

Understanding the Needs of Children Who are Deaf / HOH with Additional Developmental Disabilities

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Learning objectives

- To understand the importance of developmental progression over time
- To recognize the importance of evaluating variety of outcomes in children with additional needs
- To understand that teamwork is critical in serving children in this group of children

Why it matters

- Additional disabilities in children who are deaf/hoh ***are more common than you may realize***
- We want children to ***achieve to their maximal potential***, but often the complication of hearing and an additional disability makes it hard to know how to approach intervention
- Seeing a child meet a goal is very rewarding, even if the child is not keeping up with peers

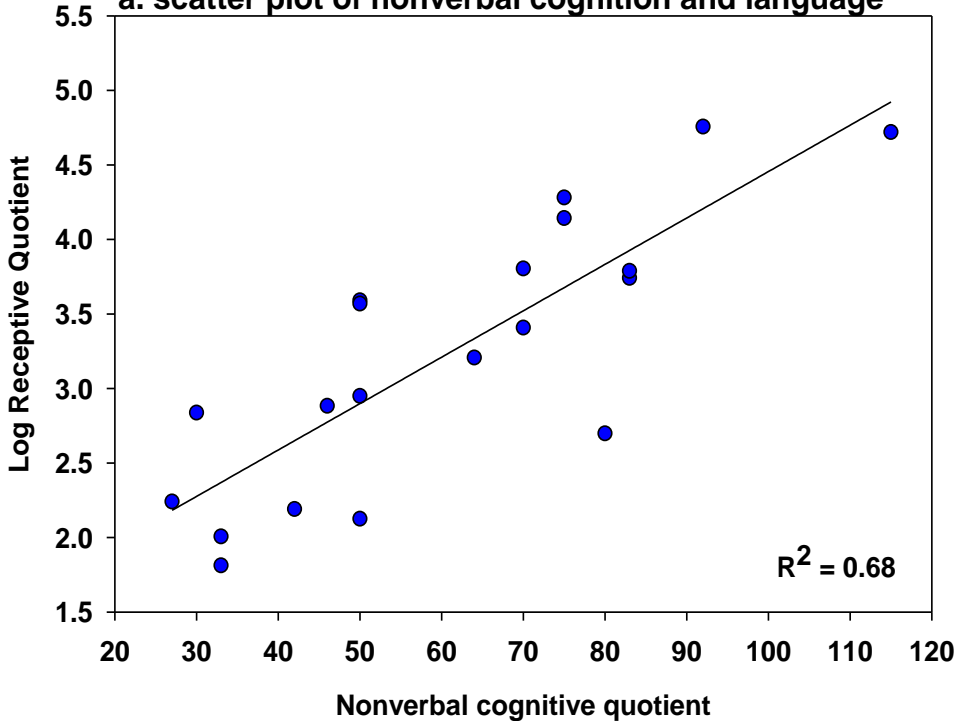
Type of Disability	Hearing Loss GRI data	General Population Variety of sources
No Additional Disability	60%	
Intellectual Disability	9.8%	2.5%
Cerebral Palsy	?	0.3%
Blindness	3.9%	0.03%
ADHD	6.6%	5-10%
Specific Learning Disability	10.7%	5-10%
Other	12%	
Autism Spectrum Disorders	4-7%	0.9%
<i>GRI-Jure</i>		

Risks and Etiologies

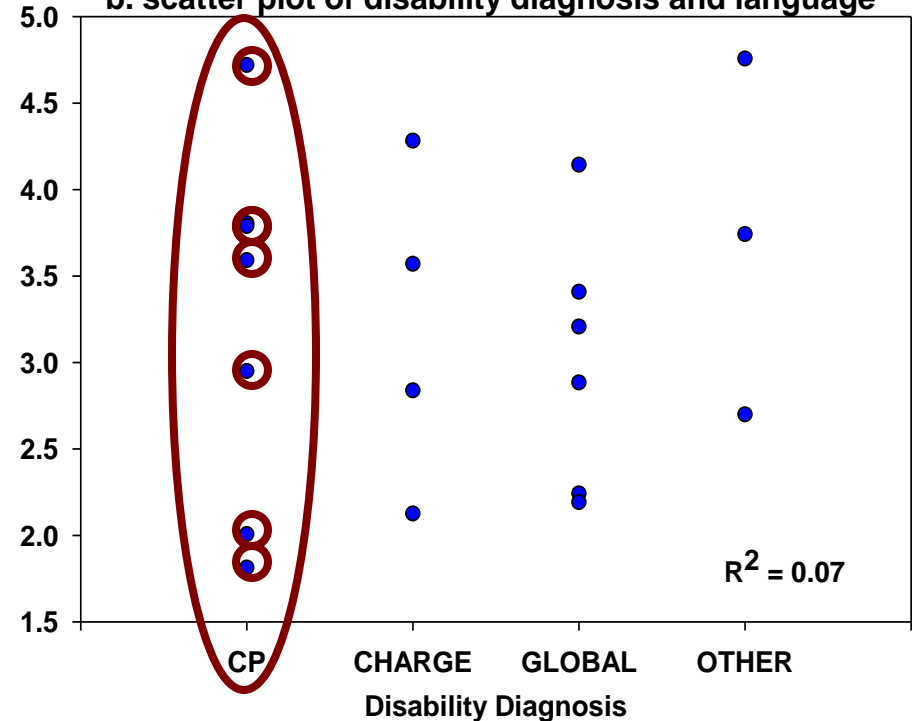
- Etiology can confer risk and does not protect from other risk factors for developmental problems
 - **Risk factors** for hearing loss often **overlap** with risk factors **for developmental delay**
 - **Risk factors** for developmental delay **can co-occur** in children with hearing loss **unrelated to the cause of hearing loss**
- Disability labels do not tend to provide an effective guide to our understanding of a child's capacities

Specific Disability Label Not Very Predictive

a. scatter plot of nonverbal cognition and language



b. scatter plot of disability diagnosis and language



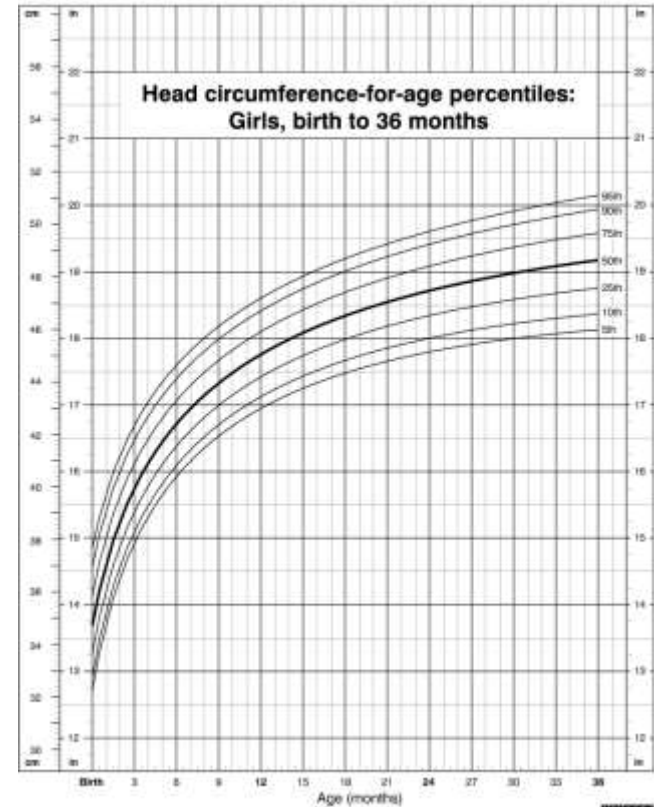
Appropriate Comparison Group

- Children who are deaf/hoh with co-existing developmental disabilities learn differently than children who are deaf/hoh without a disability, making this comparison group inappropriate
- Using developmentally matched children may be more meaningful in understanding progress and expectations (non-verbal cognitive skills provide a large contribution to the overall outcomes across disability categories)
- Understanding the range of outcomes within disability categories and using these benchmarks to measure progress and guide expectations can guide more appropriate predictors and outcomes (i.e. ASD)

Development is a Process: And it's about the brain

CDC Growth Charts: United States

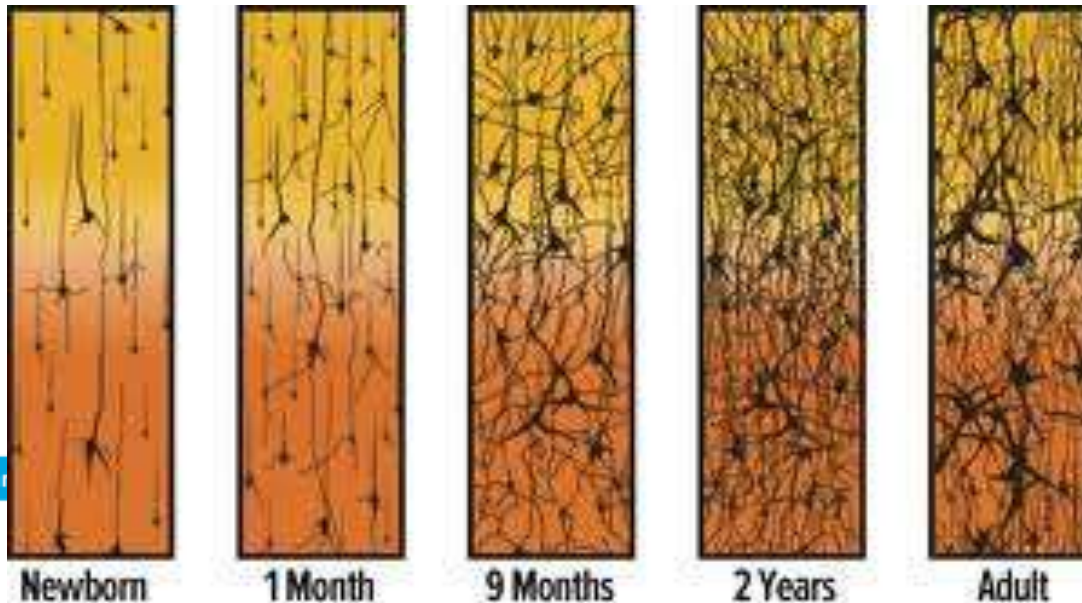
- There is rapid brain growth in the first two years of age
- Myelination of the brain continues into early adulthood



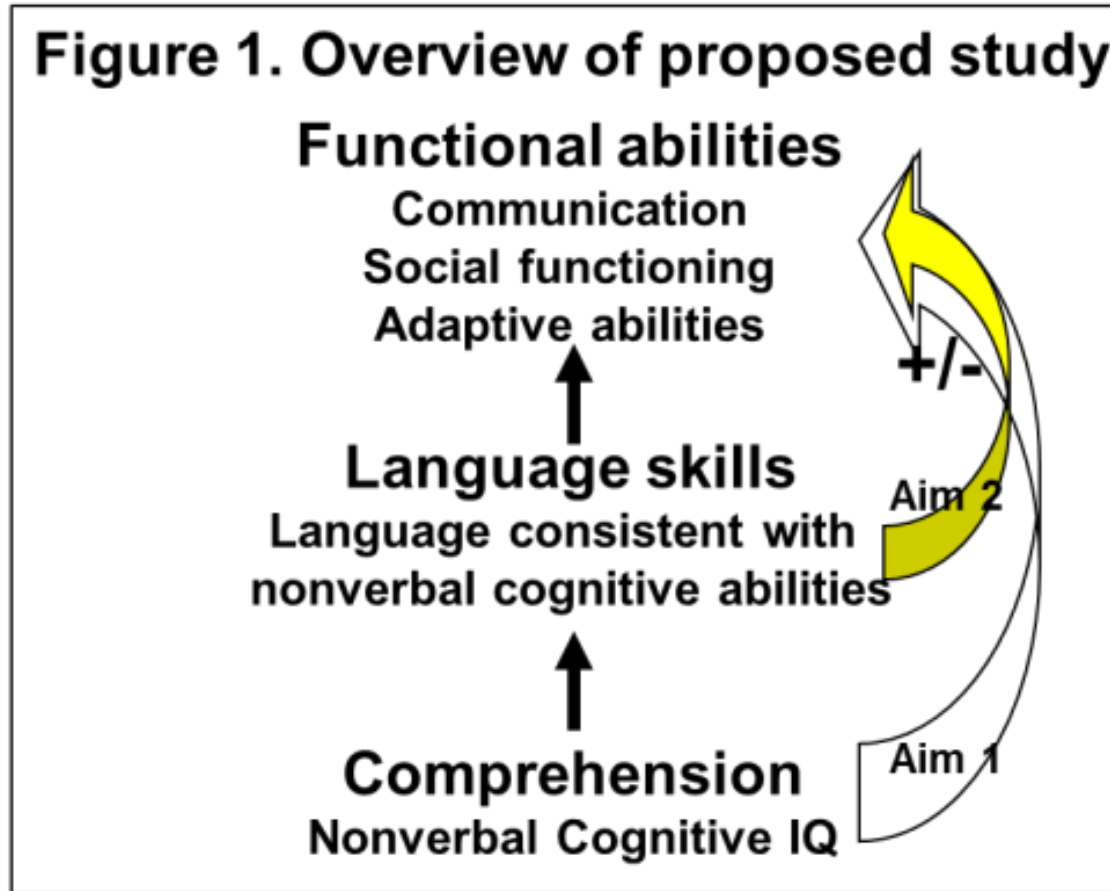
Published May 30, 2000
SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000)



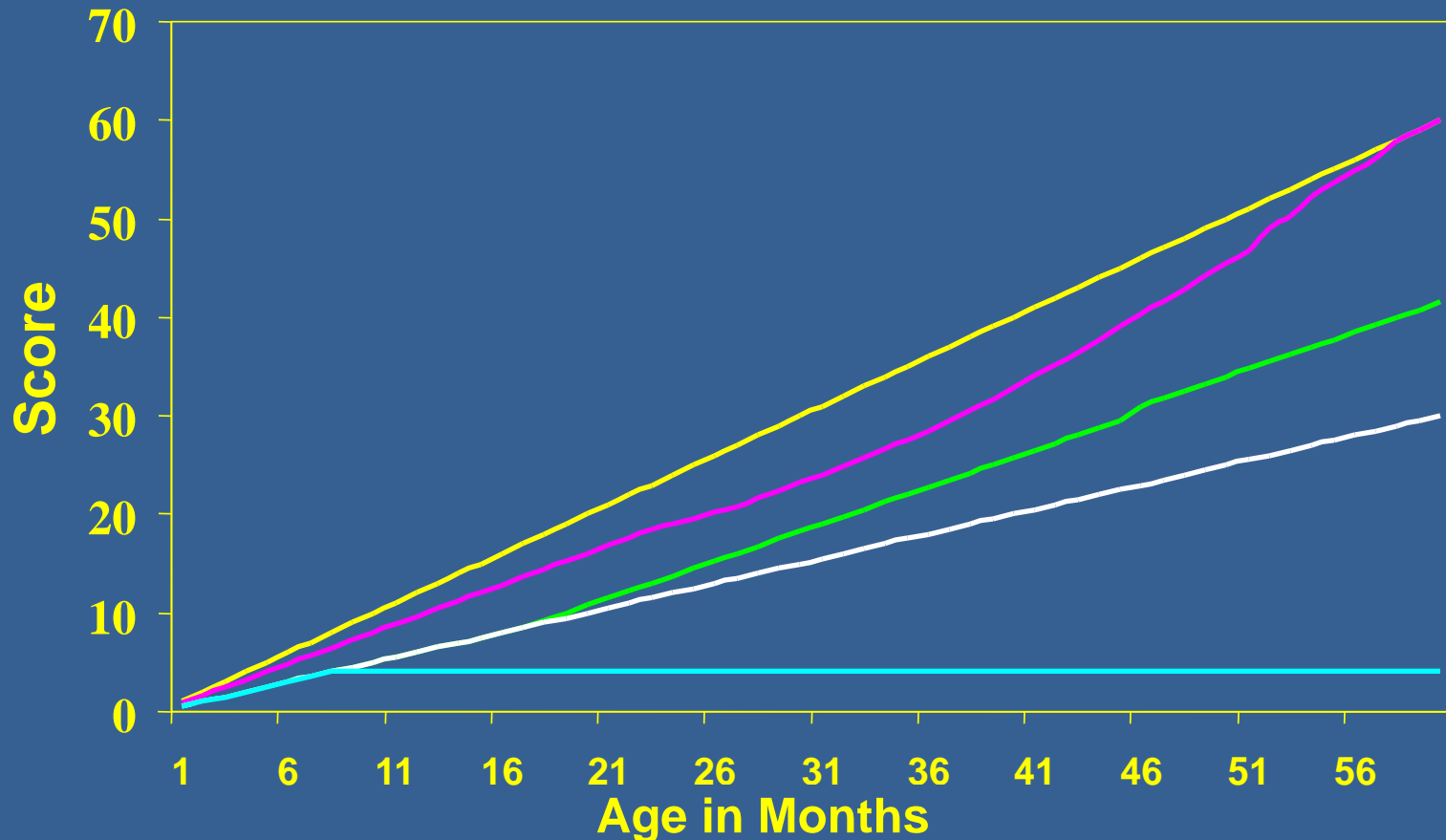
SAFER • HEALTHIER • PEOPLE



The ear is necessary, but not sufficient (top-down)



5 Possible Developmental Trajectories



- Maintained functioning comparable to age peers
- Achieved functioning comparable to age peers
- Moved nearer functioning comparable to age peers
- Made progress; no change in trajectory
- Did not make progress

-- Hebbeler, 2006

Typical vs Atypical Patterns

- Motor Development
 - Head to toe
 - Proximal to distal
 - Primitive reflexes to protective responses
 - Balance
- Delay
 - Follows the usual trajectory, just at a later time
 - Rate of progress over time is important
- Atypical development
 - Atypical patterns of motor movements
- Take home points:
 - you need a good reason to justify the motor delay in children who are deaf/hoh (inner ear malformation, vision impairment, syndrome associated with motor delay, brain-based process)
 - Gross motor delay (especially children with cerebral palsy) doesn't necessarily equate with cognitive ability

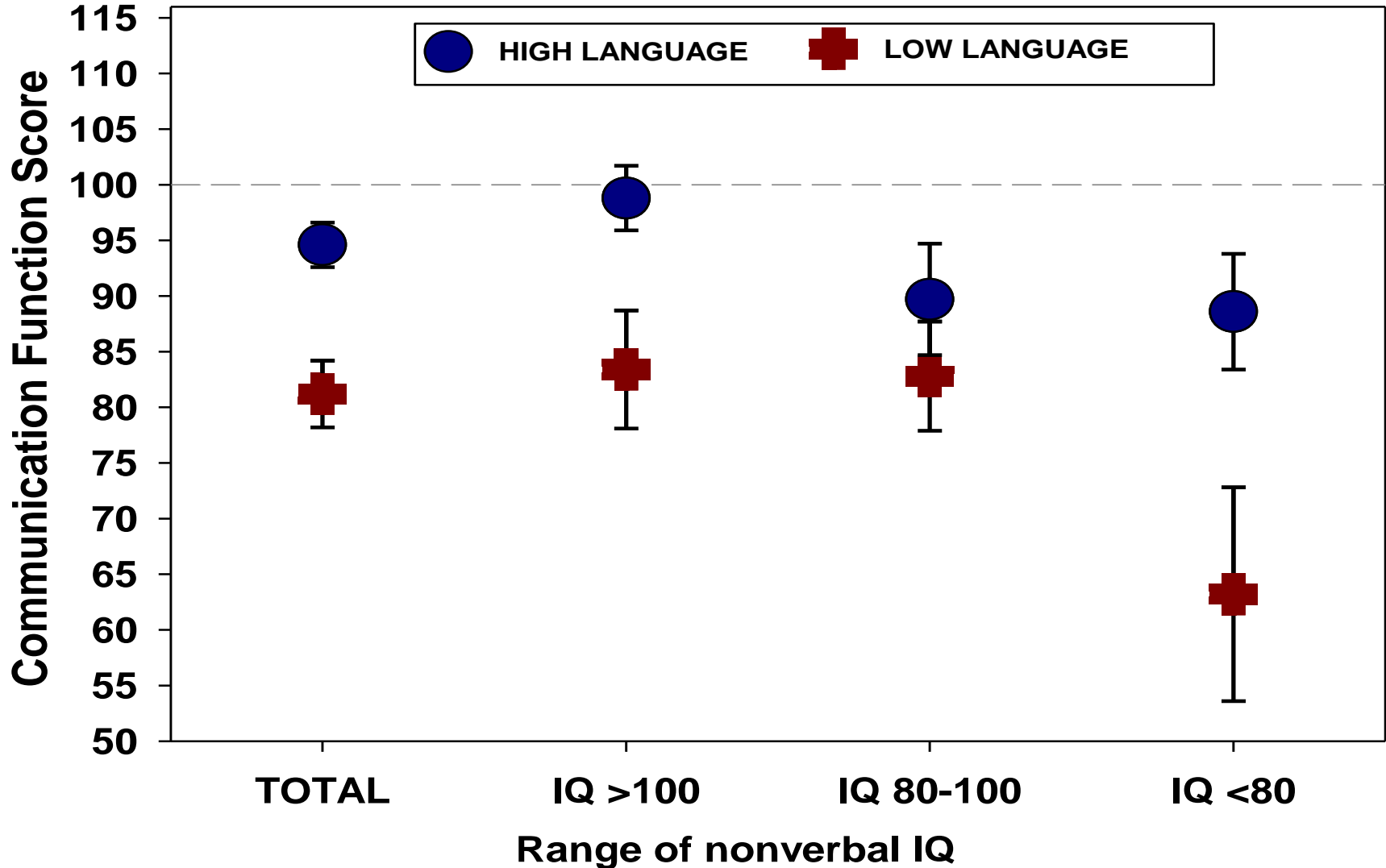
Typical vs Atypical Patterns

- Cognitive development
 - Infants and Toddlers learn through exploration of the environment and sensory input
 - Preschooler's learn through language, spatial experiences, use concrete problem solving and have magical thinking, no abstraction
 - Early Childhood begin to have more logical thinking, but still concrete
 - Late Childhood/Adolescence use abstract and logical thinking
- Delay (non-verbal problem solving for deaf/hoh):
 - Follows the usual trajectory, just at a later time
 - Rate of progress over time is important, tends to plateau
- Atypical Development:
 - May have varying learning profiles, could be suggestive of a specific learning disability

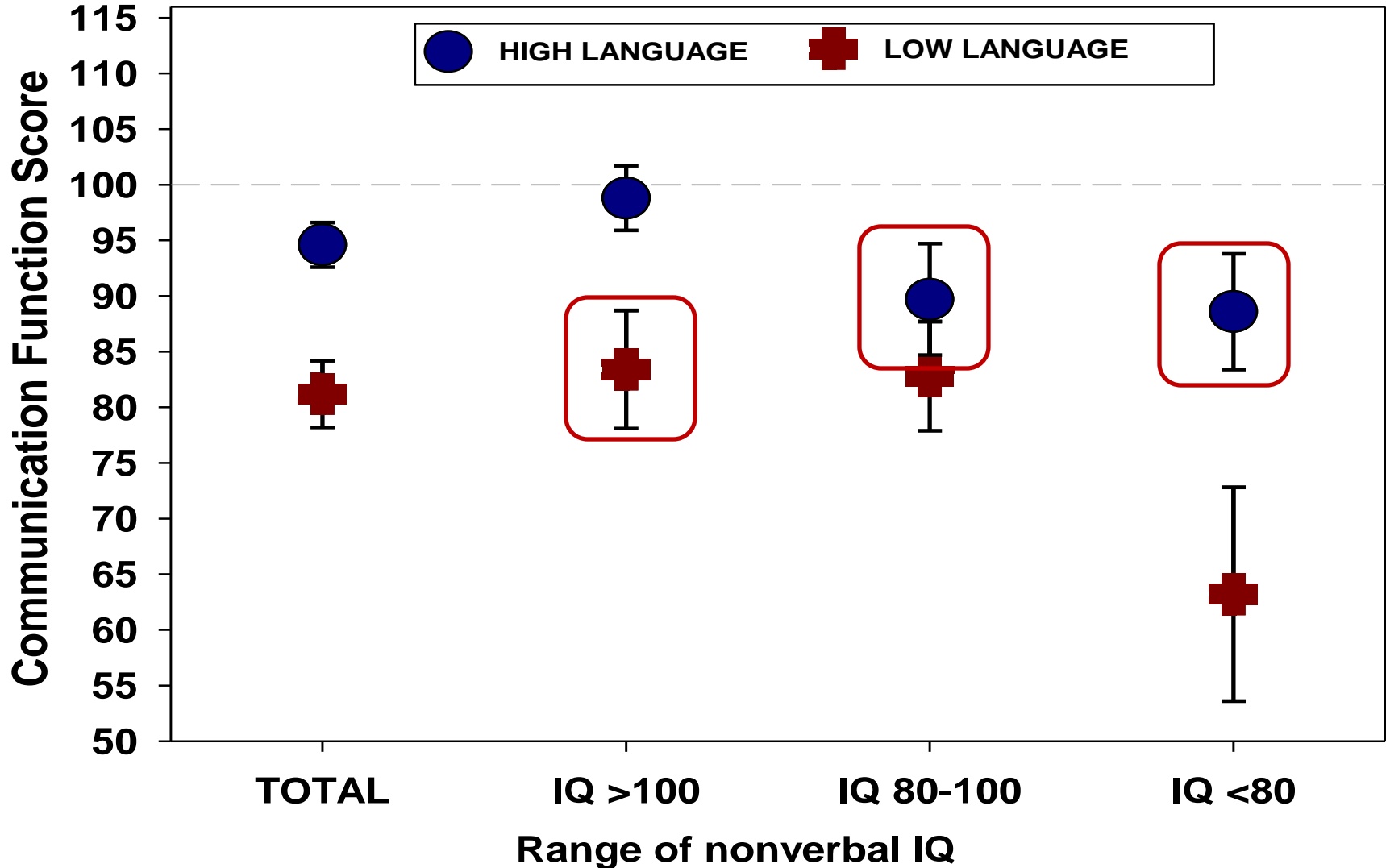
Language: Considerations

- Language
 - What is hearing?
 - What is communication environment?
 - Are there unexplained (atypical) patterns of language development (processing, good understanding, poor speech)?
 - How is a child developing in their non-verbal, gestural, and pragmatic language?
- Why the gap matters?
 - When we don't recognize cognitive potential, we miss children with high cognitive potential who have low average language levels and we have been satisfied with this

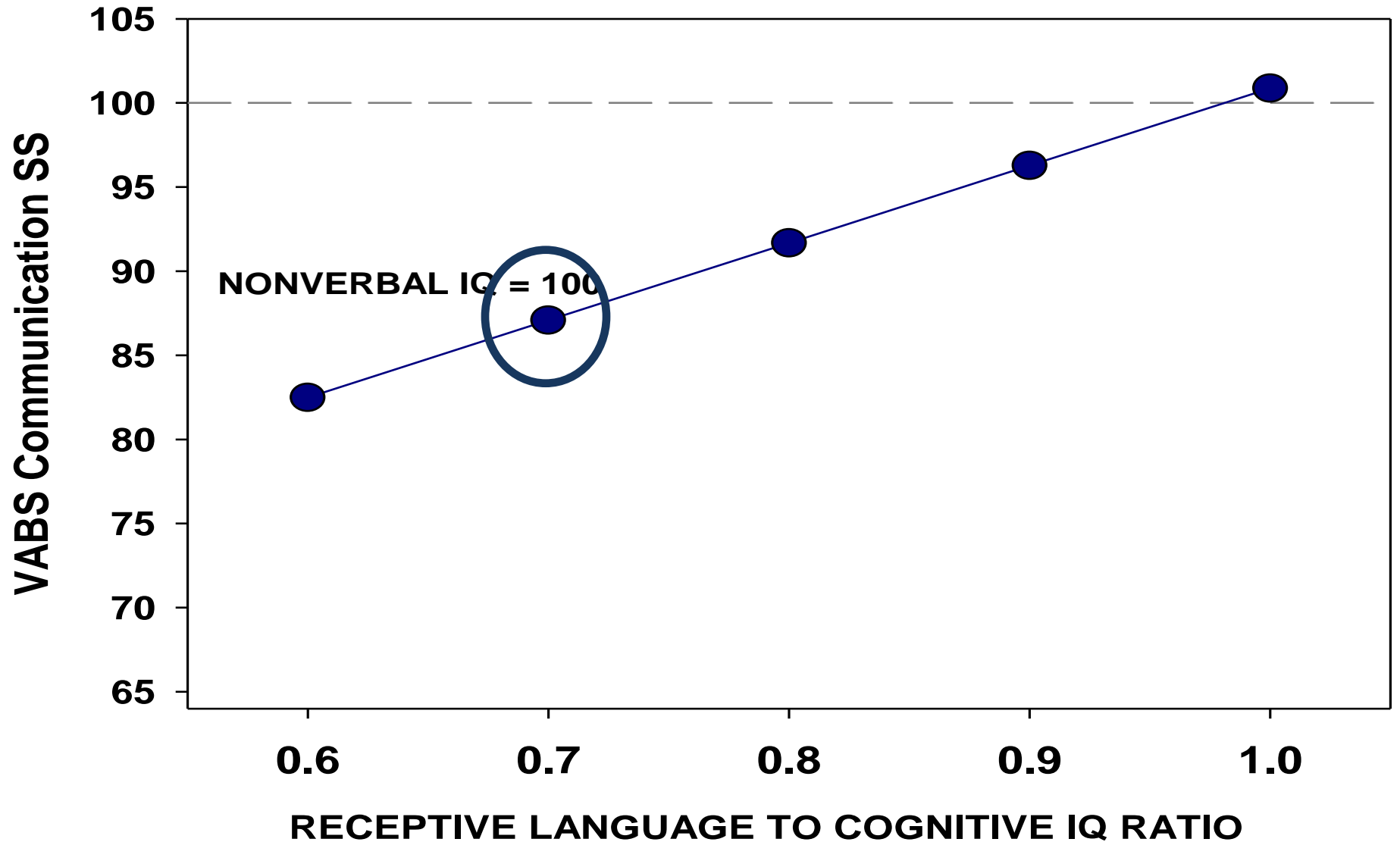
Adjusted mean Communication Scores



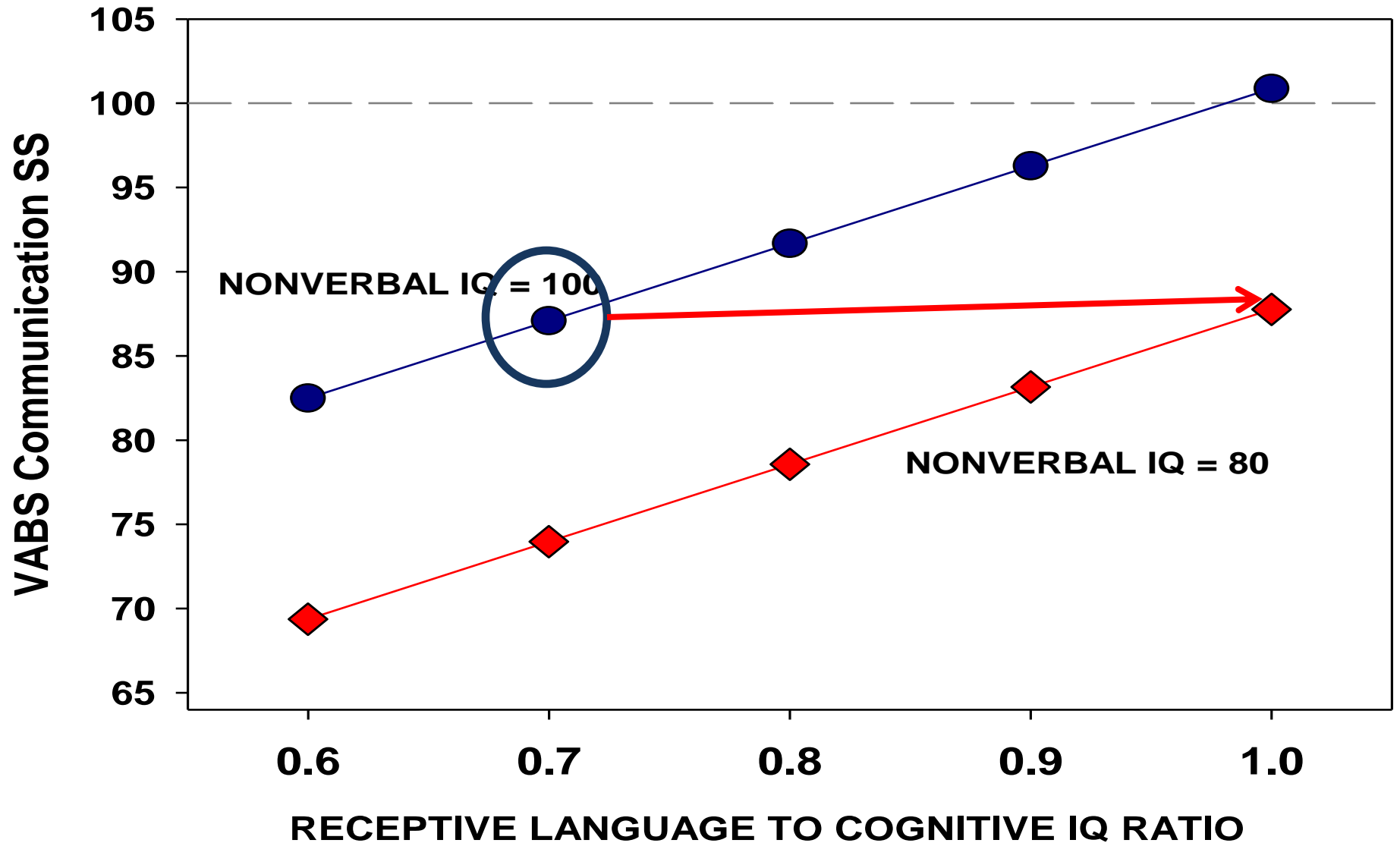
Adjusted mean Communication Scores



Estimated Functional Skills



Estimated Functional Skills



There is a place for **functional outcome measures** for children with additional disabilities

“Special needs children go through so much that people see the cochlear implant as one more thing. I feel that they need to have every opportunity available to him. I want my child to be treated like he is not special needs.”

Behavior: Considerations

- Behavior
 - Understood in the context of communication needs
 - Understood in the context of the child's overall developmental levels (i.e., if a child is functioning at a 2 year level, anticipate an attention span that is commensurate with most 2 year old's)
 - Recognize when there may be risks for emotional difficulties (parent-child relationship, exposure to abuse, domestic violence)
 - Recognize when there are neurobiological factors contributing to behavior (attention, impulsivity, hyperactivity)

Integrating the Information

- Finding a Developmental Pediatrician with an understanding of typical development in children who are deaf/hoh
- Comprehensive History (risks for hearing, development)
- Physical Examination
- Laboratory, Genetic, and Imaging studies
- Broad based developmental assessment evaluating a number of domains
 - Gross Motor
 - Fine Motor
 - Cognitive
 - Language
 - Personal-Social

Team Building

- Strive towards common goals
- Listen actively
- Communicate effectively between/among team members
- Be confident in what you know and recognize when you don't know something
- Learn from others/collaboration
- Be open to new ideas and strategies
- Think outside the box
- Consider co-treatment when appropriate
- Try something and tweak it when it doesn't work

Some important premises

- There is a high rate of additional disabilities in children who are deaf/hard of hearing
- Comparing these children to typically developing deaf/hard of hearing children when evaluating outcomes is inappropriate
- Development is ever-changing due to on-going brain development (therefore, **the earlier** we diagnose children, **the less accurate** our predictions making **surveillance necessary**)
- Most childhood development tends to follow specific patterns in early childhood (**it's about the brain**)
- Family and child support and adaptations are critical

Family Perspective

- *Deaf/hh Plus is meant to be a positive term, not in any way negative or insensitive to the child who has medical issues along with hearing loss. In fact, I see it as an "A+" or "B+," meaning the child carries additional positive qualities. But it is a gift that needs to be carefully unwrapped. And it may not appear to be a gift when you first receive it. Time helps you appreciate, understand and unfold the possibilities. And the "Plus" most often means the child and family has added responsibilities and requires additional expertise."*
- – **Candace Lindow-Davies, MN Hands & Voices**

Thank you to

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