Special considerations of implementing PerfO Assessments for Pediatric Populations

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Disclosures

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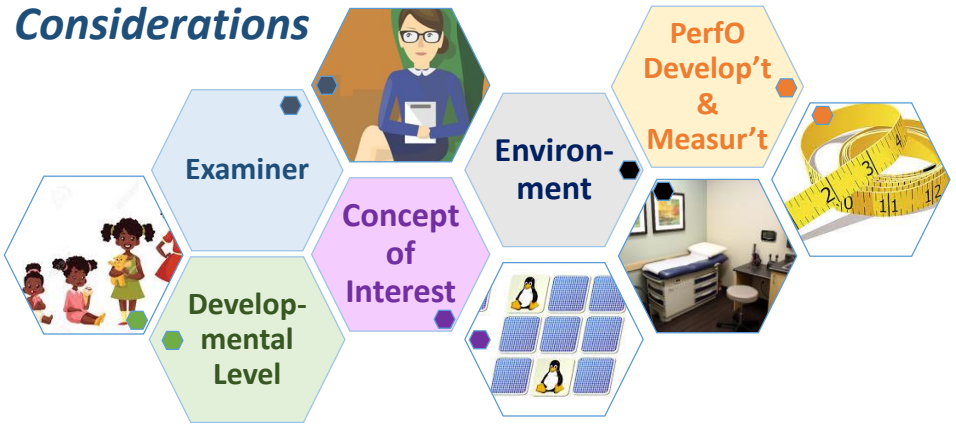
Special Considerations



1. Developmental Level of the Child

- Developmental change over time in kids
- Regression vs Development vs Stabilization

Developmental Change over Time - Cognition

	0-12 mos	12-24 mos	2-3 yrs	3-4	4-6	6-12	16-17	18+
Bayley –3 Screen	1-42 mos							
Bayley-3	1-42 mos							
BINS		3-24 mos						
Battelle-II-NU	0 – 7:11 yrs							
DAYC-2	0 – 5:11							
Developmental Profile-3		0 – 12 yrs						

Developmental Change over Time - Cognition

		0-12	12-24	2-3	3-4	4-6	6-12	16-17	18+
General Intellectual Ability (IQ)	Mullen	0-68 mos							
	WPPSI-IV			2:6-7:7					
	WISC-V						6:0-16:11		
	SB-5			2-85+					
	DAS-II			2:6- 17:11					
	KABC				3 - 18				
	KBIT-2					4 - 90			

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PerfO measures (cognitive, and to some degree, motor) are designed with an assumption of Development, not Regression

Shapiro EG, Klein KA. Dementia in Childhood: Issues in Neuropsychological Assessment with Application to the Natural History and Treatment of Degenerative Storage Diseases. In: *Advances in Child Neuropsychology, Volume 2.* SR Hooper & MG Tramontana, Eds. 1994. Springer-Verlag: New York.

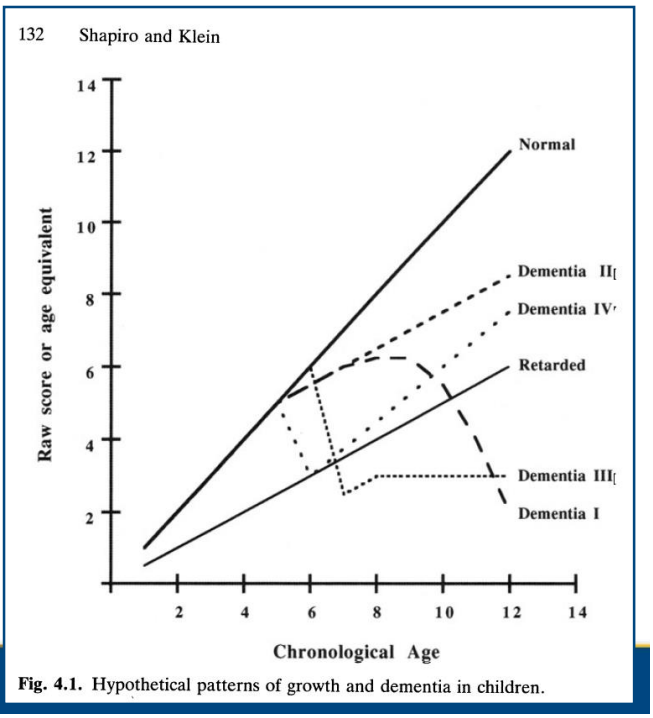
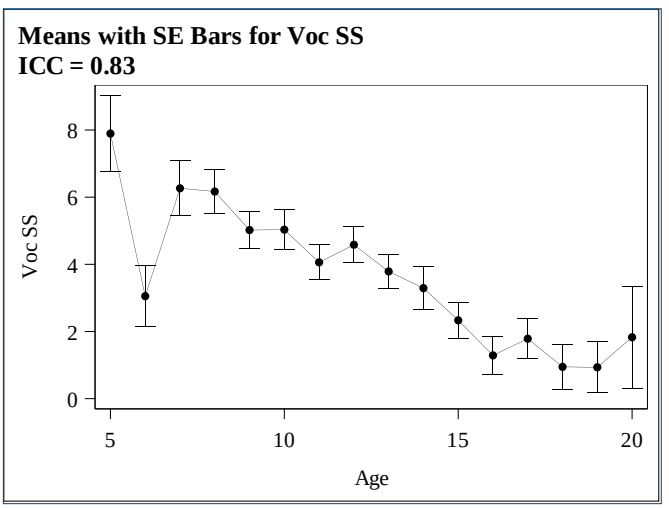


Fig. 4.1. Hypothetical patterns of growth and dementia in children.

Regression v. Development v. Stabilization?



Wechsler IQ test Vocabulary subtest

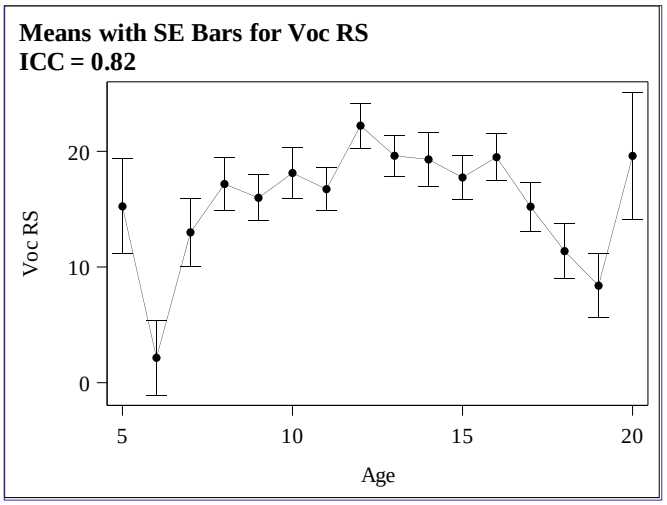
CLN3 Disease ("juvenile Batten disease")

N = 77 (42 females) 1-13 assessments

Vocabulary test, a proxy for Verbal IQ, appears to decline steadily over time, suggesting a loss of cognitive skills

Unpublished data

Regression v. Development v. Stabilization?



In fact, raw scores (not adjusted for age) show that children do continue to acquire skills first, before experiencing a decline

2. Examiner qualifications & experience

- Must understand child development & behavior
- Can elicit best performance from a wide range of developmental levels and abilities
- Must be familiar with the disease and its impacts on child behavior and cognition
- Must be able to manage challenging behaviors
  - Inattention
  - Defiance / noncompliance
  - Anxiety / shyness
  - Impulsivity and hyperactivity
- "Children do well if they can"

3. Concept of Interest targeted by the PerfO

Need to understand developmental considerations in measuring Concept of interest

(e.g., measuring "executive function" in a 4 year old can be quite different than measuring in a 14 year old…)

Different PerfO measures may need to be considered, depending on age and developmental level of child…

And…

The CoI itself may have a different operational definition, depending on age / developmental level

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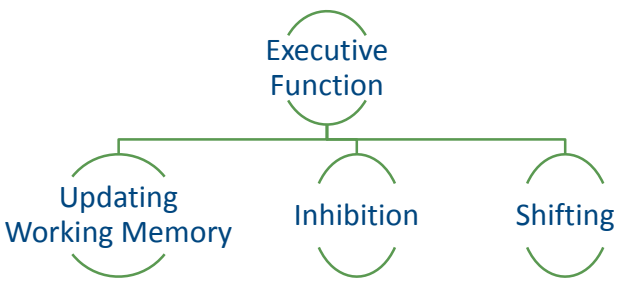

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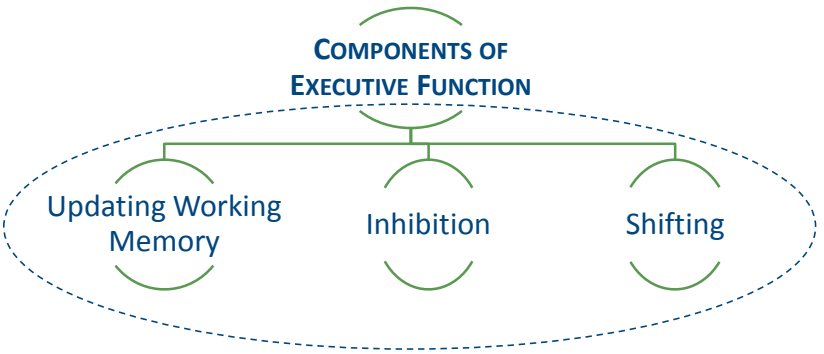

A single factor best explains performance in 7-9 year olds, and in 10-12 year olds

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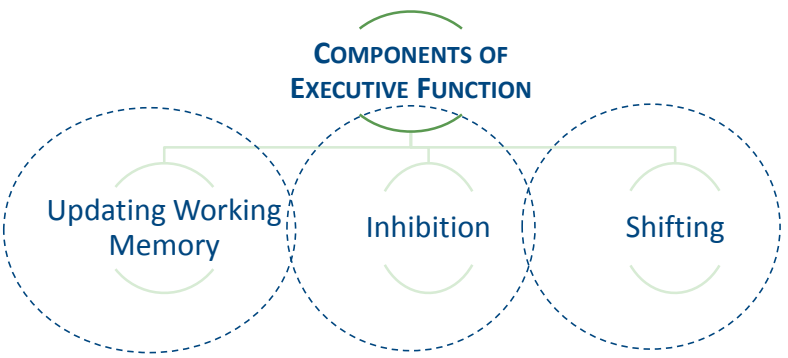

A three-factor model provided best fit for 13-15 year olds

4. PerfO Test Development & Measurement

PerfO Development / Selection

- Consider parent / child input regarding PerfO development (if possible)
- "Off-the-shelf" vs. de novo measures vs. adapted measures
- Tests must be: engaging, as easy as possible to administer, score & audit, and should be completed as quickly as possible to accomplish the goal

PerfO Measurement

- Are the age-standardized scores the most sensitive to change in the population of interest?
- Must capture full range of potential ability with adequate floor & adequate ceiling

Environment (operational considerations)

- Environmental distractors
- Medical / sensory limitations of the child
- Fatigue, jet lag, hunger, baseline temperament
- Prepare caregiver & child for what to expect at the visit
- Assessment needs to be scheduled in the proper sequence with other study activities
- Consider travel fatigue / burden
- Need for food or naps
- Need for scheduled meals or medications / treatments
- Ask parent if child's behavior / mood / energy etc. on day of testing is representative

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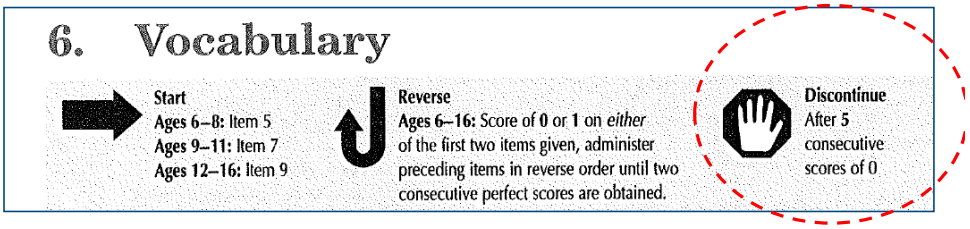
Example

Wechsler Intelligence Scale for Children – Fourth edition



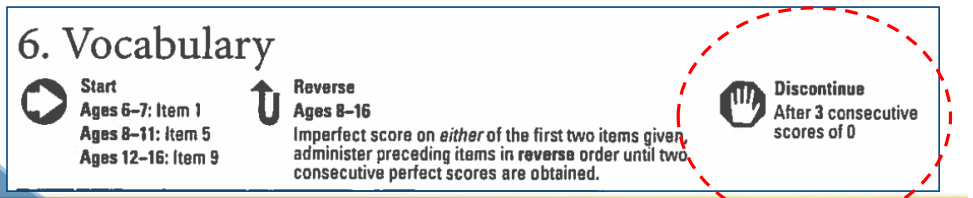
6. Vocabulary

Start
Ages 6–8: Item 5
Ages 9–11: Item 7
Ages 12–16: Item 9

Reverse
Ages 6–16: Score of **0** or **1** on *either* of the first two items given, administer preceding items in reverse order until two consecutive perfect scores are obtained.

Discontinue
After **5** consecutive scores of 0

Wechsler Intelligence Scale for Children – Fifth edition



6. Vocabulary

Start
Ages 6–7: Item 1
Ages 8–11: Item 5
Ages 12–16: Item 9

Reverse
Ages 8–16
Imperfect score on *either* of the first two items given, administer preceding items in **reverse** order until two consecutive perfect scores are obtained.

Discontinue
After **3** consecutive scores of 0