Recommended practices for family-centered early intervention with families who have infants and toddlers who are deaf or hard of hearing

Christine Yoshinaga-Itano, Ph.D.
Research Professor and Professor Emerita
University of Colorado, Boulder

Disclosure

- Member of the Joint Committee on Infant Hearing
- Received partial salary from grants from Centers for Disease Control administered through the Disability Rehabilitation Research Center in South Carolina
- Scientific Advisory Board of the LENA Foundation, the IDA Institute, and the Marion Downs Center

Best practice protocol: early intervention services

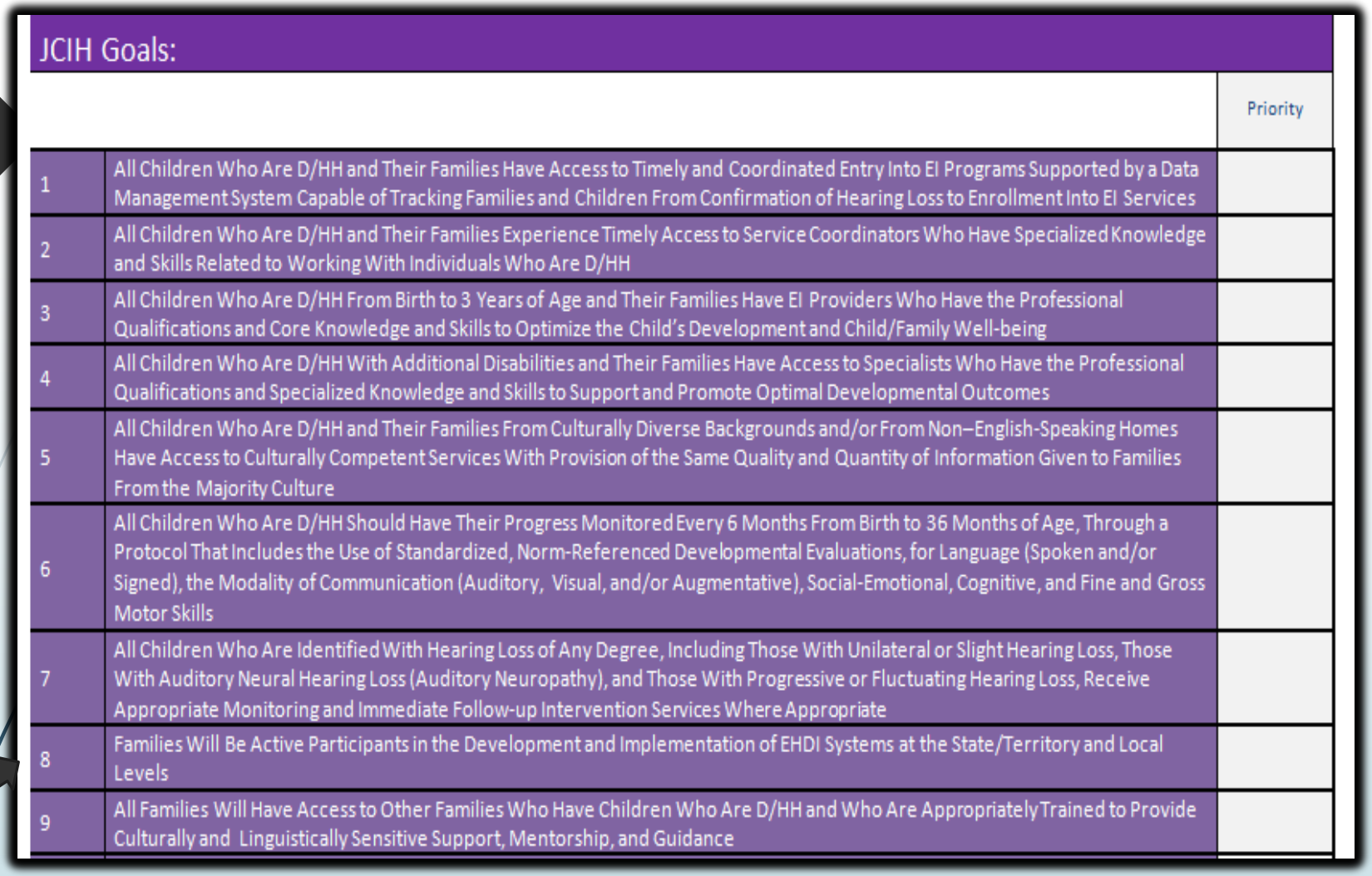
- EI supplement to JCIH 2007
- http://pediatrics.aappublications.org/content/early/2013/03/18/peds.2013-0008.citation
- First International Family Centered Early intervention Conference best practice protocol
- http://jdsde.oxfordjournals.org/content/18/4/429.abstract

Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention Following Confirmation That a Child Is Deaf or Hard of Hearing

Joint Committee on Infant Hearing

States are beginning to develop state plans

- In coordination with EHDI, Part C, specialized educational services for children who are deaf or hard of hearing and their families, individual states are beginning to collect baseline data and develop state plans
- Minnesota
- Georgia
- Washington
- Colorado
- Wisconsin
- And an increasing number of states



JCIH Goals:		
		Priority
1	All Children Who Are D/HH and Their Families Have Access to Timely and Coordinated Entry Into EI Programs Supported by a Data Management System Capable of Tracking Families and Children From Confirmation of Hearing Loss to Enrollment Into EI Services	
2	All Children Who Are D/HH and Their Families Experience Timely Access to Service Coordinators Who Have Specialized Knowledge and Skills Related to Working With Individuals Who Are D/HH	
3	All Children Who Are D/HH From Birth to 3 Years of Age and Their Families Have EI Providers Who Have the Professional Qualifications and Core Knowledge and Skills to Optimize the Child's Development and Child/Family Well-being	
4	All Children Who Are D/HH With Additional Disabilities and Their Families Have Access to Specialists Who Have the Professional Qualifications and Specialized Knowledge and Skills to Support and Promote Optimal Developmental Outcomes	
5	All Children Who Are D/HH and Their Families From Culturally Diverse Backgrounds and/or From Non–English-Speaking Homes Have Access to Culturally Competent Services With Provision of the Same Quality and Quantity of Information Given to Families From the Majority Culture	
6	All Children Who Are D/HH Should Have Their Progress Monitored Every 6 Months From Birth to 36 Months of Age, Through a Protocol That Includes the Use of Standardized, Norm-Referenced Developmental Evaluations, for Language (Spoken and/or Signed), the Modality of Communication (Auditory, Visual, and/or Augmentative), Social-Emotional, Cognitive, and Fine and Gross Motor Skills	
7	All Children Who Are Identified With Hearing Loss of Any Degree, Including Those With Unilateral or Slight Hearing Loss, Those With Auditory Neural Hearing Loss (Auditory Neuropathy), and Those With Progressive or Fluctuating Hearing Loss, Receive Appropriate Monitoring and Immediate Follow-up Intervention Services Where Appropriate	
8	Families Will Be Active Participants in the Development and Implementation of EHDI Systems at the State/Territory and Local Levels	
9	All Families Will Have Access to Other Families Who Have Children Who Are D/HH and Who Are Appropriately Trained to Provide Culturally and Linguistically Sensitive Support, Mentorship, and Guidance	

Level #1 – ALL GOALS

Individual Goal and Recommendations for#8

Goal 8: Families Will Be Active Participants in the Development and Implementation of EHDI Systems at the State/Territory and Local Levels

Rationale

Equitable partnerships between families and EI programs and systems are critical to the success of EHDI programs and the achievement of optimal outcomes for children. Family leadership and involvement are critical when developing policies and programs to ensure that the systems of care support a genuine reflection of the day-today challenges and opportunities facing families.

Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation that a Child is Deaf or Hard of Hearing.

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
8.1	Develop or revise policies and legislation related to EHDI programs that require the meaningful inclusion of qualified families as active participants in the development and implementation of EHDI systems.	☐	☐	☐	☐	☐
8.2	Report the number of professional family positions (ie, compensated rather than volunteer) and demonstrate how parents and families are involved in recruitment processes.	☐	☐	☐	☐	☐
8.3	Provide resources (professional development training and mentorship) for families to obtain the necessary knowledge and skills to participate in systems and policy development and demonstrate that training is provided.	☐	☐	☐	☐	☐

Discussion Was Most Valuable:

- Developing Priorities & Next Steps
  - *We didn't have time to discuss priorities or reflect about how this relates to our needs here in MN*
  - *What will be done with the resu*

- Clear Context
  - *Wording very open to individual interpretation and having to refer back to JCIH document is cumbersome.*

What advice would you give?

- *Come to the table not only to assess but to be informed about the works of others, your own state resources, and the possibilities for more*

- *Be sure everyone is involved and contributed and that they need to be willing and ready to scrutinize all aspects of their system without criticism.*

Goal 1: Coordinated entry into EI

All children who are D/HH and their families have access to timely and coordinated entry into EI programs supported by a data management system capable of tracking families and children from confirmation of hearing loss to enrollment into EI services.

2014 National CDC EHDI Data

Source: CDC EHDI Hearing Screening and Follow-up Survey (HSFS)

www.cdc.gov/ncbddd/hearingloss/ehdi-data.html

2014

- 204 in Ohio with identified hearing loss
- 128 total enrolled in early intervention
- 62.7% enrolled in early intervention
- 190 were eligible for enrollment but only 128 enrolled meaning that 61 children with hearing loss who were eligible did not make it to early intervention services or were undocumented.

Does Ohio have a coordinated access to early intervention

- If Part C is the access to early intervention, that indicates that it happens at the local level.
- How does the diagnosing audiologist know who to contact?
- Does the first contact with the family know deafness and hearing loss?
- Only 67% or 2/3rds of the children are making it to early intervention services

- 85.8% of Ohio babies with hearing loss referred from UNHS are diagnosed by 3 months of age.
- 64.8% of the babies with hearing loss were enrolled into early intervention by 6 months of age.

Goal 2: Service coordinators with specialized knowledge and skills related to early childhood deafness and hearing loss.

- ***All children who are D/HH and their families experience timely access to service coordinators who have specialized knowledge and skills related to working with individuals who are D/HH.***
- **Do you know the statistics for your state?**

Ohio

- Are newborns with hearing loss in Ohio receiving services – first contact from early intervention providers who have knowledge and skills in early childhood deafness and hearing loss.
- What percentage of the children in Ohio are being seen at the first contact by a service coordinator who is knowledgeable about deafness, hearing loss and young children - who cannot read the audiogram, cannot show a parent how to put the hearing aid in the child's ear, cannot trouble shoot a hearing aid, do not have knowledge about communication approaches used with children who are deaf or hard of hearing.

Goal 3: EI providers with specialized skills and knowledge in early childhood deafness and hearing loss

- ***All children who are D/HH from birth to 3 years of age and their families have Early Intervention providers who have the professional qualifications and core knowledge and skills to optimize their development and well-being.***
- **Do you know the statistics for your state?**
- **In some states, 100% of providers meet this goal.**

Ohio

- What percentages of the infants with hearing loss in Ohio are receiving early intervention services from providers who have knowledge and skills in early childhood deafness and hearing loss?
- How can you capture this data?

Goal 3a: ASL instruction available to parents statewide with native/fluent skills

- ***Intervention services to teach American Sign Language (ASL) will be provided by professionals who have native or fluent skills and are trained to teach parents/families and young children.***
- **Do you know the statistics for your state?**

- If a parents has received information about sign language and wants to learn sign language, are the providers fluent or native communicators in sign language?
- How would a parents obtain this knowledge?
- What metrics are in place to evaluate the skills of the individuals providing the services?
- Does the parent have to choose between sign language services and spoken language services

Goal 3b: EI providers available statewide with expertise in developing listening and spoken language

- ***Intervention services to develop listening and spoken language will be provided by professionals who have specialized skills and knowledge.***
- **Do you know the statistics for your state?**

- If a parent wants to learn listening and spoken language, can that parent be assured that the early intervention provider has knowledge and skills in how to develop listening and spoken language skills in children who are deaf or hard of hearing?
- How is this assured?

Goal 4: Children who are Deaf/Hard of Hearing Plus

- ***All children who are D/HH with additional disabilities and their families have access to specialists who have the professional qualifications and specialized knowledge and skills to support and promote optimal developmental outcomes.***
- ***Deaf/Hard of Hearing Plus is more than expertise in each disability but how they are manifested together.***
- **Do you know the statistics for your state?**

Additional disabilities

- How many of the children in your state from UNHS have additional disabilities?
- What are they?
- Who provides service to these children and families?
- Are providers knowledgeable about dual diagnoses or any other combination Deaf/HH Plus? e.g. deafness and autism
- Who provides services to these children?

Goal 5: Cultural and Linguistic diversity

- ***All children who are D/HH and their families from culturally diverse backgrounds and/or from non-English-speaking homes have access to culturally competent services with provision of the same quality and quantity of information given to families from the majority culture.***
- **Do you know the statistics for your state?**

Children from cultural and linguistically diverse backgrounds

- Can these children be assessed and tracked in their native language?
- Are there providers who are fluent in the family's language and knowledgeable about early childhood deafness and hearing loss?
- Are interpreters adequately trained?
- Do you know if these families are receiving the same information as the families who speak English.
- Do you have materials available for parents and providers in Spanish, Mandarin, Arabic, and other languages

Language Outcomes of Children from Spanish-Speaking Families: A Multi-State Perspective

Participants in NECAP

- Arizona
- California
- Colorado
- Idaho
- Indiana
- Texas
- Wyoming

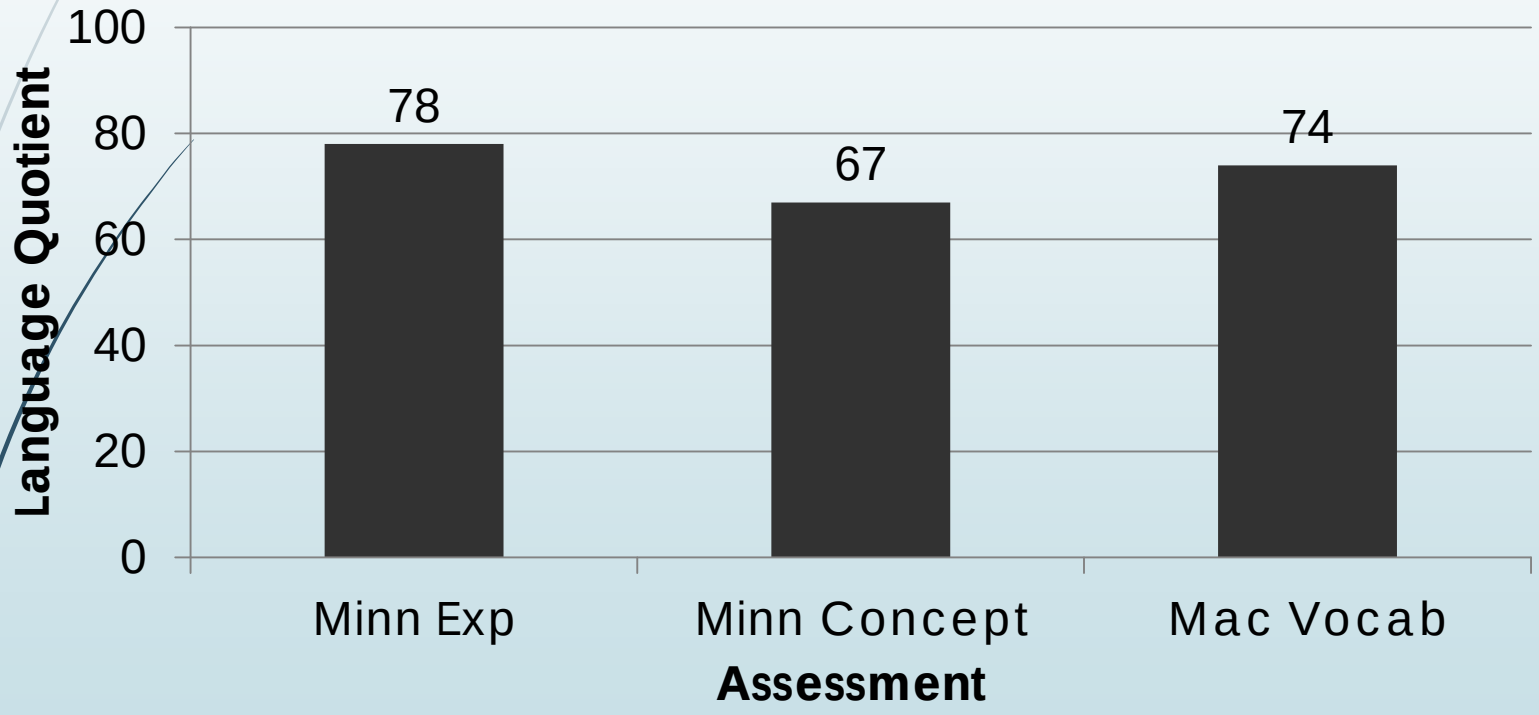
Determining Language Quotient

- Language Age/Chronological Age x 100
  - If LQ = 100, Language Age = CA
  - If LQ < 100, Language Age < CA
  - If LQ > 100, Language Age > CA
- LQs of 75+ are within the normal range compared to hearing children Below 70 are 2 SD below the mean

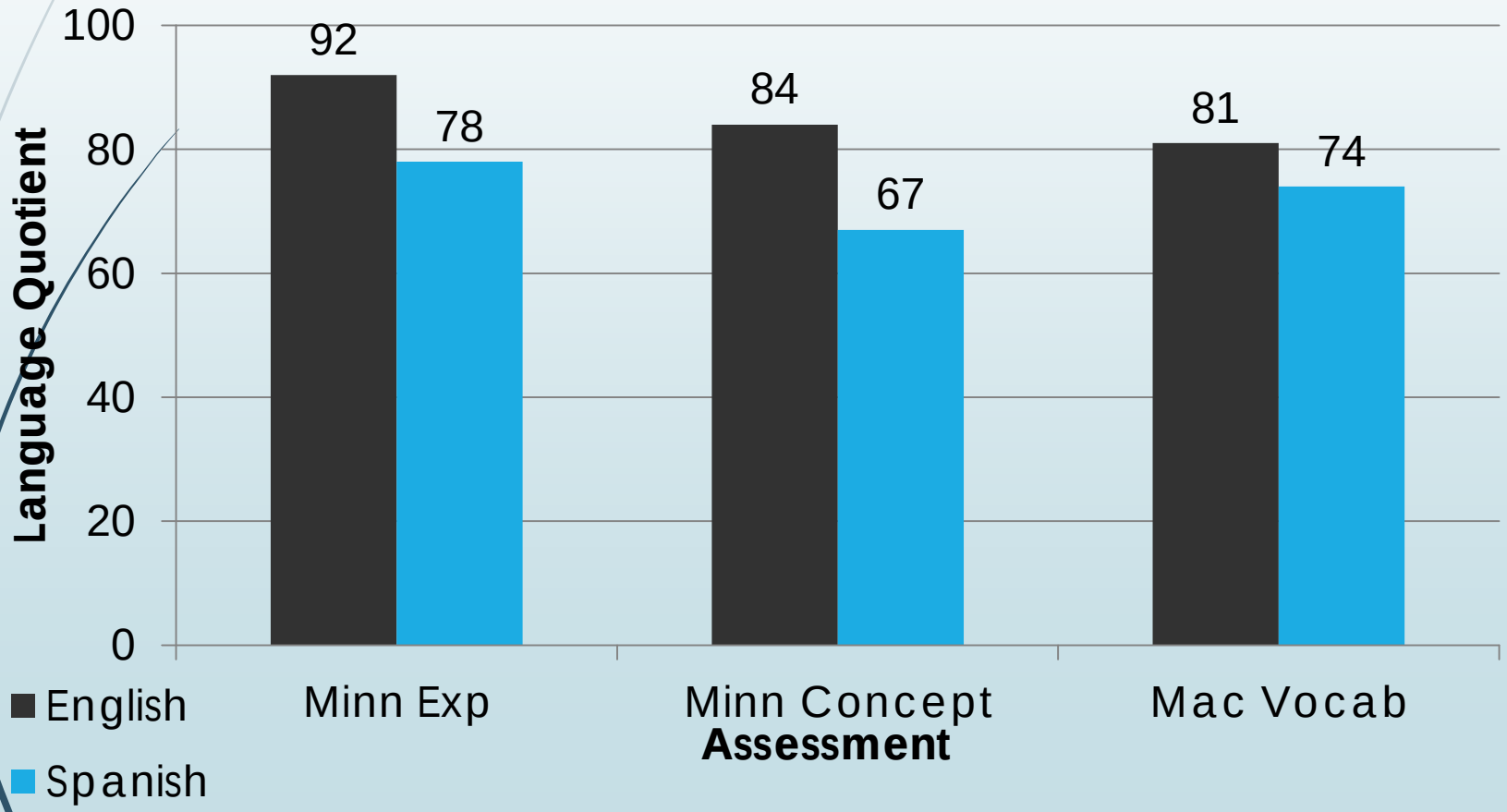
Instruments: Parent Questionnaires

- Child Development Inventory: Minnesota – Spanish-speaking version – typically developing hearing control group
- MacArthur-Bates Communicative Development Inventories – Norms for Spanish-speaking

Median Language Quotients



Median Language Quotients: English vs. Spanish



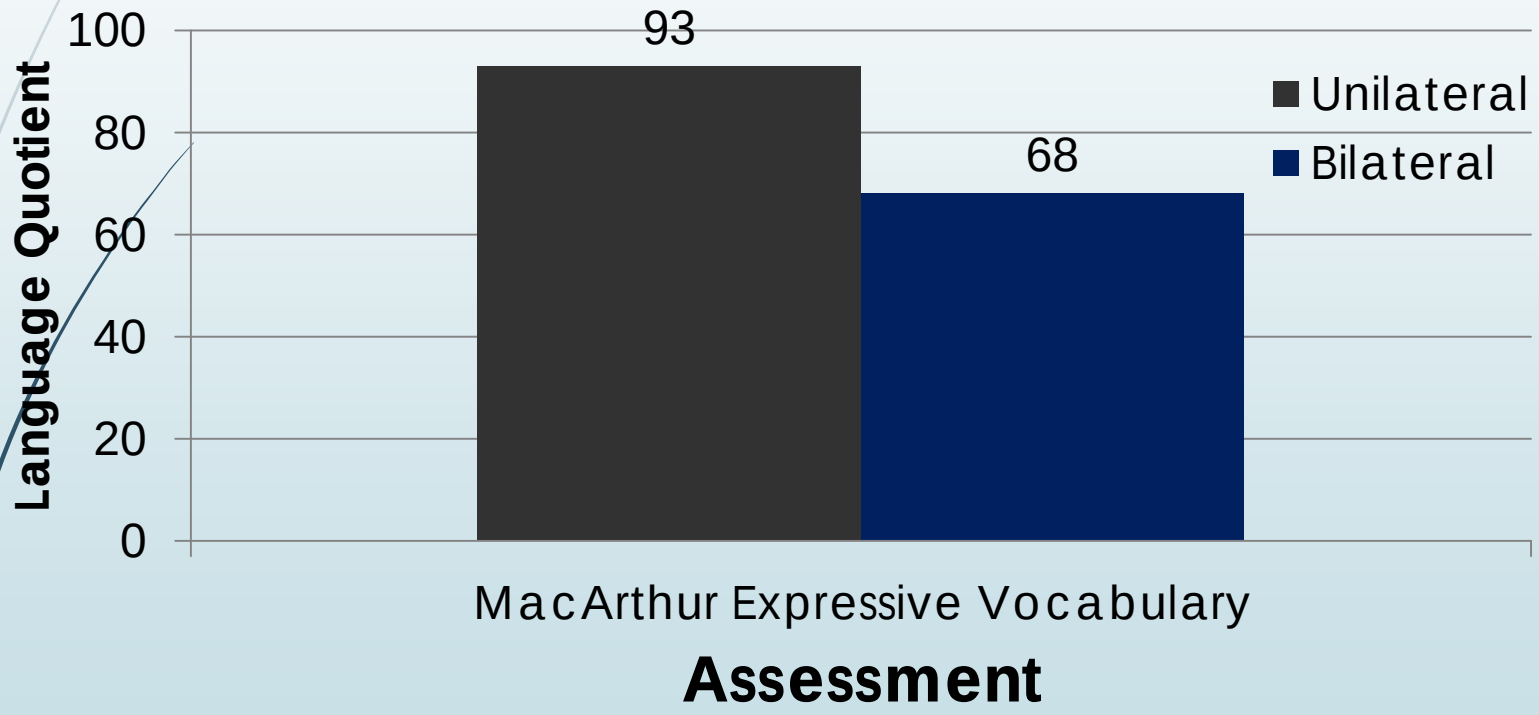
Bates-MacArthur Exp Vocabulary: Sub-Group Comparisons

- No significant difference ($p > .05$) between:
  - Boys vs. girls
  - Mothers with vs. without a high school diploma

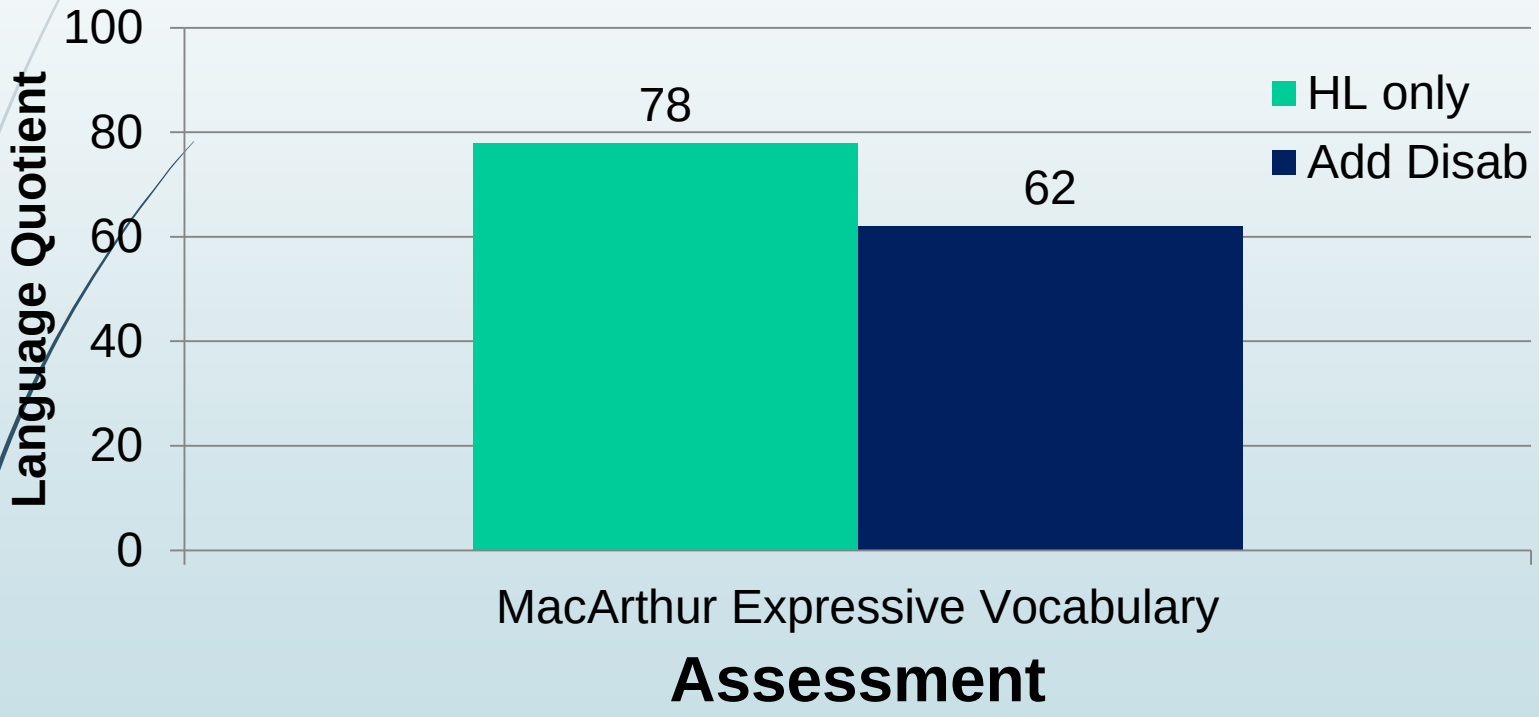
Bates-MacArthur Exp Vocabulary: Sub-Group Comparisons

- Significant differences ($p < .05$):
  - Unilateral vs. bilateral hearing loss
  - No additional disabilities vs. having additional disabilities
  - Mild/Mod vs. mod-severe to profound hearing loss
  - Identification of hearing loss by vs. after 6 months of age

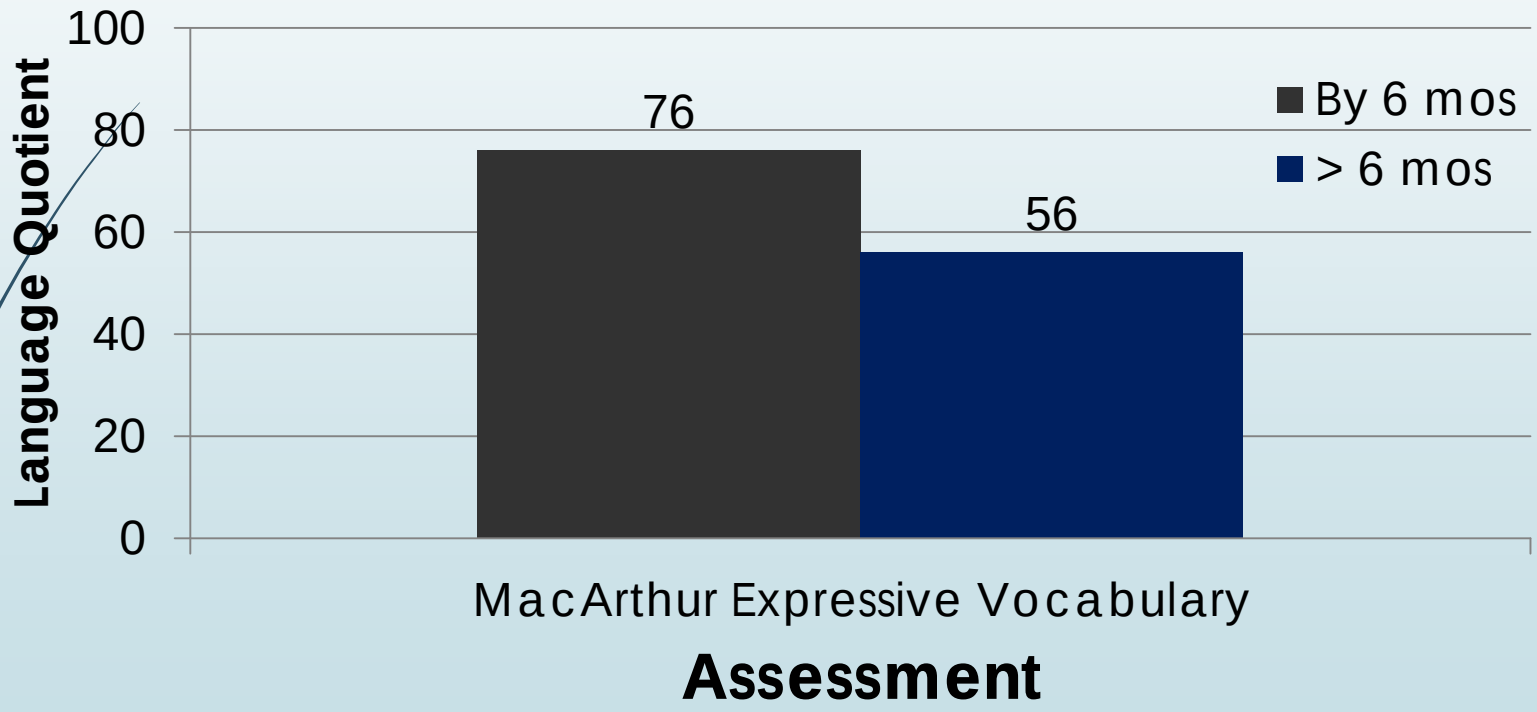
Unilateral vs. Bilateral Hearing Loss



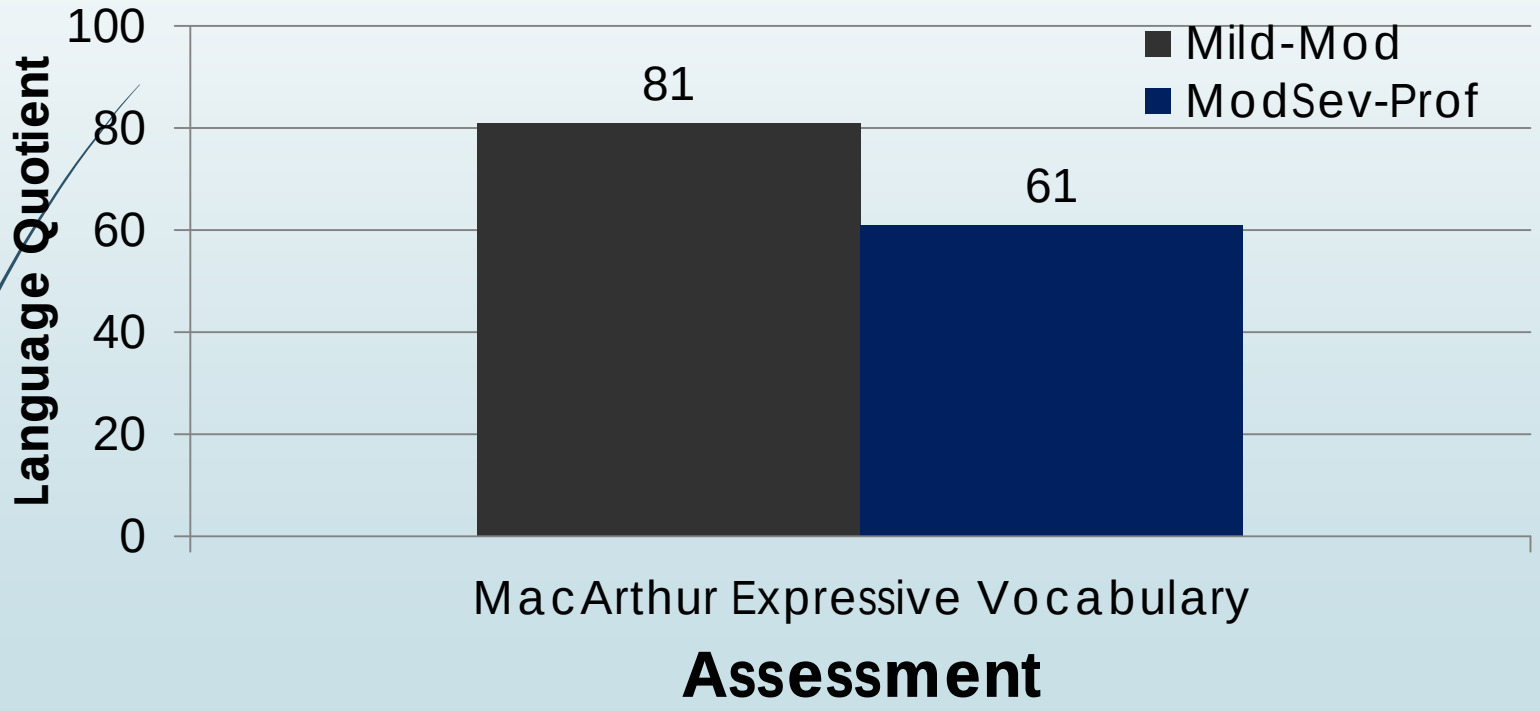
Additional Disabilities vs. Hearing Loss Only



Identification by 6 months vs. Later



Mild to Mod Hearing Loss vs. Mod-Sev to Profound Hearing Loss



Goal 6: Progress Monitoring

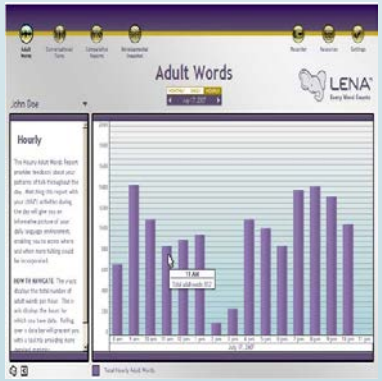
- ***All children who are D/HH should have their progress monitored every 6 months from birth to 36 months of age, through a protocol that includes the use of standardized, norm-referenced developmental evaluations, for language (spoken and/or signed), communication (auditory, visual, and/or augmentative), social-emotional, cognitive, and fine and gross motor skills.***
- **Do you know the statistics for your state?**

State Protocol for assessing developmental progress

- Are instruments used standardized and normed on children with normal hearing and typical development?
- Do you know how the children in Ohio are doing?
- Meinzen-Derr, J, Wiley, S. & Choo, D.I. (2011) Impact of Early intervention on Expressive and Receptive Language Development among Young Children with Permanent Hearing Loss. American Annals of the Deaf, 155(5), 580-591 DOI: 10.1353/aad.2011.0010
- Results indicated that children enrolled in early intervention by 6 versus after 6 months had higher language development scores on the criterion reference checklist, the Language Development Scale.

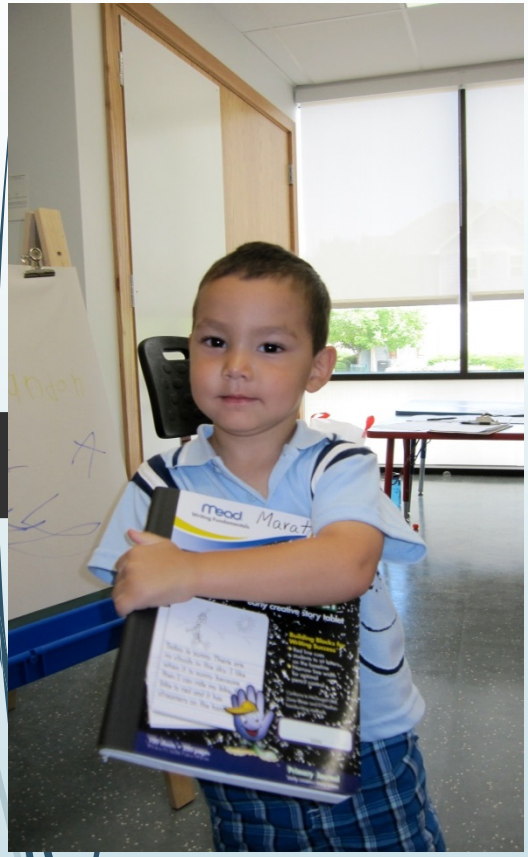
Measurement Tool

- Digital recorder children wear
- Records continuously for 16 hours
- Audio transferred to computer
- Speech recognition software processes file, automatically analyzing audio stream



LENA technology – only spoken language assessment

- Adult Word Count
- Child Vocalizations
- Conversational Turns
- Automatic Vocalization Analysis AVA score
- Vocal duration score – syllables per utterance
- Developmental Snapshot
- Capable of keeping program data -



NECAP:

NATIONAL EARLY CHILDHOOD ASSESSMENT PROJECT: DEAF AND HARD OF HEARING

States collecting outcomes of children identified through UNHS/EHDI programs

Acknowledgement

- This project was supported financially by the Centers for Disease Control through a cooperative agreement with the Disability Research and Dissemination Center at the University of South Carolina
- Award Number: 15-2763/11520-FB44

NECAP Project Overview

- CDC-supported project to collect language outcome data on deaf and hard-of-hearing children birth to 4 across the United States
  - Establish individual state databases
  - Establish national database
  - Explore feasibility of interfacing with existing EHDI databases

States Represented in Results

- Arizona
- California
- Florida
- Idaho
- Indiana
- Maine
- Minnesota
- New Mexico
- North Dakota
- Oregon
- Texas
- Utah
- Wisconsin
- Wyoming

MacArthur-Bates Communicative Development Inventories

- Parent report instrument
- Words arranged in semantic categories
- Parents indicate words their child can produce in spoken and/or sign language
- Raw scores are converted to age scores using the 50th percentile

MacArthur-Bates Communicative Development Inventories

- Words and Gestures (396 words)
  - 8 to 18 months language level
- Words and Sentences (680 words)
  - 16 to 30 months language level
- Inventory selection is based on the child's estimated productive vocabulary size

Assessments Completed

- 1,705 assessments completed
- 989 children assessed 1 to 6 times

Portion of Database Analyzed

- Chronological age 8 to 39 months
- Completed the MacArthur Communicative Development Inventory
- Correct inventory selected for child's vocabulary size
- Most recent assessment
- 705 children/assessments

Inclusion Criteria

- Multiple regression indicated that presence of additional disabilities and number of ears affected (unilateral vs. bilateral loss) were significant predictors of language outcomes ($p < .001$)

Participant Criteria

- Children with unilateral vs. bilateral hearing loss were considered separately
- Children with additional disabilities thought to affect speech/language development were included
- Children from both English-speaking and Spanish-speaking homes are included.

Study 1: Inclusion Criteria

- Bilateral hearing loss
- With and without additional disabilities thought to affect speech/language development
- Most recent assessment
- Correct version of MacArthur selected
- Spanish and English speaking
- N = 549

Study 1 – Bilateral Hearing Loss: Participant Characteristics

- Chronological age
  - Range = 8 to 39 months
  - Mean = 24.5 months
  - SD = 8 months
- Boys = 53%; Girls = 47%
- English = 89%; Spanish = 11%

Study 1 – Bilateral Hearing Loss: Participant Characteristics

Age at...	Mean (mos)	Range (mos)
Identification	4.7	.25 to 38
Amplification	7.4	.5 to 39
Intervention	7.3	.25 to 38

*57% of children met the EHDI guidelines of screening, identification by 3 months of age and intervention by 6 months of age

Study 1 – Bilateral Hearing Loss: Participant Characteristics

Highest degree completed	% of primary caregivers
Less than HS	12%
High school diploma	40%
Vocational or Associates	18%
Bachelor's degree	22%
Graduate degree	8%

Determining Language Quotient

- Language Age/Chronological Age x 100
  - If LQ = 100, Language Age = CA
  - If LQ < 100, Language Age < CA
  - If LQ > 100, Language Age > CA
- LQs of 80+ are within the normal range compared to hearing children

Study 1 – Bilateral Hearing Loss: Language Outcomes (n = 549)

- MacArthur-Bates Language Quotient
  - Range = 30 to 178
  - Mean = 78
  - SD = 21

➨78 is within 2 standard deviations of the mean – but just barely

Predicting Language Outcomes

- Linear regression used with MacArthur Language Quotient as the dependent variable
- Due to missing data (primarily on degree of hearing loss and mother's level of education), n = 524

Predicting Language Outcomes

- Independent variables that were NOT significant ($p > .05$) and removed from the final model:
  - Language of home (English vs. Spanish)
  - Gender

Predicting Language Outcomes

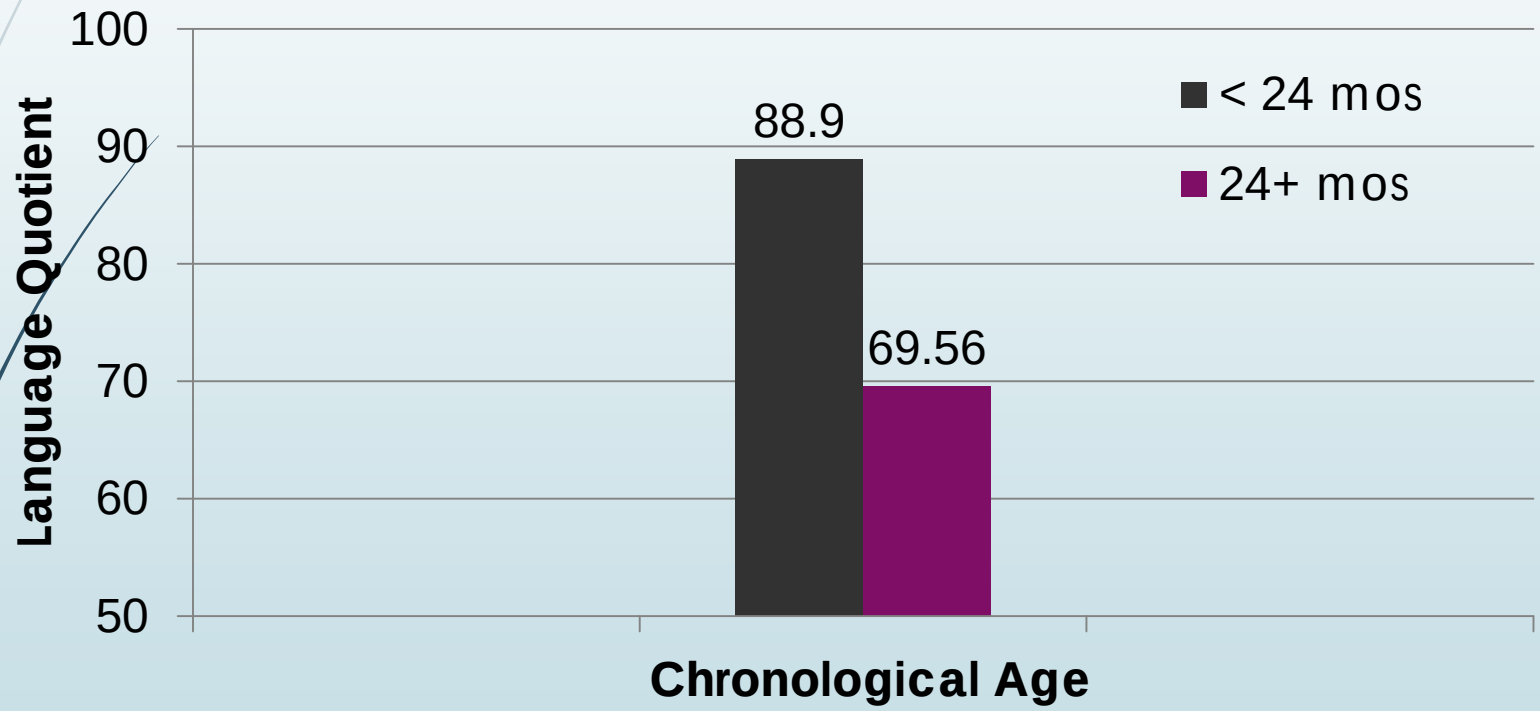
- Independent variables that WERE significant predictors ($p < .01$):
  - Chronological age
  - Degree of hearing loss (mild/mod vs. mod-severe to profound)
  - Mother's level of ed (< B.A vs. B.A or higher)
  - Meeting EHDI guidelines (screening by 1, identification by 3 months and intervention by 6 months)
  - Deaf/Hard of Hearing adult in the home

Regression Analysis: Predicting Language Quotient

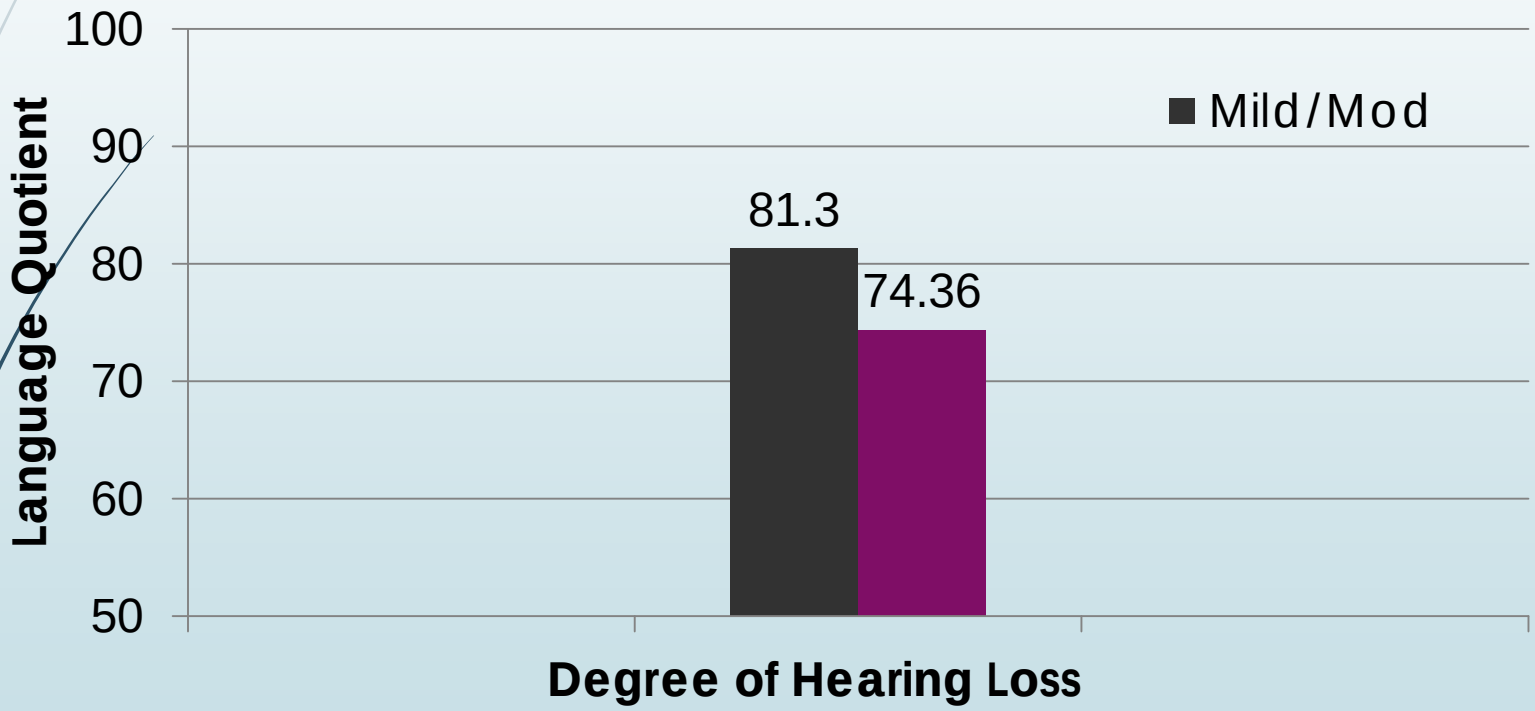
Independent variables	B (unstd coeff)	Beta (std coeff)	*p*
Chronological age	-1.26	-.48	<.001
Degree of loss (mild/mod vs. higher)	-6.59	-.16	<.001
Mother's education (<B.A. vs. B.A or above)	6.76	.16	.001
Meets EHDI guidelines	-6.04	-.15	.001
Deaf adult in the home	6.84	.14	.002

38% of the variance is explained by this model

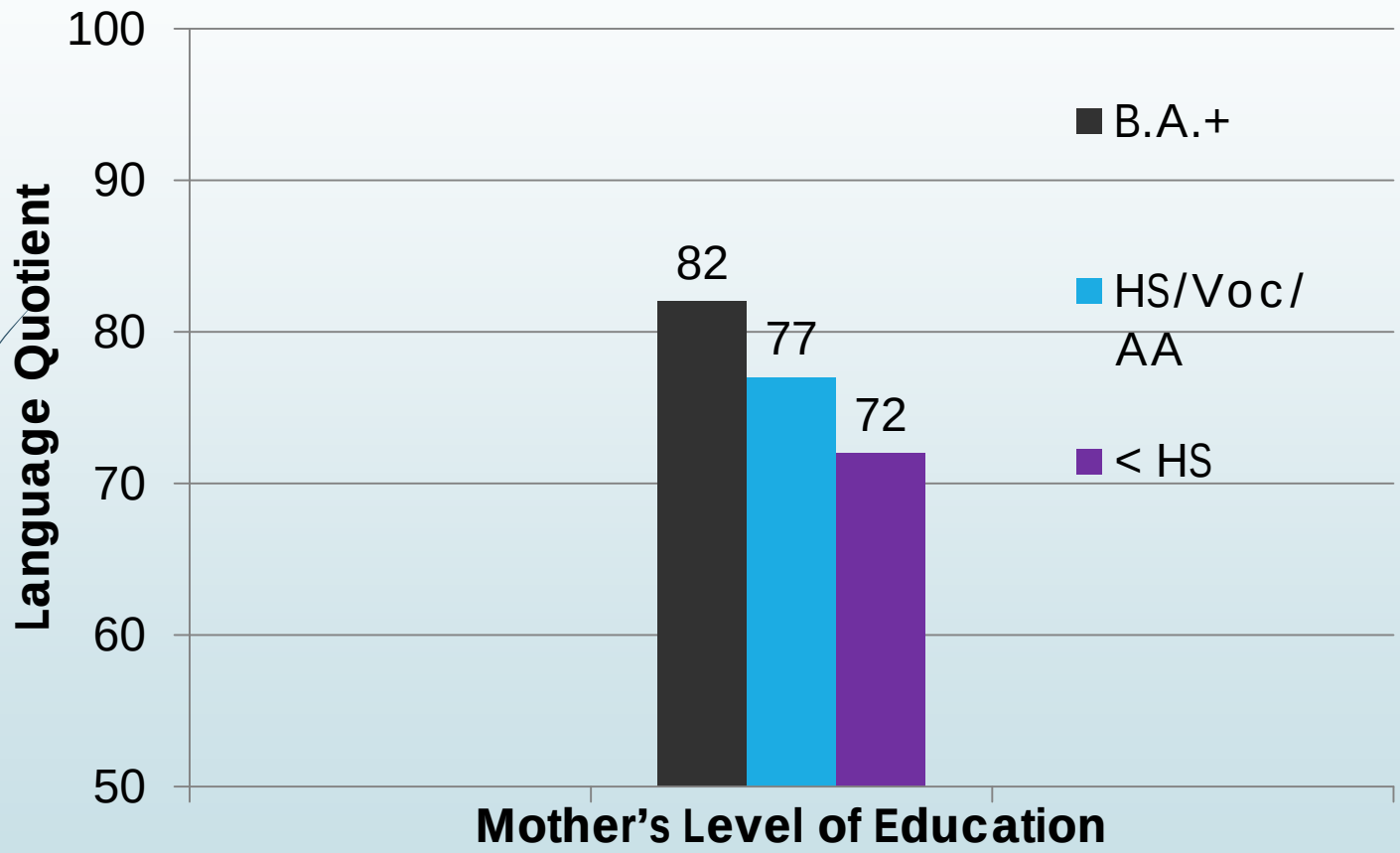
Chronological Age Group



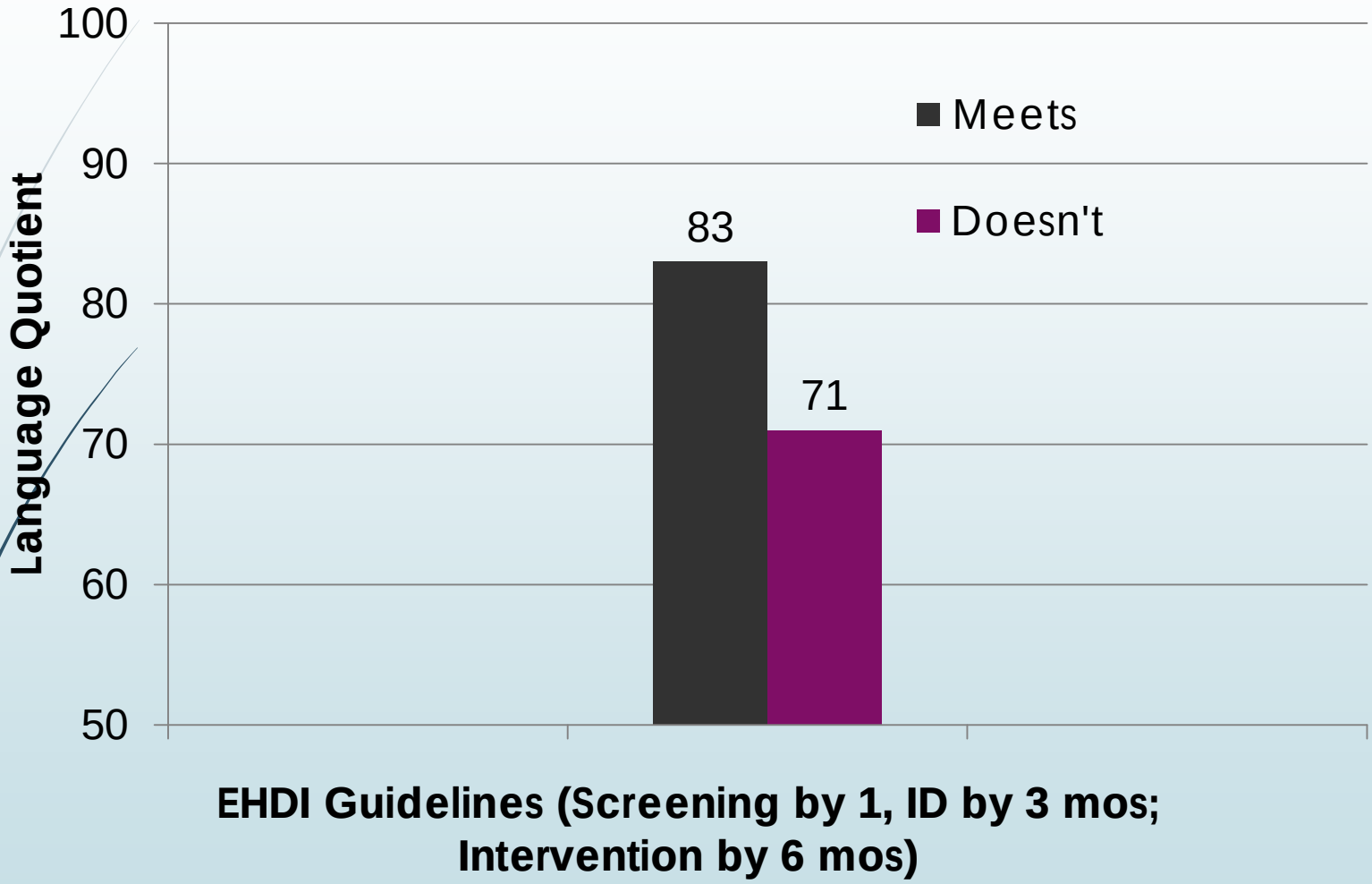
Degree of Hearing Loss



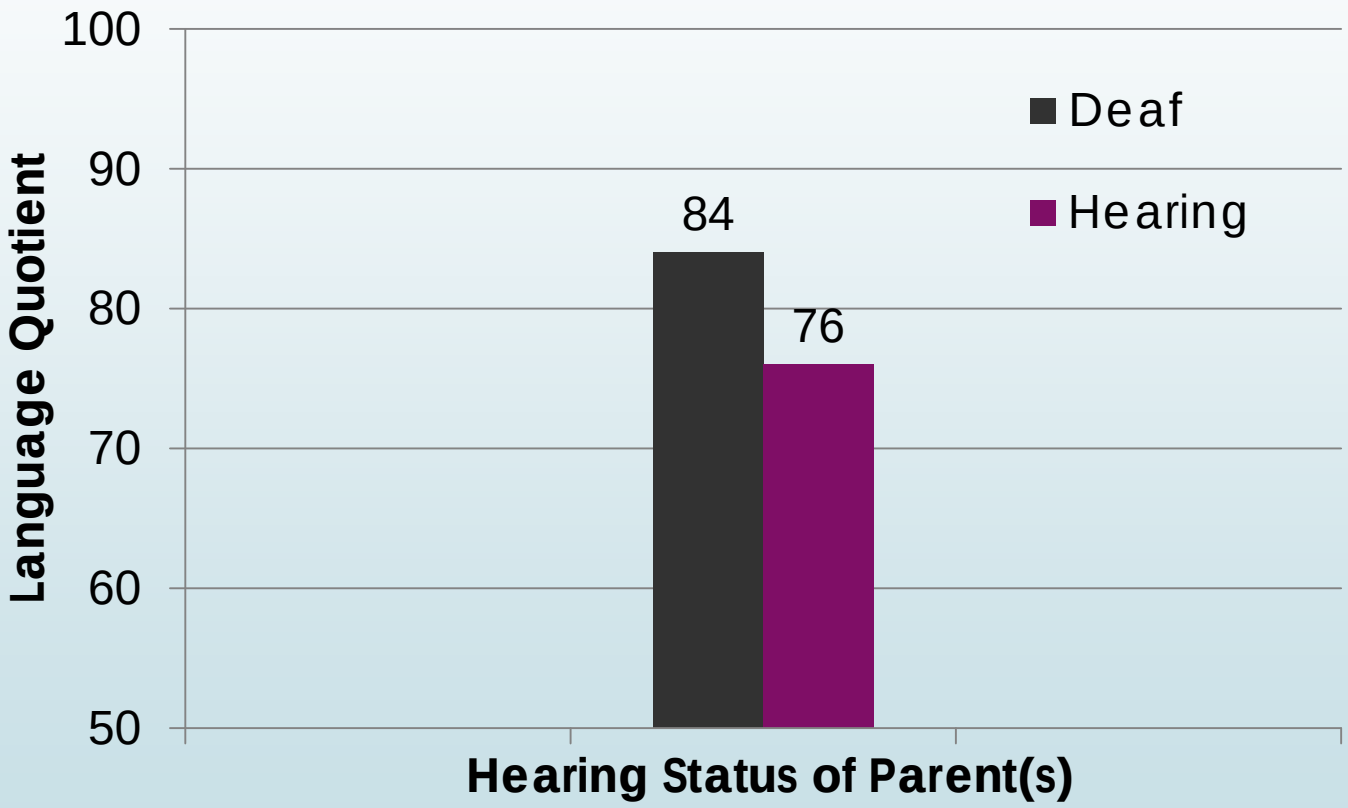
Mother's Level of Education



Adherence to EHDI Guidelines



Deaf/Hard of Hearing vs. Hearing Parent(s)



Goal 7: Special Populations

All children who are identified with hearing loss of any degree, including those with unilateral or slight hearing loss, those with auditory neuropathy spectrum disorder (ANSD), and those with progressive or fluctuating hearing loss receive appropriate monitoring and immediate follow-up intervention services where appropriate and when eligible.

Do you know the statistics for your state?

Study 2: Inclusion Criteria

- Unilateral hearing loss
- No additional disabilities thought to affect speech/language development
- Most recent assessment
- Correct version of MacArthur selected
- N = 137

Service Provision to Children with UHL in Participating States

- All children living in a state where children with UHL are categorically eligible for early intervention
- Intervention directors estimated they receive referrals for 80% to 100% (depending on the state) of their UHL birth to 3 population
- Directors estimated 50% to 95% of UHL referrals enroll in intervention
  - Higher percent in deafness-specific programs

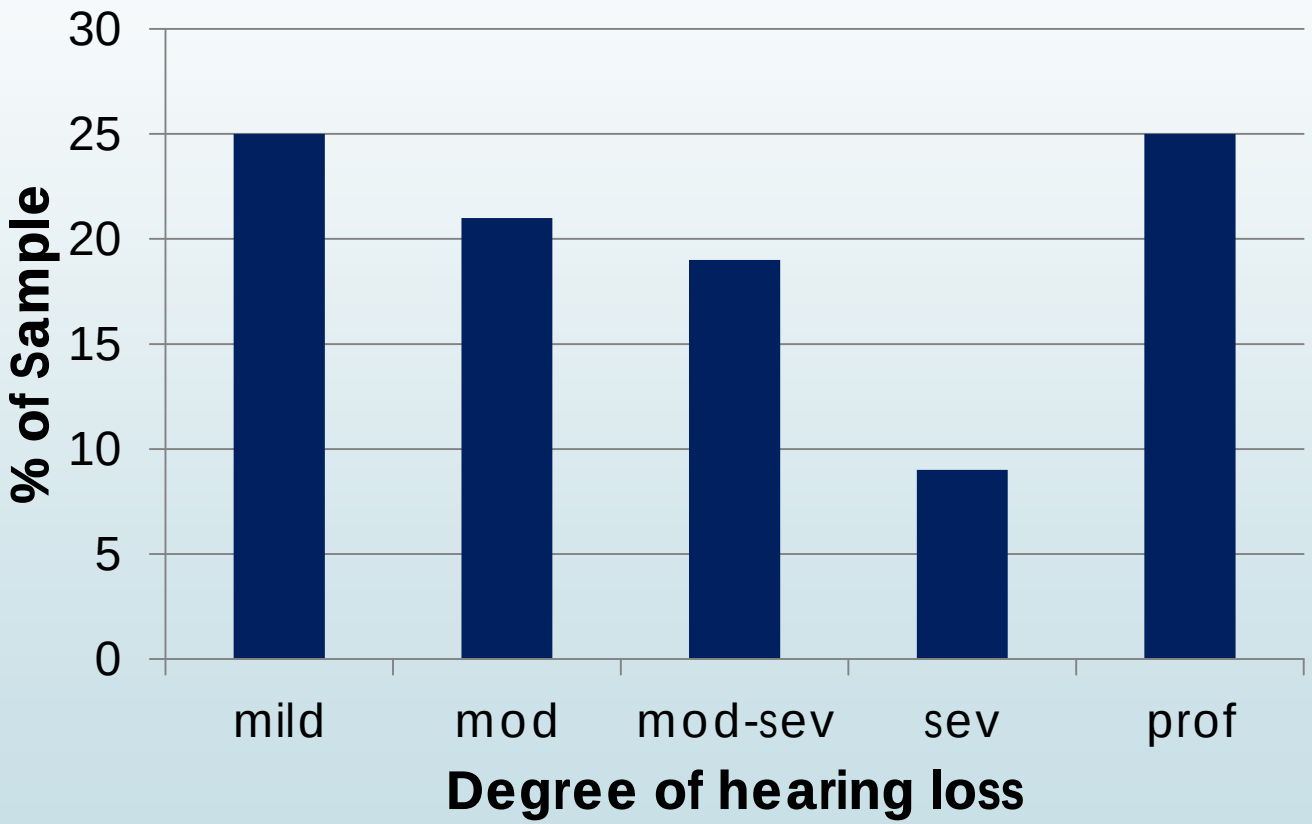
States Contributing to Unilateral Outcomes Analysis

- California
- Florida
- Idaho
- Indiana
- Maine
- North Dakota
- Texas
- Utah
- Wisconsin
- Wyoming

Study 2 – Unilateral Hearing Loss: Participant Characteristics

- Chronological age
  - Range = 9 to 38 months
  - Mean = 23.5 months
  - SD = 8.3 months
- Boys = 62%; Girls = 38%
- English = 82%; Spanish = 18%
- Right ear = 52%; Left ear = 48%

Degree of Hearing Loss in Affected Ear (available for 75 children)



Study 2 – Unilateral Hearing Loss: Participant Characteristics

Type of Amplification Used	% of children
None	42%
Hearing aid	34%
Bone conduction hearing aid	23%

Study 2 – Unilateral Hearing Loss: Participant Characteristics

Age at...	Mean (mos)	Range (mos)
Identification	3.1	.25 to 18
Amplification	9.4	.5 to 36
Intervention	6.4	.5 to 27

*60% of children met the EHDI guidelines of identification by 3 months of age and intervention by 6 months of age

Amount of Intervention

- 40% of families receive EI services once a month
- Median = 120 minutes per month

➢ Children with bilateral loss in NECAP: Median = 300 minutes per month

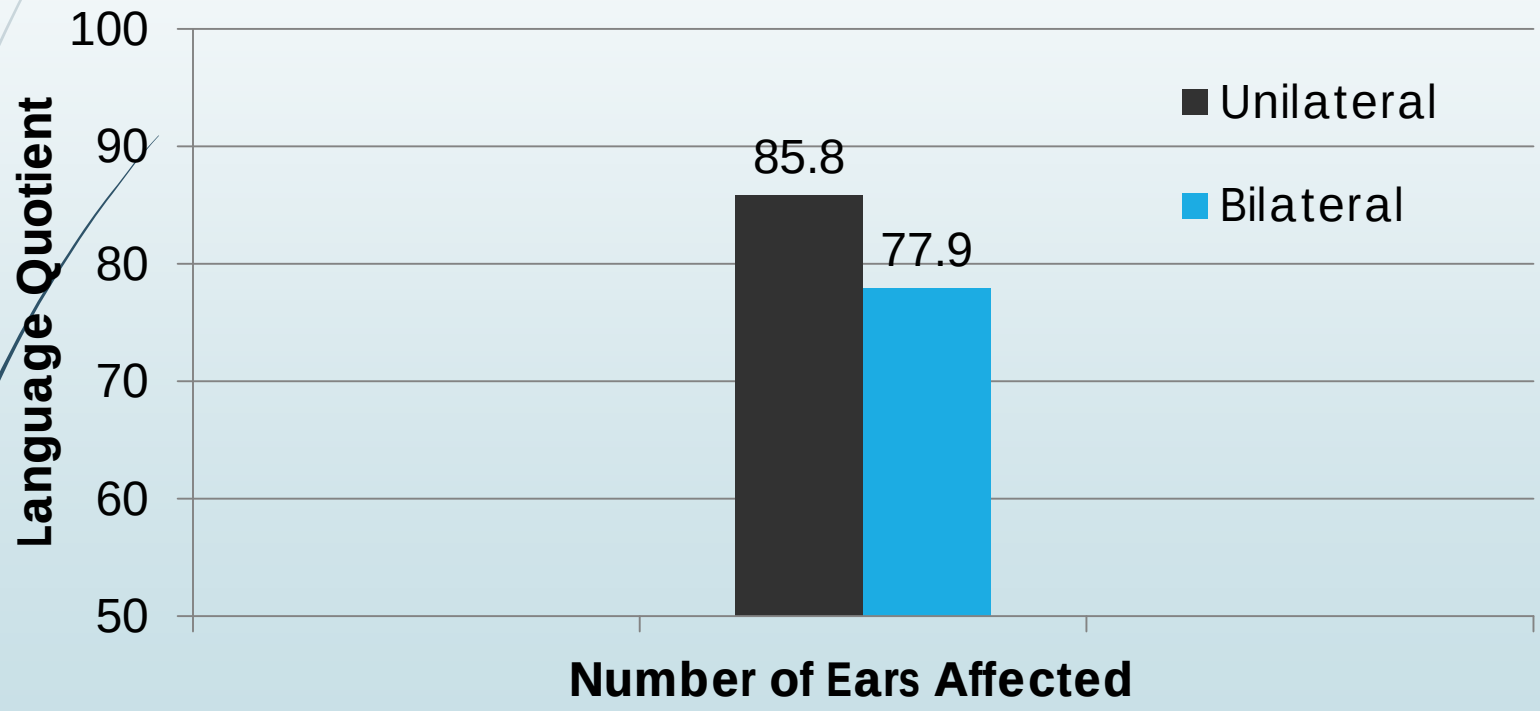
Study 2 – Unilateral Hearing Loss: Participant Characteristics

Highest degree completed	% of primary caregivers
Less than HS	17%
High school diploma	29%
Vocational or Associates	17%
Bachelor's degree	26%
Graduate degree	11%

Study 2 – Unilateral Hearing Loss: Language Outcomes (n = 137)

- MacArthur-Bates Language Quotient
  - Range = 45 to 160
  - Mean = 86
  - SD = 19.3
- Percentage of children with LQ of 80+
  - 63%

Unilateral vs. Bilateral Outcomes



Predicting Language Outcomes

- Linear regression used with MacArthur Language Quotient as the dependent variable
- Two models constructed:
  - Not including audiologic variables (n = 132)
  - Including audiologic variables (n = 72)

Predicting Language Outcomes

- Independent variables that were NOT significant ($p > .05$) and removed from the final model:
  - Language of home (English vs. Spanish)
  - Gender
  - Meeting EHDI guidelines
  - Deaf adult in the home
  - Affected ear (right vs. left)
  - Degree of loss in affected ear

Predicting Language Outcomes

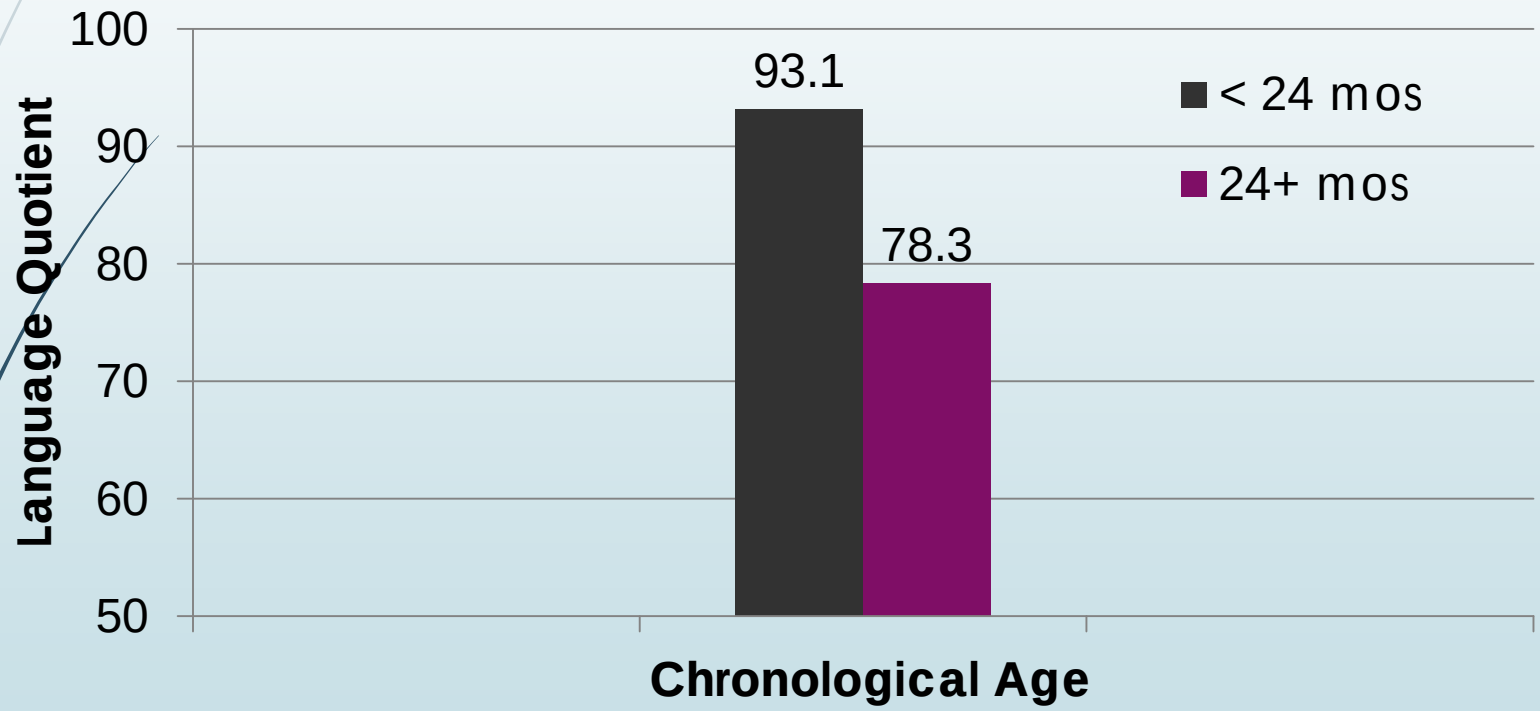
- Independent variables that WERE significant predictors (p < or = .05):
  - Chronological age
  - Mother's level of ed (< B.A vs. B.A or higher)

Regression Analysis: Predicting Language Quotient (n = 132)

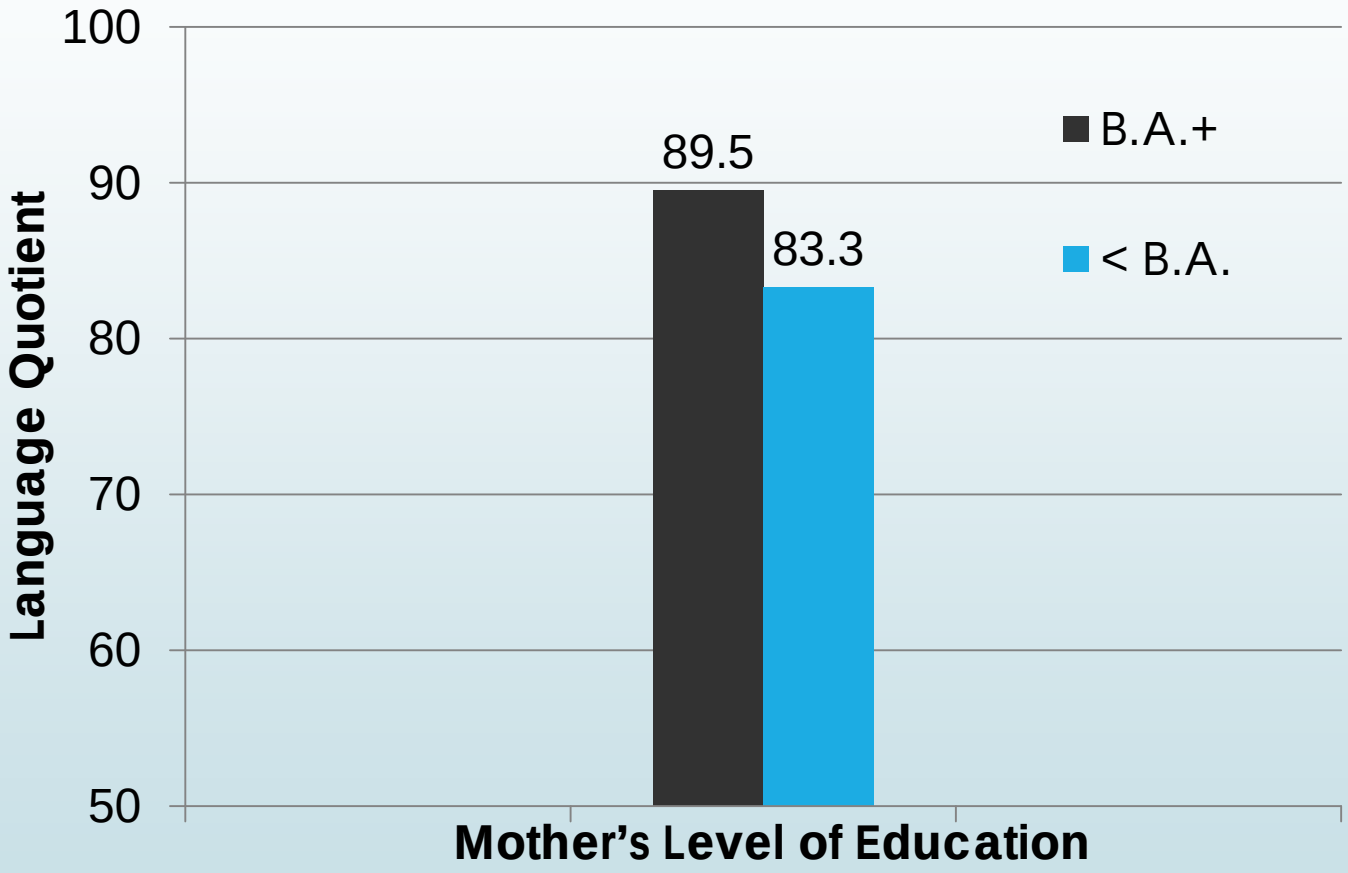
Independent variables	B (unstd coeff)	Beta (std coeff)	*p*
Chronological age	-1.15	-.49	<.001
Mother's education (<B.A. vs. B.A or above)	5.99	.15	.05

26% of the variance is explained by this model

Chronological Age Group



Mother's Level of Education

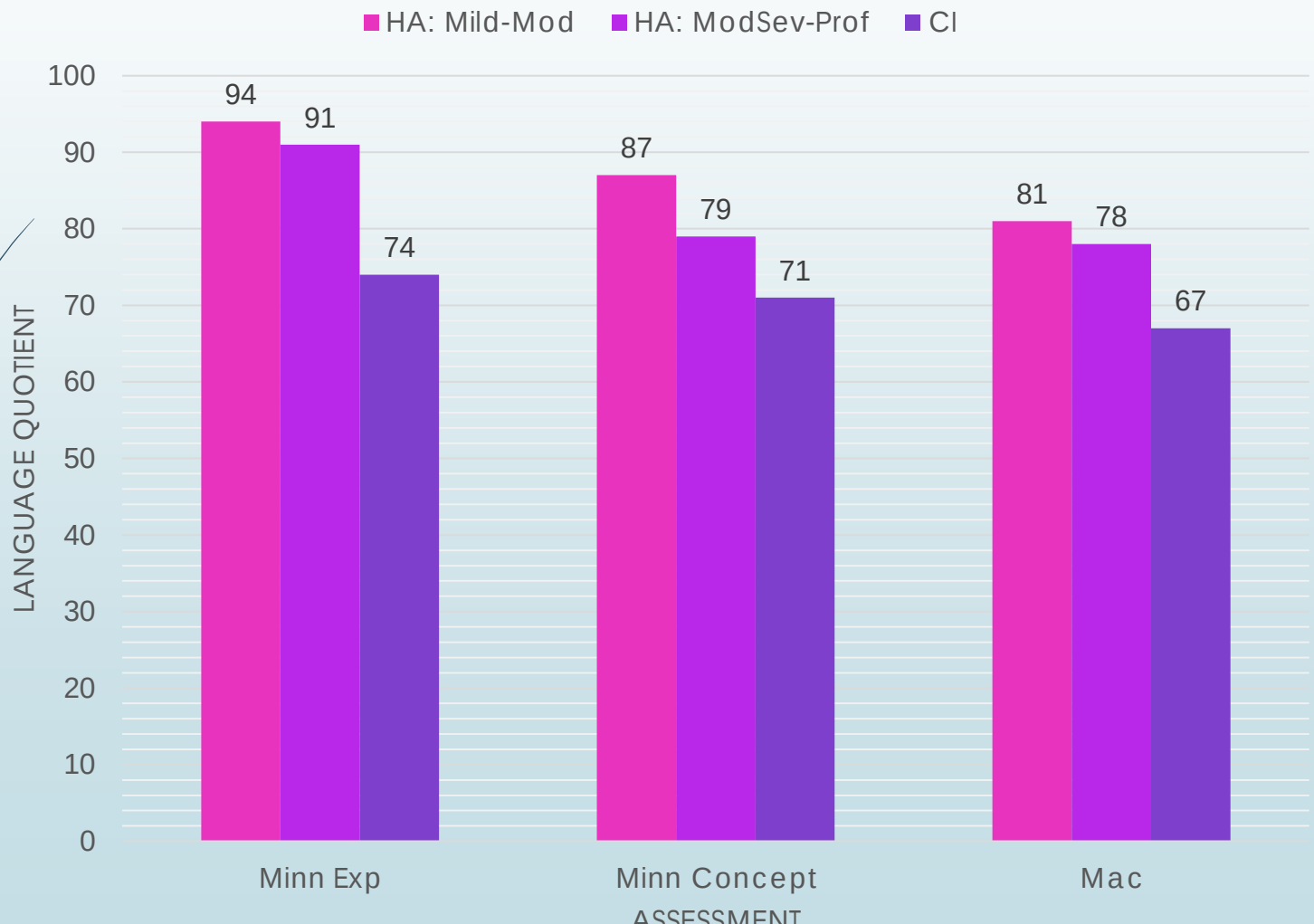


Clinical Implications

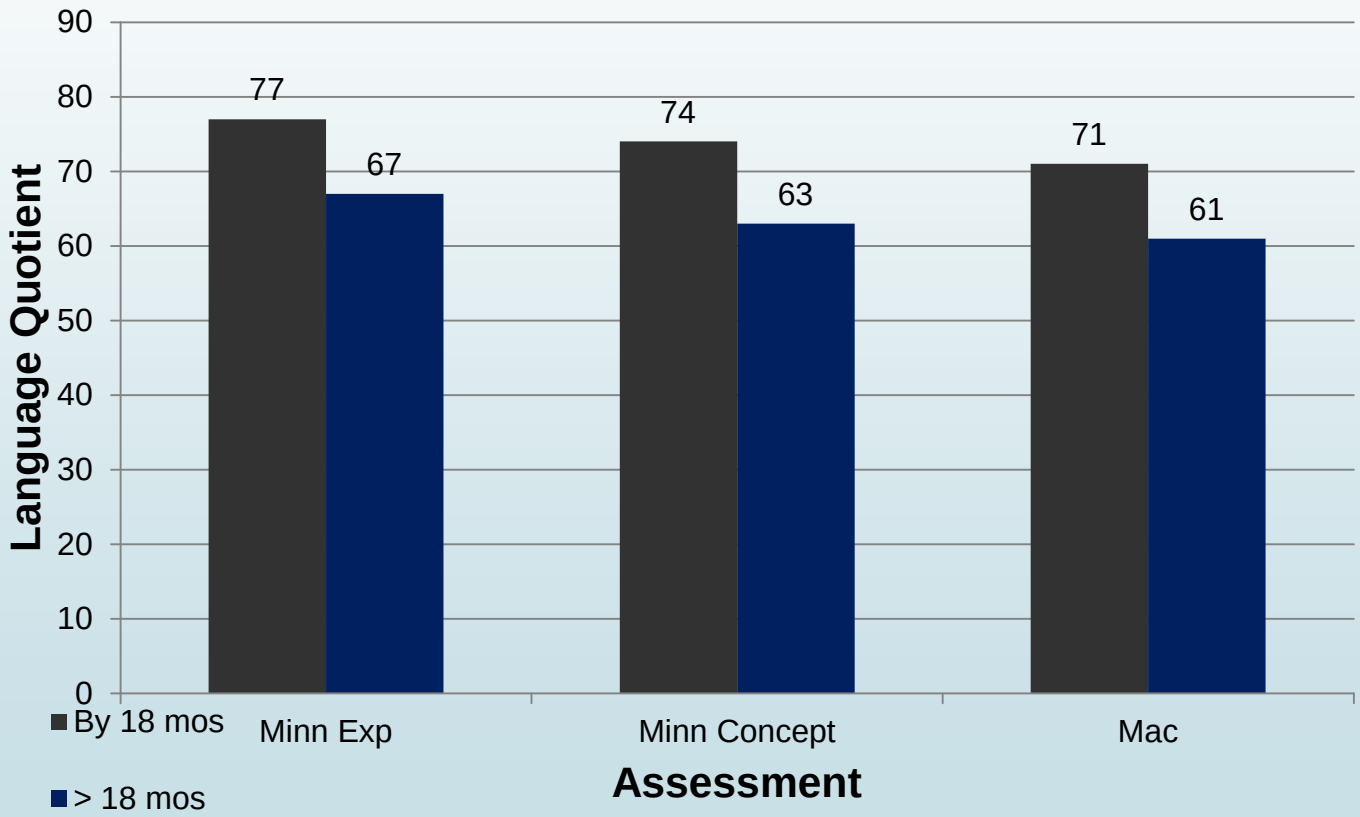
- Children with UHL should be re-evaluated just after turning 2 years old and again at transition to preschool so that data-driven decisions can be made regarding delivery of intervention services

Children with cochlear implants

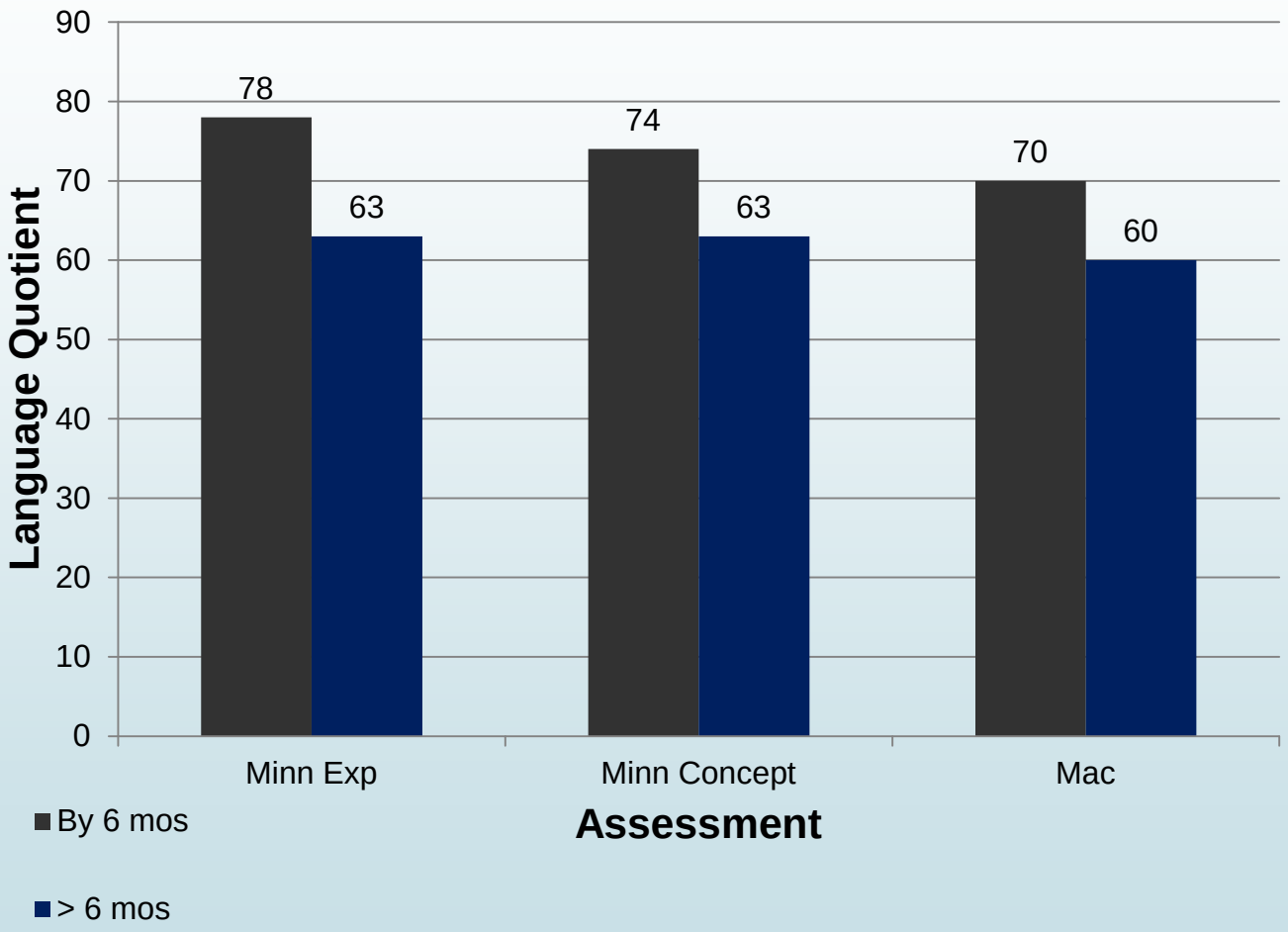
Children with cochlear implants: NECAP no add disabilities



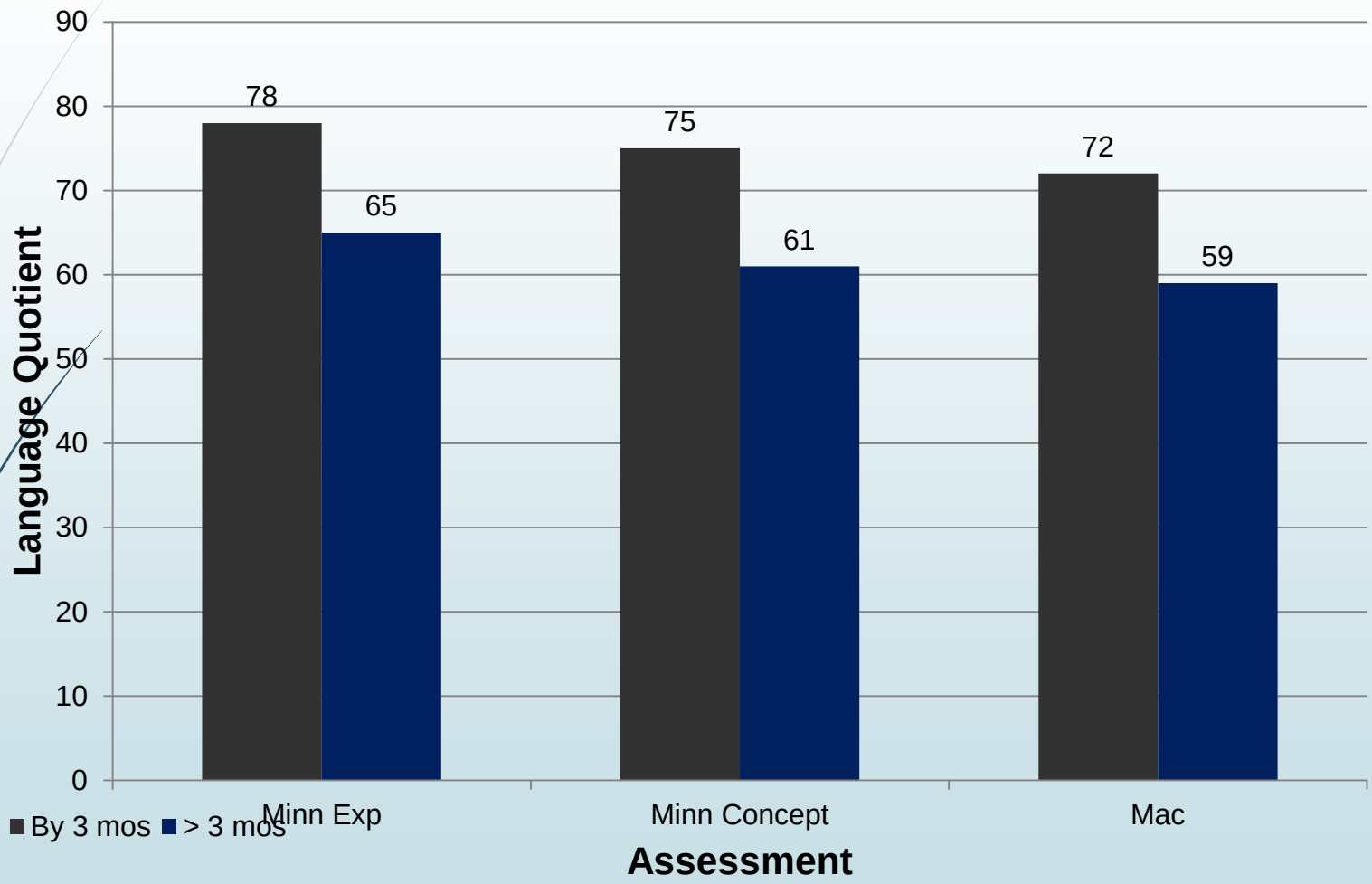
Age of cochlear implant activation



Enrollment in early intervention



Age of identification of hearing loss



Children with cochlear implants

- Meeting 1-3-6 is a powerful predictor of outcome of children with cochlear implants
- More powerful than age of activation – though they follow the same trends

Goal 8: Participation of Families

- ***Families will be active participants in the development and implementation of EHDI systems at the state/territory and local levels.***
- **Do you know the statistics for your state?**
- ***Advisory Board representation***
- ***Other evidence?***

How active are your parents/families in Ohio?

- Ohio has an active Hands and Voices chapter
- Ohio AG Bell Chapter

Goal 9: Family-to-family support

- ***All families will have access to other families who have children who are D/HH and who are appropriately trained to provide culturally and linguistically sensitive support, mentorship, and guidance.***
- **Do you know the statistics for your state?**
- **18 states have Guide By Your Side states with statistics.**

Guide-by-Your Side

- Ohio Hands and Voices Chapter
- Apparently, Guide By Your Side is coming to Ohio soon!

Goal 10: DHH Partnerships

- ***Individuals who are D/HH will be active participants in the development and implementation of EHDI systems at the national, state/territory, and local levels. Their participation will be an expected and integral component of the EHDI systems.***
- **Do you know the statistics for your state?**
- **Advisory Board representation**
- **DHH EI providers, audiologists, physicians, sign language instructors, administrators?**

Goal 11: DHH children with DHH adult support

- ***All children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH.***
- **Do you know the statistics for your state?**
- **Do you have a Deaf Child's Bill of Rights – assuring that every child who is deaf or hard of hearing has access to peers who are deaf or hard of hearing and adult role models?**

Goal 12: Fidelity of Intervention

- ***All children who are D/HH and their families are assured of fidelity in the implementation of the intervention they receive.***
- **Do you know the statistics for your state?**
- **E.g. Colorado has developed about 10-15 fidelity of intervention provider questionnaires on different intervention topics/strategies.**
- **Observation, self-assessment, Mentors**