Measuring and assessing health literacy in the early years

Russell Rothman MD MPP
October 17, 2011

Associate Professor, Internal Medicine & Pediatrics
Director, Center for Health Services Research
Chief, Internal Medicine & Pediatrics
Co-Director, Community Engaged Research

Acknowledgements

- Vanderbilt
  - Tom Elasy MD MPH, Robert Dittus MD MPH
  - Shelagh Mulvaney PhD
  - Kerri Cavanaugh MD MPH, Mimi Huizinga MD MPH
  - Dianne Davis RD CDE, Becky Gregory RD CDE
  - Ken Wallston PhD. Phil Ciampa MD
  - Ayumi Shintani PhD, Tebeb Gebretsadik MPH
  - Disha Kumar BS, Jessica Sparks BA, Ryan Housam BA, Hilary Weiss BS, Kirbee Bearden
  - Shari Barkin MD MHs
  - Bettina Beach PhD
  - Sunil Kripalani MD
  - Heidi Silver RD PhD
  - Richard White MD (Meharry)
- NYU
  - Shonna Yin MD MSc
  - Linda van Schaick PhD
  - MaryJo Messito MD
  - Elaine Galland RD
  - Benard Dreyer, MD
  - Alan Mendelsohn, MD

- UNC
  - Eliana Perrin MD MPH
  - Joanne Propst-Finkle JD
  - Alice Ammerman PhD RD
  - Darren DeWalt MD MPH

- Miami
  - Lee Sanders MD MPH
  - Vivian Franco MPH
  - Anna Maria Patino Fernandez, PhD
  - Daniela Quesada, MPH
  - Sheah Rarback, RD
  - Sarah Messiah, PhD
  - Lourdes Forster, MD

VANDERBILT UNIVERSITY
MEDICAL CENTER

Outline of Talk

- Assessment of Health Literacy and Numeracy
- Assessing Health Literacy in Younger Children (Parents)
- Assessing Health Literacy in Older Children
- Future Opportunities

What is Health Literacy?

- Health literacy: "the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions"
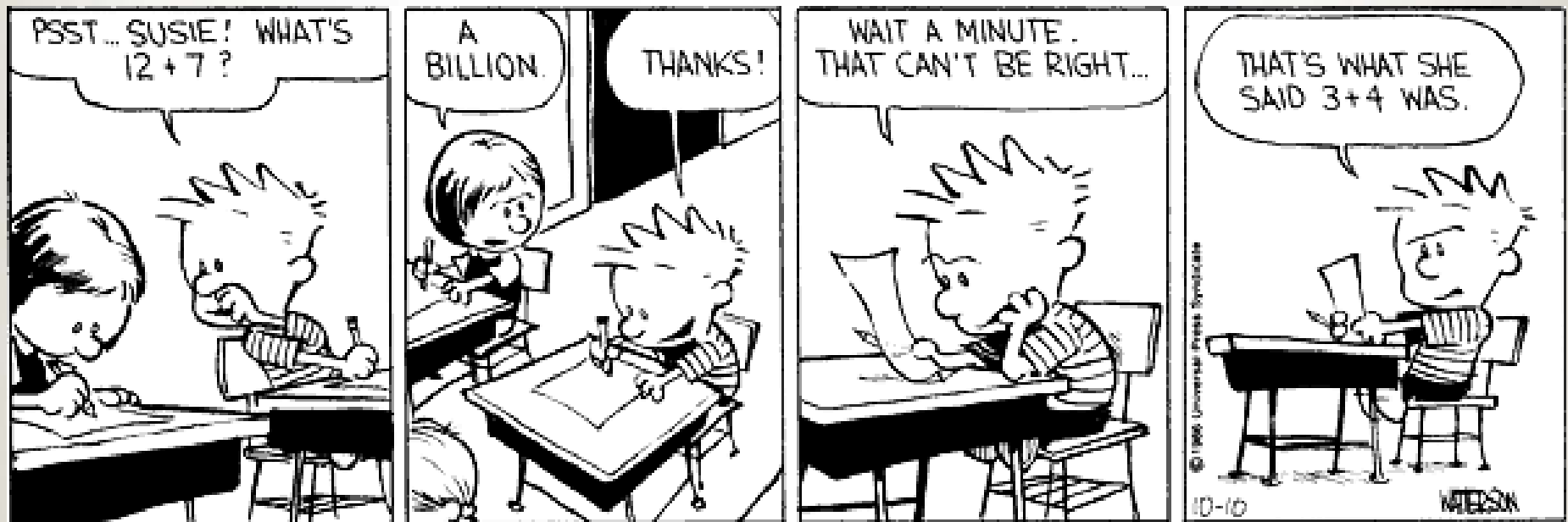
Components of Literacy
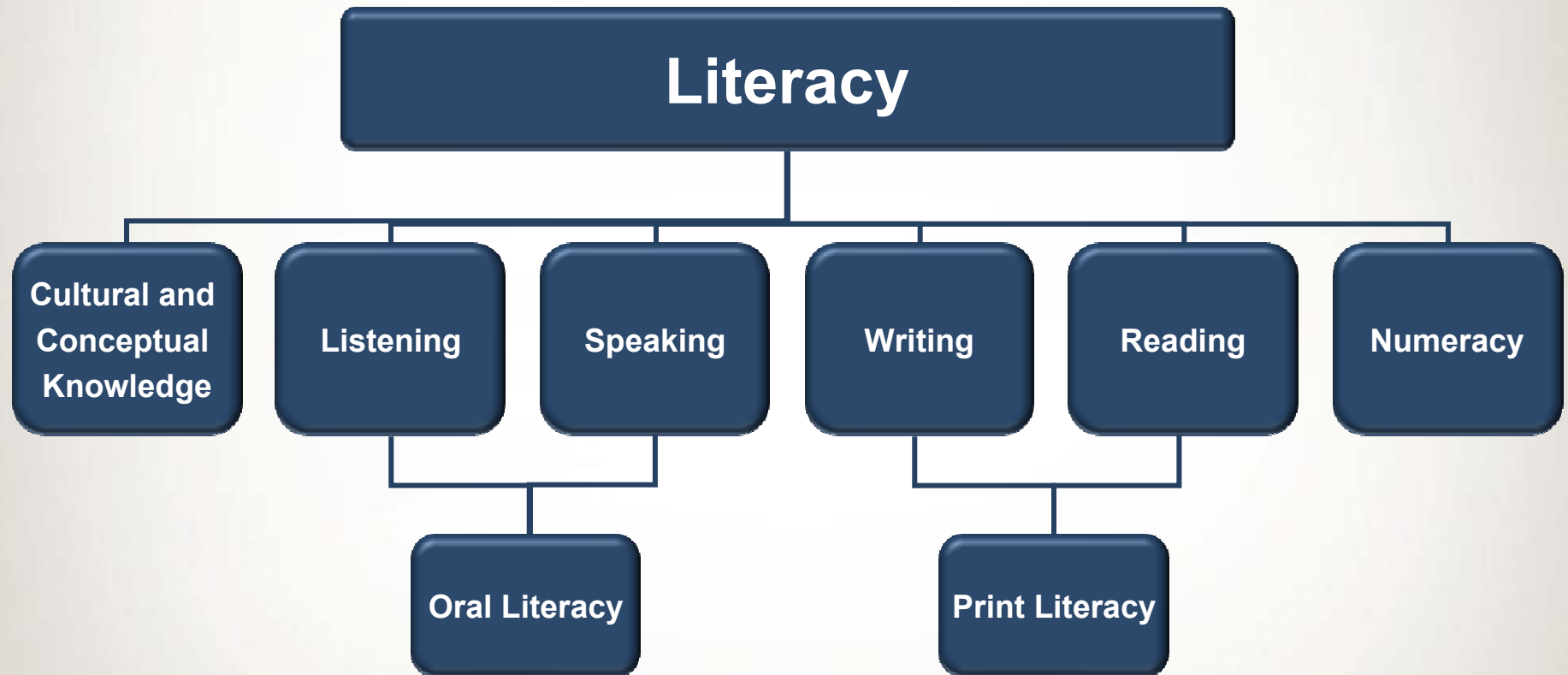
Numeracy

- A component of overall literacy
- "The ability to understand and use numbers and math skills in daily life"
- Calculations, deduction/logic, interpretation of graphs/labels, time, probability, etc.

Rothman et al, J Health Comm, 2009

Numeracy vs Literacy

- Highly correlated with literacy, but not perfect

Calvin and Hobbs, Bill Watterson, Universal Press Syndicate, Released on: Friday, Oct 10th 1986.

Literacy Measurement in Pediatrics

Consider the 4D's

- **Development:** Consider the developmental ability of the child, including his or her cognitive, emotional, and physical development.

- **Dependency:** Children depend on parents or other adults for accessing and receiving health care.

- **Differences in Epidemiology:** Children experience a unique pattern of health, illness, and disability that is different from that of adults.

- **Demographics:** Many children are living in poverty and have other socioeconomic issues that may affect their development and health care.

Forrest, Simpson et all. JAMA, 1997
Rothman et al, Pediatrics 2009

Literacy and Child Health

- Approximately 1/3 of adolescents and caregivers have low health literacy

- Approximately 1/3 of younger children (< 8) have literacy levels below grade level

- Limited studies have linked poor caregiver health literacy to worse knowledge, behaviors and outcomes related to child health

- A few small studies have demonstrated poor child literacy is linked to worse health related behaviors

Sanders et al, Archives of Peds, 2007

Assessing Health Literacy in Younger Children (0-8)

- Current health literacy assessment tools are geared towards adults or adolescents

- Adult Tools typically test adult health situations or adult related words

- Most tools assess print literacy (and possibly numeracy) but not other aspects of functional literacy

- Ceiling effects noted with use of current adult literacy tests for parents

- Limited tools available for non-English speaking families

Current Pediatric Health Literacy Tools

- Parental Literacy
  - PHLAT (Pediatric Health Literacy Assessment Test)
  - Parental Diabetes Numeracy Test
- Child Literacy
  - WRAT (Wide Range Achievement Test)
  - Other Literacy assessment tools (ex. Woodcock-Johnson, Burt Reading Test, PIAT, SORT, Key-Math, K-Tea, etc)

Parental Health Literacy Activities Test (PHLAT)

Kumar et al, Academic Pediatrics, 2010
Yin et al, Academic Pediatrics, 2011, in press
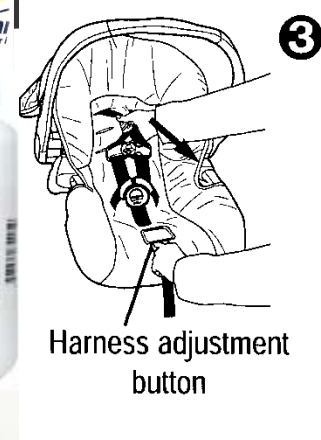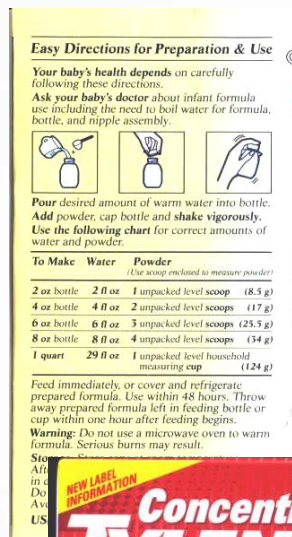
Patient Characteristics

Variable (n=182)	Avg or Percent
Age of Caregiver (yrs)	25.6
Latino or Hispanic	11%
Relationship to Child is Mother	87%
On WIC	78%
Education Level ≤ HS	58%
Adequate Literacy (STOFHLA)	99%
Numeracy Skills ≤ 8th grade (WRAT)	83%
Parental Health Literacy Test Score	68%

Reading a Thermometer

•You are told by your baby's pediatrician to call him if the baby has a temperature of 100.4⁰F or greater.

•The thermometer looks like the following:

$$100.2F$$

- Should you call the doctor?

    ___   YES

    X   NO

- Correct Response: 69%

Mixing Formula

- **Using the instructions provided on the Enfamil powder formula, how much water and formula would you add to make a 4oz. bottle?**

  - Amount of water added: __4__
    Number of scoops added:__2__

    - **Correct Response: 90%**

- **Using the instructions provided for the Enfamil concentrated formula, how much water and formula would you add to make a 4oz. bottle?**

  - Amount of water added:__2__
    Amount of concentrate added:_2__

    - **Correct Response: 47%**

Easy Directions for Preparation & Use

Your baby's health depends on carefully following these directions.
Ask your baby's doctor about infant formula use including the need to boil water for formula, bottle, and nipple assembly.

Pour desired amount of warm water into bottle.
Add powder, cap bottle and **shake vigorously.**
Use the following chart for correct amounts of water and powder.

To Make	Water	Powder (Use scoop enclosed to measure powder)
2 oz bottle	2 fl oz	1 unpacked level scoop (8.5 g)
4 oz bottle	4 fl oz	2 unpacked level scoops (17 g)
6 oz bottle	6 fl oz	3 unpacked level scoops (25.5 g)
8 oz bottle	8 fl oz	4 unpacked level scoops (34 g)
1 quart	29 fl oz	1 unpacked level household measuring cup (124 g)

Feed immediately, or cover and refrigerate prepared formula. Use within 48 hours. Throw away prepared formula left in feeding bottle or cup within one hour after feeding begins.
Warning: Do not use a microwave oven to warm formula. Serious burns may result.
Storage: Store cans at room temperature. After opening can, keep tightly covered, store in dry area and use contents within one month. Do not freeze powder or prepared formula. Avoid excessive heat.
USE BY DATE ON CAN END.

MUST ADD WATER

Easy Directions for Preparation & Use

Your baby's health depends on carefully following these directions.

Ask your baby's doctor about infant formula use including the need to boil water for formula, bottle and nipple assembly.

Clean can lid, **shake** can well, and **open. Mix equal amounts** of concentrated formula and warm water. **Shake** or **stir** well.
Warning: Do not use a microwave oven to warm formula. Serious burns may result.
Feed immediately, or cover and refrigerate prepared formula. Use within 48 hours. Throw away prepared formula left in feeding bottle or cup within one hour after feeding begins.
Storage: Store unopened cans at room temperature. Avoid excessive heat. Do not freeze.
**USE BY DATE ON CAN END.**

Growth Chart

At your baby's 2-month follow-up appointment, her doctor tells you that according to the infant growth curve, she is in the 25th percentile for weight. What does this percentile mean?

a) Out of 100 babies, your baby is bigger than 25 of them.

b) Out of 100 babies, your baby is smaller than 25 of them.

c) Out of 100 babies, your baby is bigger than 75 of them.

d) Out of 100 babies, your baby is bigger than 52 of them.

Correct Response: 51%

Birth to 36 months: Girls
Length-for-age and Weight-for-age percentiles
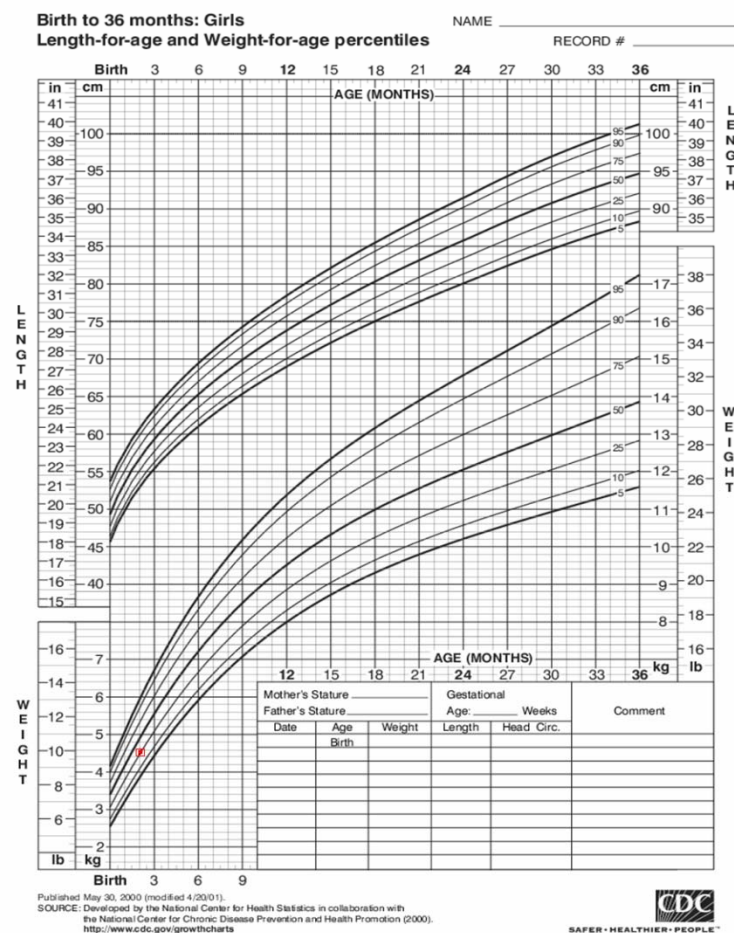
Psychometrics

	Phlat Full (20 items)	Phlat-10	Phlat-8
Total Score (mean/median)	68% / 70%	65% / 70%	70% / 75%
KR – 20	0.76	0.70	0.66
STOFHLA (r)	0.44	0.41	0.41
WRAT-STD (r)	0.55	0.54	0.51
Income (r)	0.33	0.28	0.27
Education (r)	0.28	0.24	0.27
PHLAT – Full (r)		0.91	0.87

$p < 0.05$ for all spearman (r) comparisons

Spanish PHLAT

- 176 Spanish speaking parents of children <3-0 months recruited

- 77% with adequate literacy on TOFHLA, <1% with >9th grade math skills.

- Mean PHLAT-10-Spanish score was 41.6%. KR-20 = 0.51

- PHLAT-10-Spanish correlated with higher years of education (r=0.49), S-TOFHLA (r=0.53) and WRAT-3 (r=0.55) scores (p<0.001 for all)

- 8 item version showed similar characteristics

OTC Cough and Cold Products

- 180 parents of young children at Vanderbilt, UNC, UMiami
- Over 80% would give products to children < 2 yrs of age
- Greatly influenced by pictures, claims on product
- Lower numeracy assoc with poorer understanding

•Lokker et al, Pediatrics, 2009

PHLAT Conclusions

- Significant parental deficits in skills related to early parenting
- Skill deficits are correlated to underlying literacy and numeracy
- Ceiling effects with TOFHLA, but still identified significant literacy issues in parents with PHLAT
- PHLAT appears to be valid/reliable in English and Spanish speaking families
- Opportunities to improve our communication efforts and parental education/anticipatory guidance

Color Coding of Growth Charts

- Recruited parents of children age 2-8
- Given plain and color coded growth charts to interpret

Numeracy Ability Based on WRAT Score

Oettinger, Acaedic Pediatrics, 2009
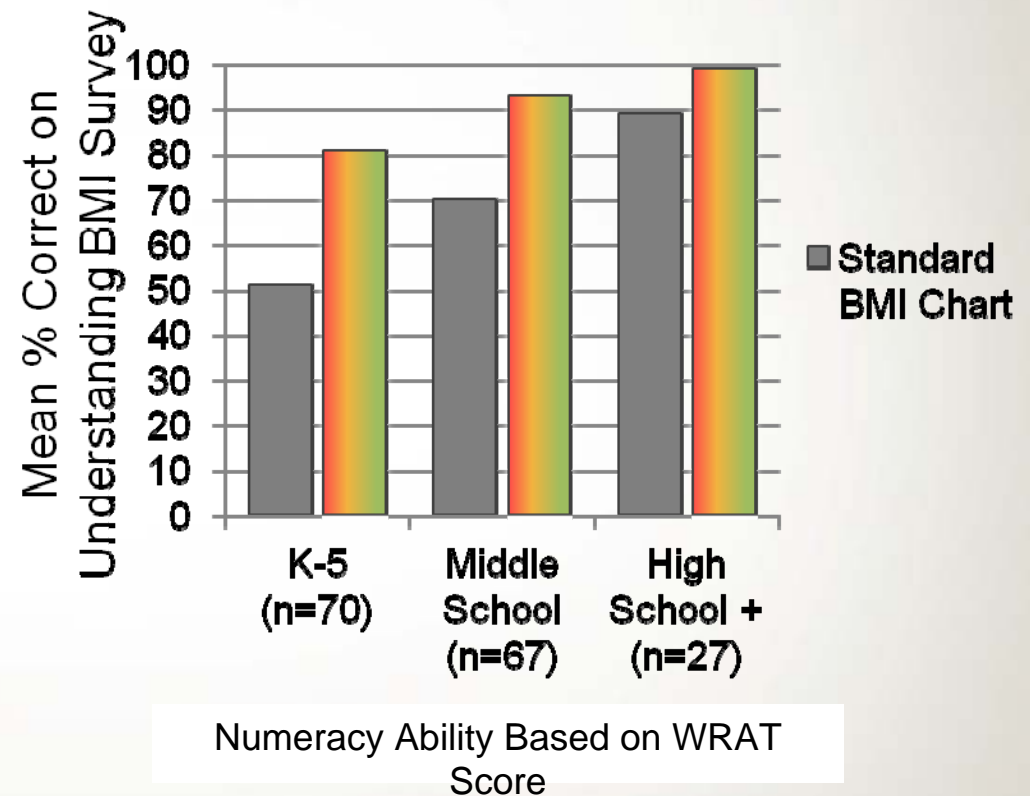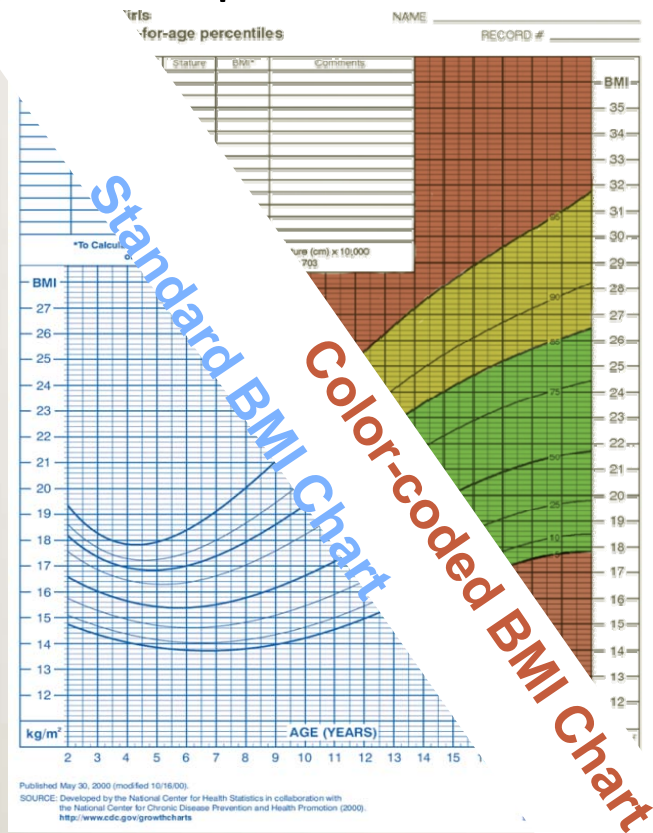
National Initiative (GreenLight)

- **Project supported by NIH (NICHD). Collaboration between Vanderbilt, UNC, NYU, and UMiami**

- **Will enroll 850 English and Spanish speaking families with children age 2 months and follow for 22 months. Intervention sites will focus on obesity prevention, while control sites will focus on injury prevention.**

- **Will train intervention Pediatric providers in improved health communication skills and give them a literacy sensitive toolkit to use with families to promote healthy lifestyles for their children.**

Greenlight Measurement Opportunities

- Administered to parents
  - PHLAT at Baseline and 12 months
  - S-TOFHLA at Baseline
  - Subjective Literacy Scale (Chew et al) at Baseline
  - Newest Vital Sign at 9 months
  - WRAT-Arithmetic at 9 months

Current Adolescent Health Literacy Tools

- Adolescent Literacy
  - WRAT
  - Other literacy assessment tools (ex. SORT, PIAT, K-tea, Keymath)
  - REALM-Teen
  - Adolescent Diabetes Numeracy Test

Numeracy and Diabetes

Math phobic's nightmare!

Diabetes and Numeracy Study

- Developed adolescent scale from previously validated adult Diabetes Numeracy Test

- 2 Samples of adolescent patients with diabetes (61 and 72 participants)

- Mean score on Diabetes Numeracy Test was 75% (SD 22)

- Trouble Spots
  - Interpreting serving sizes
  - Fractions or decimals
  - Applying multi-step regimens (ex. sliding scale and carb-ratios)
  - Applying titration instructions

Huizinga et al, BMC Health Services Res, 2008

Cavanaugh et al, Annals of Internal Medicine, 2008

Mulvaney et al, in revision, JHC, 2011

VANDERBILT UNIVERSITY
MEDICAL CENTER

Serving Size

Nutrition: Carbohydrate Counting

You ate 1 and 1/2 cups from the food labeled below. How many grams of carbohydrate did you eat?

Nutrition Facts
Serving size: ¾ cup
Servings per container 10
Amount per Serving
Calories 150 Calories
Total Fat 7g
Total Carbohydrates 18 grams
Dietary Fiber 3g
Sugars 3g
Protein 3g

ANSWER: 36 grams

Sample 1: 68% correct

Sample 2: 56% correct

Monitoring

- Your target blood sugar is between 60 and 120. Please circle the values below that are in the target range (circle all that apply):

  55

  145

  118

Correct Response: Circle 118 only

Percent Correct: 88% and 93%

Insulin Correction Scale (I)

- You are told to follow the sliding scale shown here. The sliding scale indicates the amount of insulin you take based upon your blood sugar levels:

If Blood sugar is:	Units of Insulin
130-180	0
181-230	1
231-280	2
281-330	3
331-380	4

- Percent Correct: 98 and 99%

VANDERBILT ❖ UNIVERSITY
MEDICAL CENTER

DNT and other measures

SAMPLE 1	Self-Management (SSCA-R)	Diabetes Responsibility (adolescent)	Parent Education	WRAT3	HbA1c
ADNT-39	.12 (.350)	.09 (.506)	**.29 (.028)**	**.40 (.001)**	**-.22 (.086)**

SAMPLE 2	Self-Management (DBMS)	Diabetes Responsibility (parent)	Diabetes Problem Solving	HbA1c
ADNT-14	.03 (.820)	**-.29 (.022)**	**.27 (.023)**	**-.34 (.004)**

COMBINED	Child Age	Gender	Pump Use	Diabetes Duration	HbA1c
ADNT-14	**.194 (.026)**	.002 (.986)	**.326 (.000)**	-.005 (.951)	**-.291 (.001)**

Conclusions

- Performance on DNT was fair
- Disconnect between what is taught and what patients can do.
- Performance on DNT was correlated with literacy and math skills.
- Performance on DNT was also modestly correlated with A1C

Adolescents with Diabetes

- Web-based intervention to promote problem solving skills
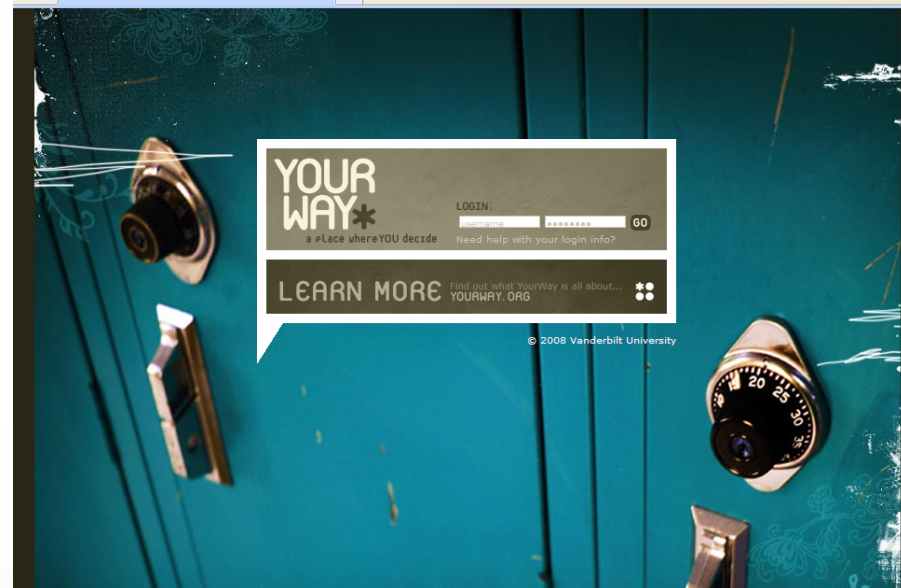
Challenges and Opportunities

- Need to develop better assessment tools of parental literacy in the context of child care
- Need to develop better assessment tools of child health literacy
- Determine when to assess parent, child, or both
- Tools need to assess more than just print literacy
- Tools need to be validated longitudinally
- Develop tools for assessment in Non-English Patients

Questions