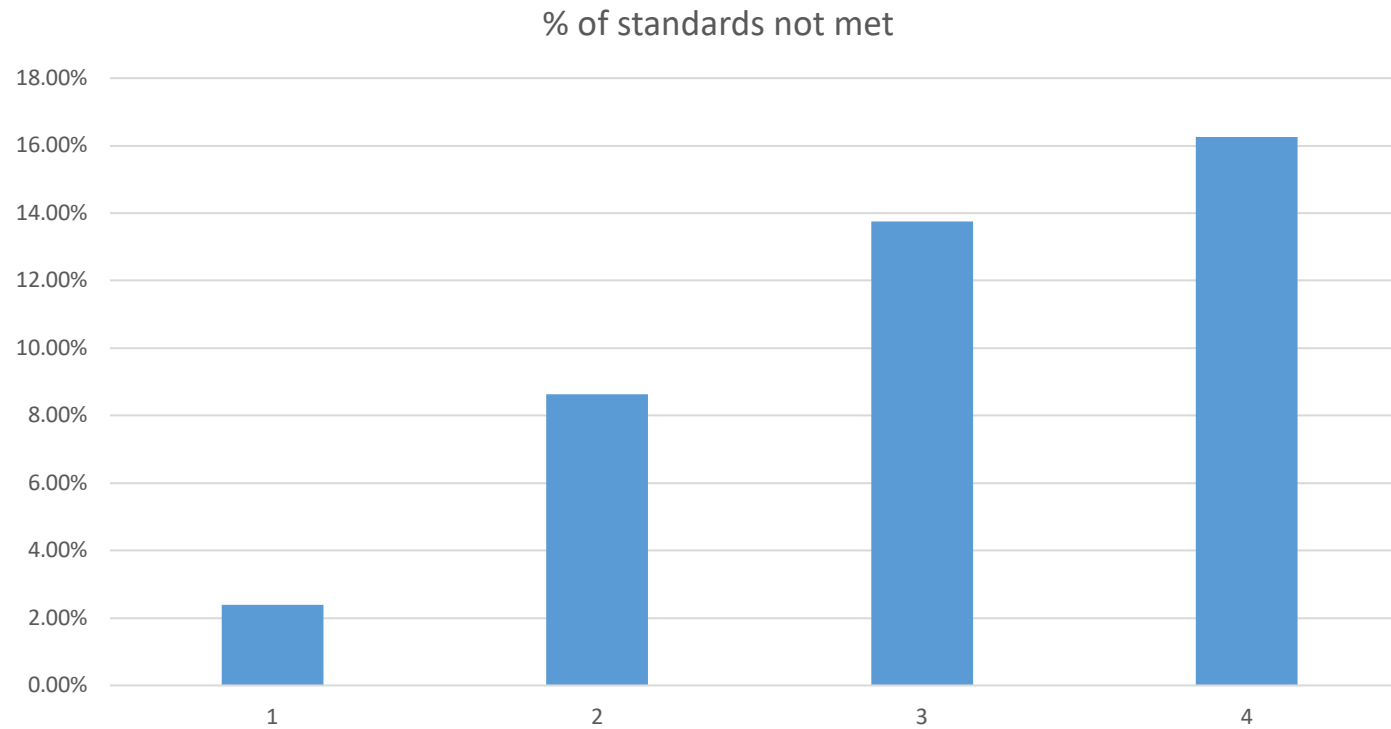


Percentage of states meeting the standard - SHOULD (N=48)



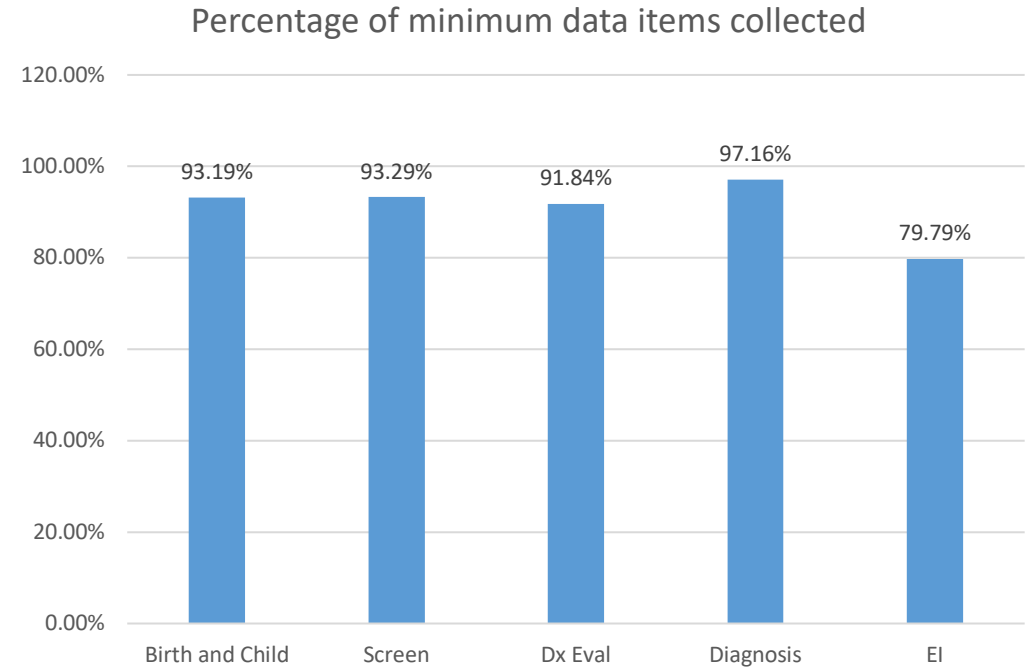
- 4.4 The EHDI-IS **SHALL** receive and document information on Part C EI (i.e. date when the Individual Family Service Plan or IFSP is signed).
- 4.5 The EHDI-IS **SHALL** receive and document information on other non-Part C early intervention services enrollment, in accordance with scope of practice, organizational policy and jurisdictional law.
- 4.6 The EHDI-IS **SHOULD** provide the ability to receive and document recommended audiologic intervention method upon a hearing loss diagnosis from providers.
- 4.7 The EHDI-IS **SHOULD** provide the ability to receive and document data on early intervention outcomes.
- 4.8 The EHDI-IS **SHOULD** provide the ability to compare and match infants in the system with those in the EI system to identify missed cases.
- 4.9 The EHDI-IS **SHOULD** provide the ability to notify parents, healthcare and EI providers of infants' need for EI services.

% of standards not met for each goal



Data Items: Minimum

- Total: 39 items
 - Birth and Child: 10
 - Hearing Screening/Rescreen: 13
 - Diagnostic Evaluation: 6
 - Diagnosis: 6
 - Early Intervention: 4
- Out of 47 states (one state did not provide this information)
 - 100% collecting: ID, Name, DoB, Gender, Birthing facility name, home birth or not, date and results of newborn hearing screening, date and result of rescreen.
 - 85-99%: Plurality/Order, birth facility contact, NICU status, screening facility info, reason for not screened, screening disposition, Dx evaluation date and result, evaluation site, audiologist, date and result of diagnosis, date of referral to EI, IFSP date.
 - 70-84%: Date of referral to Dx, provider referred to, **reason for no Dx evaluation (79%)**, Part C eligibility
 - 60-69%: Date of transfer
 - <60%: Non-part C enrollment date



Data Items: Core

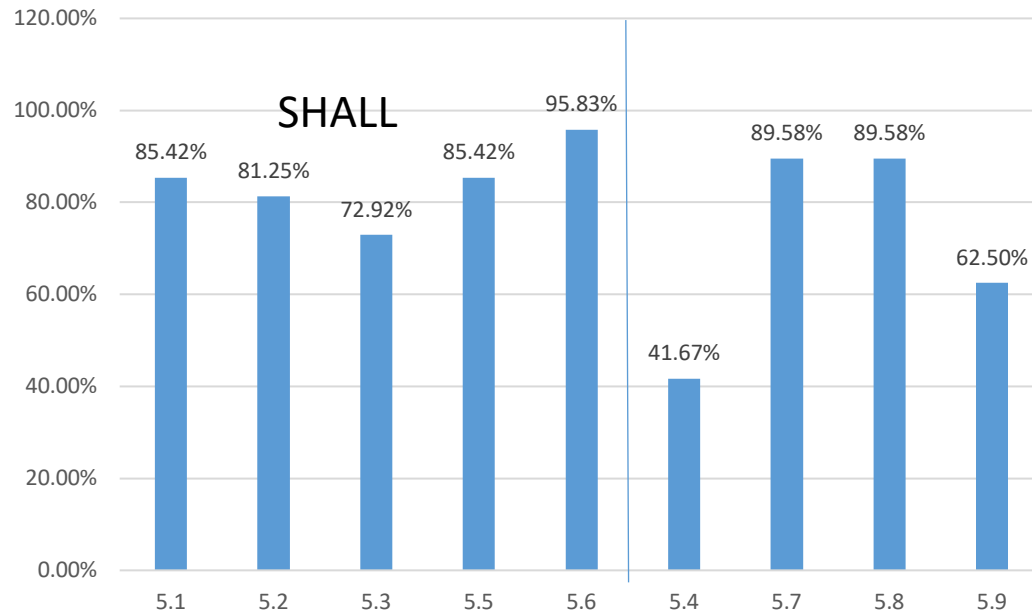
- Total: 14 items
 - Mother's demographics: 6
 - Screening/Rescreen: 6
 - Dx Eval: 2
- Out of 47 states
 - 100%: Mother's name
 - 90-99%: Mother's DoB, residence addr, screening/rescreen method, diagnostic evaluation method
 - 80-89%: Mother's race, ethnicity, education, transferring and receiving facility contacts

Data Items: Expanded

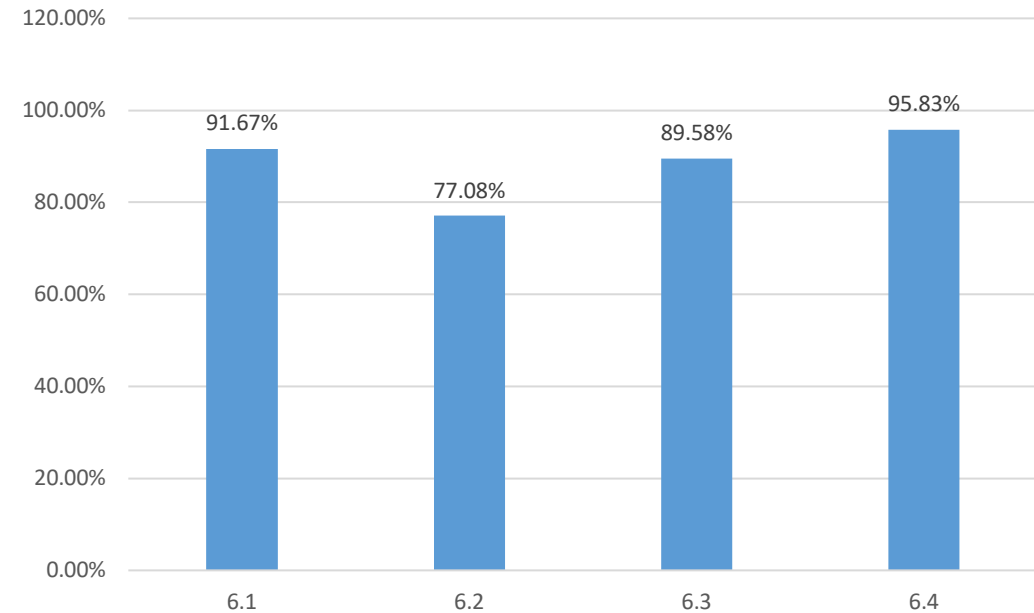
- Total: 18 items
 - Birth and Child: 4 items
 - Paternal demographics: 5 items
 - Screening: 4 items
 - Dx Eval: 3 items
 - EI: 2 items
- Out of 47 states
 - $\geq 85\%$: Time of birth (87.2%), Screening disposition (91.5%), Dx evaluation disposition (89.3%)
 - 70-84%: Birth weight, risk factors (collected at birth), follow-up appt. date
 - 60-69%: Insurance type, Father's name, risk factors (collected at dx eval), intervention method
 - 50-59%: Father's addr. , race, ethnicity, time of screening
 - $< 50\%$: Adoption status, # of days in NICU, father's education, EI outcome

Goals #5-6

Goal #5- Percentage of states meeting the standards
(N=48)



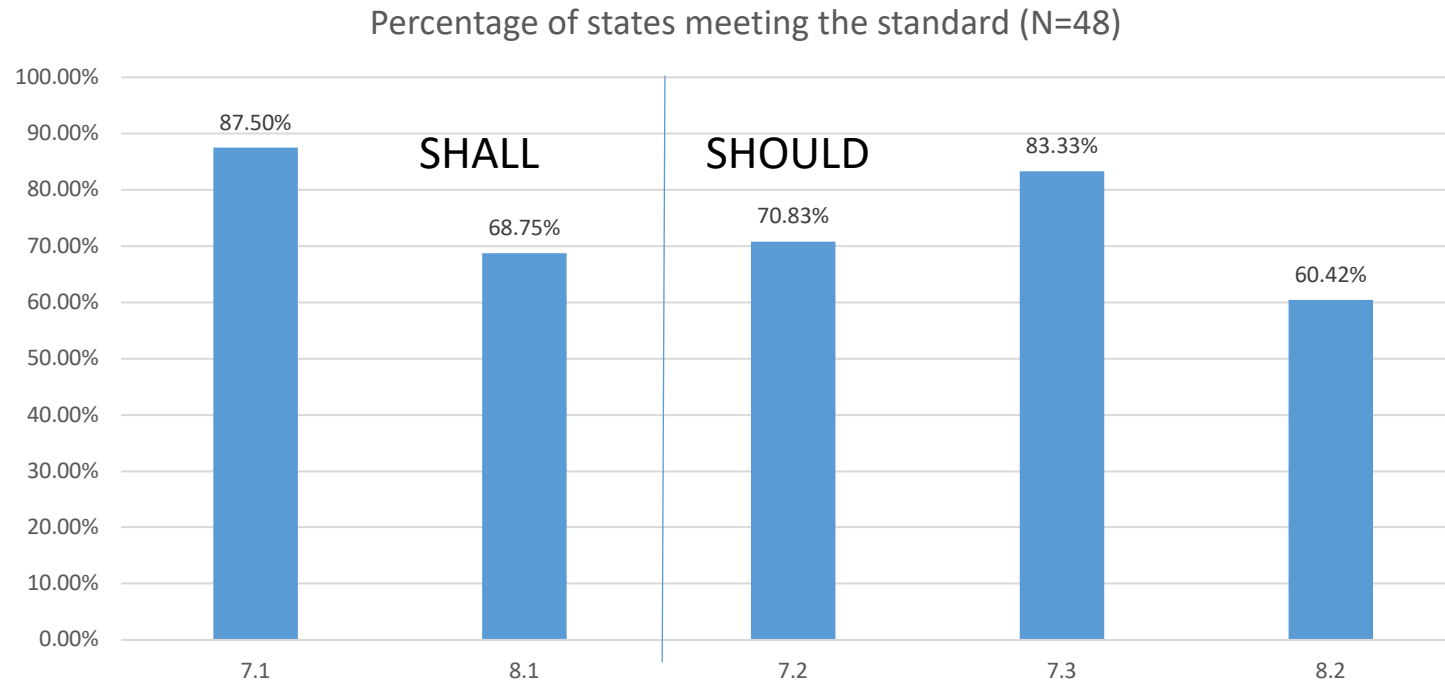
Goal #6 - Percentage of states meeting the standards
(N=48)



- 5.7 The EHDI-IS SHOULD allow re-activating a case when new information has arrived that illuminate the disposition of a case
- 5.8 The EHDI-IS SHOULD provide the ability for staff to record notes and phone interactions with the public (parents, providers, hospitals) under each child's file.

6.2 The EHDI-IS SHALL have written data sharing and confidentiality/privacy agreements with any other information systems which the system links to and/or share data with.

Goals #7-8



- 8.1 The EHD-IS SHALL provide the ability to generate, present, and transmit standard and/or custom-defined reports (e.g. CDC HSFS survey, loss to follow-up, or other important indicators by geographic, demographic, provider, or provider groups, hospital performance report) for authorized users without assistance from system vendor or IT personnel
- 7.3 The EHD-IS SHOULD provide the ability for authorized users to export data to other data management and analytical software tools such as MS Excel, SAS, SPSS, etc.

Limitations

- Results were self-reported and interpretation of rating may differ from state to state
- Reported capacity of a functionality does not necessarily indicate active utilization of that functionality.

Conclusion

- Standards and best practices exist that can guide EHDI-IS development and maintenance activities; Alignment with these standards and best practices reduces variability across EHDI-IS and helps them use resources more efficiently to provide the most value for EHDI programs, providers, patients, and parents.
- Continuously monitoring the progress of each EHDI-IS can help jurisdictions identify areas for improvement.