Considerations for Collecting and Documenting Language Outcomes from 1 to 36 months of Age for Infants Identified as Deaf or Hard of Hearing

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Disclaimer

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention (CDC).

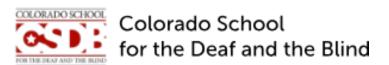
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Presenter/Authors' Background

- ODDACE Outcomes and Developmental Data Assistance Center for EHDI Programs
- 17 partnering programs
- Supported programs in collecting and documenting language outcomes
- Current status: No longer adding new partners or collecting outcomes data
- Long-term outcome: Determine factors related to better language outcomes

Today's Topics

- Collecting language outcomes:
 - Why is this beneficial?
 - Which assessment(s) will you used?
 - Who will administer the assessment?
- Establishing partnerships
- Documenting language outcomes:
 - What fields will you include?
 - How will you represent the data?

Benefits of Collecting and Documenting Language Outcomes

Benefits to Intervention Programs Benefits to EHDI Programs





Benefits of Documenting Language Outcomes

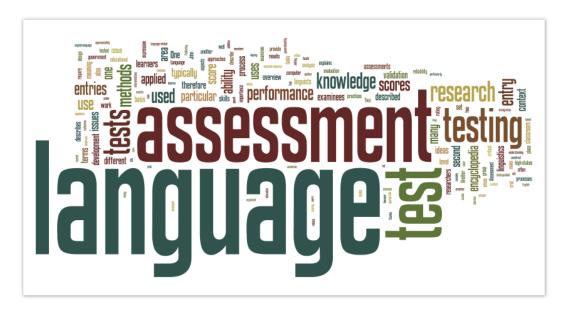
- Benefits to children and families:
 - Monitors progress of individual children
 - Provides objective data when making intervention decisions
- Benefits to the program:
 - Identifies program strengths and challenges
 - Provides data that can support funding requests
 - Meets state mandates (e.g., LEAD-K, outcomes-oriented House and Senate bills, etc.)

Documenting Language Outcomes: Benefits to EHDI Programs

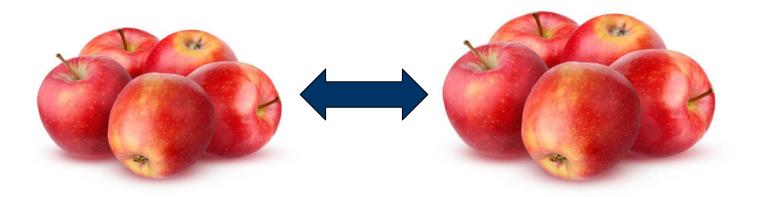
- Examine association with various EHDI benchmarks
- Identify associations with socio-demographic disparities
- Respond to funding guidelines
 - Current HRSA supplement focused on language outcomes
 - Next 5-year HRSA funding cycling includes collection of language outcomes at the end of the performance period

Considerations in Collecting Outcomes

Selecting the Assessment(s)



Consistency



Consistent Assessments:Why?

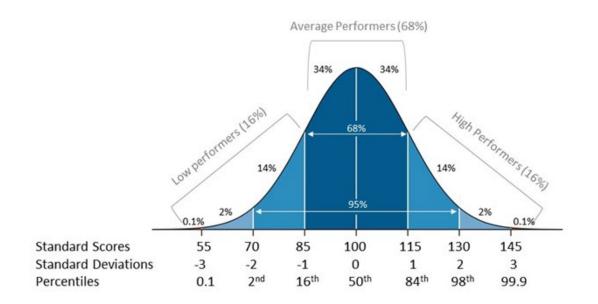
- Combining apples with apples
- Different tests measure different components of language
- Some tests are known to "test high"; others are more likely to identify delays
- If you were looking at % of children who passed an ear-related outcome: Would you combine a "pass" on a tympanogram with a "pass" on a pure tone screen?

Consistent Assessments:Why?

- Multiple assessments = Multiple small samples
- Using a consistent assessment battery allows you to aggregate results across your entire program/state

Higher numbers of children improve stability and validity of your results

Norm-Referenced



Norm-Referenced Assessments: Definition

- During test development, norm-referenced assessments were given to hundreds/thousands of children
- Based on this, you know the average range for children at specific ages
- You can see (and report) if a child's performance falls within or outside this average range

Norm-Referenced Assessments: Why?

- If only age scores are provided, difficult to determine if child is in the average range
- How do you decide if an age score below the child's age is concerning?
 - Child may not score exactly at their actual age, but may still be within the average range
 - A 6-month difference may not be problematic if the child is 5 years old but may be concerning if they are 24 months old

Norm-Referenced Assessments: Why?

- Provides standard scores and/or percentile ranks
- Objectively measures if child's skills are within the average range
- Partners may request reports of "percent of children in the average range"

Norm-Referenced Assessments: Why?

- Provides parents with objective information so they know how their child is performing relative to the average range
- Objectively monitors growth/progress
- Adds to factors considered at IEP/IFSP meetings
- May provide evidence for service eligibility as child transitions to Part B

Sensitivity to Language Gaps



Assessments that May Miss Language Gaps

- Assessments that use a basal/ceiling approach
 - Points given for all items below the basal
 - Child may have gaps (have not yet acquired some earlier developing skills)
 - So, they may get credit for many items they can't actually do

Reasons Assessments May Miss Language Delays

- Assessment may include general communication questions
- Level of linguistic complexity of response is often not specified
 - e.g.: "Tells you what he/she is doing"
 - "eat" vs. "I'm eating a turkey sandwich with cheddar cheese"
 - Both get 1 point

Reasons Assessments May Miss Language Delays

- Assessment includes pre-verbal items
 - Shakes head "no"
 - Points at things
- These are typically not delayed in children who are D/HH
- Many points come from pre-verbal skills which may boost child into the average range
- This is true of most 5-domain assessments (since they start at 1 month of age)

Who will complete the assessment?



Who will complete the assessment?

Many benefits associated with:

The parent and the interventionist who works with the family

Parent Input: Why?

Incorporating the parents' deep knowledge of their child's skills...

- Improves accuracy and validity of the assessment (esp. in the Birth to 3 period)
- Provides an opportunity for families to become better observers/reporters of their child's skills

Early Interventionist: Why?

- Efficient (and cost effective) because already meeting with family
- Early interventionists are typically knowledgeable about administering developmental assessments
- Trust relationship already established (increases likelihood of completion)
- Interventionist is knowledgeable about the child's skills

Interventionist and Parent: Why?

- Combination of an evaluator familiar with the child and parent will allow for:
 - Cross-checking (two sets of eyes/ears)
 - More comprehensive and accurate documentation of child's skills
- Reduces test time
 - Parent and/or evaluator can get started independently based on their knowledge

Who will complete the assessment?

Other options

- Evaluator(s) hired by a program/agency
 - Parent Guides
 - Periodic home visitors (e.g., public health nurses, service coordinators, consultants)
 - Grad students (partner with a university)
 - A coordinator is hired/designated and sends assessments via mail, email, or links in a text
- Likely these individuals will want training

Summary: Lessons Learned from ODDACE – One Possible Framework

- Consistent assessment across all children
- Standardized, norm-referenced
- Sensitive to identifying language gaps
- Has a version normed on Spanish-speaking children
- Works well in sign language
- Covers the full age range of interest

Summary: Lessons Learned from ODDACE – One Possible Framework

- Facilitated by someone who knows the child's skills/abilities
- Includes parent input



Summary: Lessons Learned from ODDACE – One Possible Framework

- Ideally, a 5-domain assessment + a specific language assessment
- If just one assessment: A specific language assessment (known to be sensitive to language gaps/delays)

Using only a 5-domain assessment is likely to underestimate language delays

Creating Partnerships



EHDI & EI: One model for collaboration

EHDI shares outcome reports with EI

EHDI refers to Early Intervention (EI)

EHDI maintains database

El monitors developmental progress

El shares developmental outcomes with EHDI

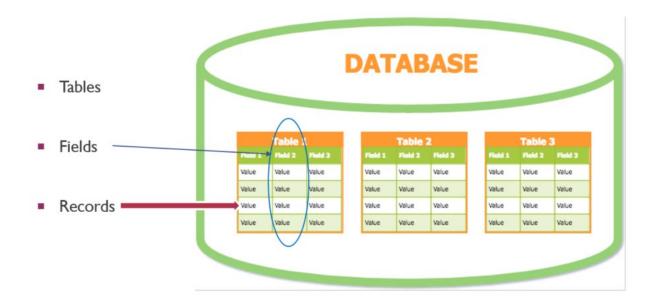
Benefits of an EHDI-EI Partnership

- Cost effective
 - El providers weave assessment into their visits with a family
 - EHDI programs weave fields into an existing database
- Capitalizes on existing expertise
 - El providers knowledgeable about assessment administration
 - EHDI coordinators knowledgeable about databases and running reports

Role of an Outside Contractor

- If an outside contractor supports the EHDI –
 Early Intervention partnership, they may...
 - Score assessments
 - Send back individual child summary reports
 - Periodically summarize language outcomes program/statewide
 - Create and populate a database that can be uploaded to the EHDI database
 - Include variables beyond the EHDI database increasing the depth of possible analyses

Database Field Considerations



Documenting Language Outcomes: Database Considerations

IMPORTANT!

Include one or more fields to document presence of additional disabilities

- Document if the disabilities are thought to impact language development
- You will likely want to characterize and explore associations with language outcomes separately for these two groups

- Don't rely on a single "has disabilities" checkbox (if the item is blank you won't know if it means there are no disabilities or the status is unknown or wasn't documented)
- Use radio buttons:

☐ Yes	\bigcap No	Don't know

- If results from various tests are included, indicate what assessment was used so subsamples can be formed for analysis
- If child has results at multiple time points, determine how this will be stored and accessed

- Include a field for the child's chronological age at the time of the test
- If the language outcome is a "language age score," create a "language quotient" field
 - language age divided by chronological age

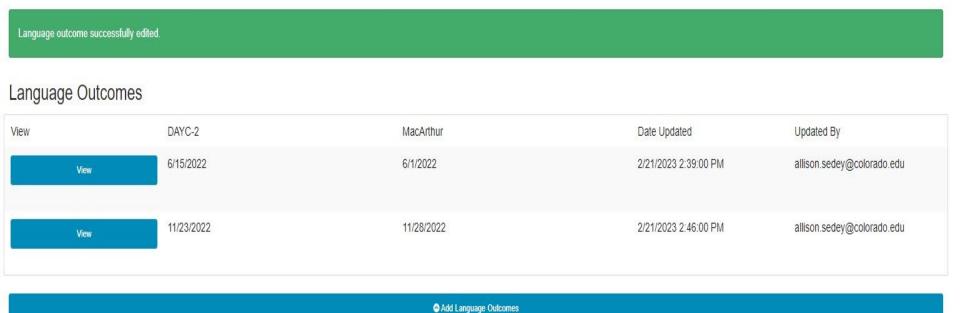
- If the assessment provides both an age score and percentile rank (or std score)...
 - > Include both
 - Then you are set regardless of if you need/want to report on the percentage of children in the average range or the percentage of children performing within a specific percentage of their actual age

Determine how you will enter scores that are above or below the range of the test...

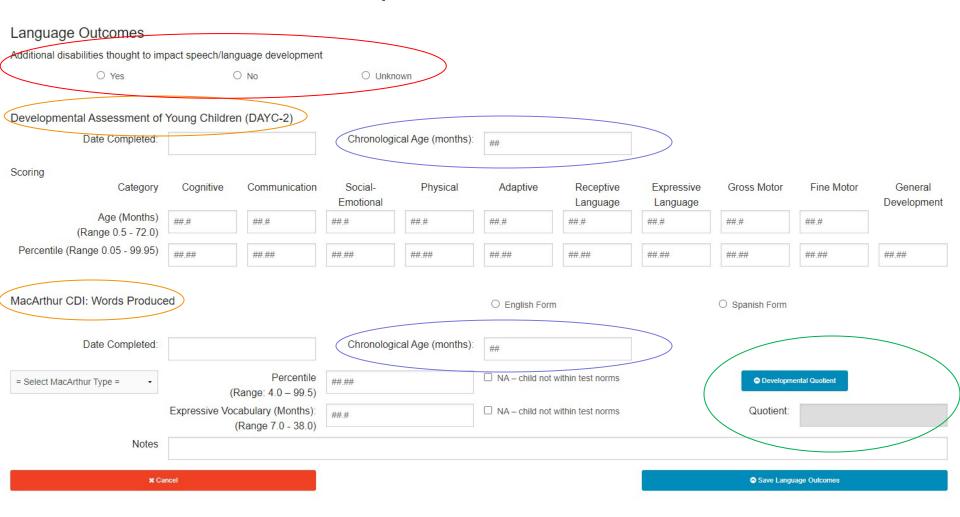
- < 5th %ile
- Age score > 36 months



Sample Database Set-Up: Documenting Scores Over Time



Sample Database Fields



Technical Assistance

- Interested in talking more about this topic?
- ODDACE personnel available for technical assistance through August 2024 regarding:
 - Options as you develop systems to collect language outcomes
 - Considerations in documenting language outcomes within an EHDI (or other) database
- Contact: oddace@colorado.edu