Health Literacy and Health Reform: Where do Children Fit In?

Institute of Medicine
November 10, 2010

Lee M. Sanders, MD, MPH
Poor Child Health Outcomes Associated with Low Literacy

<table>
<thead>
<tr>
<th>Child / Family Health Behaviors</th>
<th>Maternal / Child Health Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tobacco use*</td>
<td>Maternal depression**</td>
</tr>
<tr>
<td>Substance use</td>
<td>Injury-prone behaviors*</td>
</tr>
<tr>
<td>Decreased breastfeeding*</td>
<td>Poor access to child primary care</td>
</tr>
<tr>
<td>Poor nutritional choices**</td>
<td>Child mental health / behavioral problems*</td>
</tr>
<tr>
<td>Adolescent STDs</td>
<td>Child development</td>
</tr>
<tr>
<td>Violence / Injury</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lifestyle Indicators</th>
<th>Health System Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tobacco use</td>
<td>Immunizations</td>
</tr>
<tr>
<td>Physical inactivity</td>
<td>Mental health</td>
</tr>
<tr>
<td>Overweight and obesity</td>
<td>Violence and injury prevention</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>Access to health care</td>
</tr>
<tr>
<td>Responsible sexual behavior</td>
<td>Environmental quality</td>
</tr>
</tbody>
</table>

*Adj. for SES; **Strong association

Life Course Perspective on Health Literacy

Biology/Genetics

Prenatal

Infant

Child

Adolescent

ENVIRONMENT

SES

Culture

Community

FAMILY ENVIRONMENT

HEALTH LITERACY
(Parents / Caregivers)

HEALTH SYSTEM

HEALTH OUTCOMES
- Life Expectancy
- Functional Capacity (incl, Health Literacy)
- Disease / Disability
- School and Job Performance

Figure adapted from Halfon, 2002.
Making ACA work for Children in Low-Literacy Families

1. **To Extend Coverage to All Children:** Simplify the CHIP and Medicaid Enrollment Process

2. **To Improve the Quality of Child Health Care:** Tailor Medical Services for Low-Literacy Parents of Children, especially those with Complex Chronic Illnesses

3. **To Improve Child Patient Safety:** Promote National Standards for Safe-Use Labeling of Liquid Pediatric Medication

4. **To Improve the Skills of the Pediatric Workforce:** Require Health Literacy Training for Post-graduate Training
Child Health Insurance

Background

- At least 5 million US children are uninsured... but eligible!

- Children of low-literacy parents are at highest risk
  - Uninsured (NAAL 2009)
  - Unmet health needs, ER visits
  - Decreased access to preventive services (e.g., WIC, TANF) (Pati 2010)

- Most parents cannot complete insurance forms
  - 2 in 3 are unable to fill in names and birth dates (NAAL, Yin 2009)
  - 1 in 2 CHIP forms are written > the 10th-grade level (Sanders 2007)

- CHIPRA and ACA (Sec. 1413, 2715, and 3306)
  - Financial incentives to states for “eligibility simplification efforts”
Readability of CHIP Forms in all 50 states

Federal “Standard” (assessed by Lexile score)
CHIP Enrollment Form: Sample

<table>
<thead>
<tr>
<th>Applicant – Person Applying for Child or Children</th>
<th>Social Security Number (optional)</th>
<th>Home Phone:</th>
<th>Work Phone:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name Last</td>
<td>First</td>
<td>MI</td>
<td>Date of Birth</td>
</tr>
<tr>
<td>Gender:</td>
<td>M</td>
<td>F</td>
<td>Are you pregnant?</td>
</tr>
<tr>
<td>Marital Status:</td>
<td></td>
<td></td>
<td>How many people are in the household:</td>
</tr>
</tbody>
</table>

**Other Adults in household:** If more adults reside in the household, please attach an additional sheet with the same information in the same order as listed below.

<table>
<thead>
<tr>
<th>Name Last</th>
<th>First</th>
<th>MI</th>
<th>Date of Birth</th>
<th>Gender</th>
<th>Social Security Number (optional)</th>
<th>Relationship to Applicant Above</th>
<th>Citizenship of United States (optional)</th>
<th>Marital Status</th>
<th>Is this adult pregnant?</th>
<th>Ethnic Group</th>
<th>Other:</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**REMINDER:** Shaded fields must be completed or the application will not be processed!
Simplifying Child Insurance: ACA-specific Recommendations

1. Enforce grade-level standards for paper- and web-based insurance enrollment forms

2. Tailor CHIP Outreach Campaigns for low-literacy and limited English-proficiency parents

3. Bundle eligibility assessment for all maternal and child health programs (e.g., WIC, SNAP, CHIP, Medicaid, school lunch programs)

4. Assess eligibility for all maternal and child-health programs at school entry and at school health clinics
QI and Family-Centered Care

Background

Health Disparities for Children with Low-literacy Parents
- Asthma (ED visits), Diabetes (HgbA1c), Obesity (family behaviors)
- Children with Chronic Conditions
  - < 15% of all US children
  - > 70% of child-health expenditures

Family-Centered “Medical Home” May Moderate these Disparities
- Care Coordination
- Culturally Effective Care
- Comprehensive Care

ACA supports Quality-Improvement Initiatives for Child Health
- Section 3501 and 3506 (Quality Improvement for Chronic Care)
- Section 4306 (Childhood Obesity Demonstration Projects)
- Section 2951 (Early Childhood Home Visiting Programs)

(DeWalt 2007, Sanders 2010, Rothman 2006)
(Perrin 2009)
## Barriers to Care Coordination: Language and Literacy

<table>
<thead>
<tr>
<th></th>
<th>Good Coordination</th>
<th>Poor Coordination</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Child's Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2 y</td>
<td>118 (7.8)</td>
<td>23 (4.6)</td>
<td>0.014</td>
</tr>
<tr>
<td><strong>Child's Health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor/Fair</td>
<td>242 (16.7)</td>
<td>79 (16.7)</td>
<td>0.995</td>
</tr>
<tr>
<td><strong>Parent's ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>432 (28.7)</td>
<td>180 (35.9)</td>
<td>&lt;.01</td>
</tr>
<tr>
<td><strong>Parent's Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>423 (27.9)</td>
<td>115 (22.8)</td>
<td>&lt;.01</td>
</tr>
<tr>
<td><strong>Parent's Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; High School</td>
<td>570 (37.9)</td>
<td>158 (31.8)</td>
<td>&lt;.01</td>
</tr>
<tr>
<td><strong>Language Spoken at Home</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spanish</td>
<td>293 (19.4)</td>
<td>121 (24.1)</td>
<td>&lt;.01</td>
</tr>
<tr>
<td><strong>Know the name of child's Nurse CC</strong></td>
<td>1284 (85.7)</td>
<td>193 (39.1)</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>

Sanders LM, Lipshultz H, 2010
Low-literacy Intervention for Child Obesity Prevention

- NICHD R01 (U. Miami, Vanderbilt, NYU, UNC)
- Sample: 1,000 English- and Spanish-speaking families with children aged 2 to 24 months.
- Intervention: Pediatric providers trained in improved health communication skills, aided by a literacy-sensitive toolkit
Family-Centered Care

ACA-specific Recommendations

1. **Building Health Literacy through the Medical Home.**
   - Literacy-sensitive models of family-centered care, particularly for children with chronic conditions
   - AHRQ’s Center for Quality Improvement (Section 3501)
   - State-based Early Childhood Home Visiting Programs (Section 2951)
   - Low-literacy measures of child-health quality
   - Center for Medicare and Medicaid Innovation (CMI)

2. **Low-literacy Decision Aids for Children with Special Needs.**
   - The CDC and NIH (Section 3506) should develop low-literacy decision aids for both children special needs and their parents.
   - This should include easy-to-use personal health records.

3. **Demonstration Projects for Childhood Obesity (Sec. 4306)**
   - Develop tools to simplify literacy- and numeracy-sensitive tasks (food labels, portion sizes)
Pediatric Liquid Medication

Background

- Errors are common among low-literacy parents
  - 25% of OTC medications have no dosing device
  - Many dosing devices use nonstandard markings
  - 50% error rate on Rx medications (Yin 2008)

- Sec. 3507 (Presentation of Prescription Drug Benefit and Risk Information)
  - HHS to standardize drug labels
  - Consult “health literacy” evidence and expertise
#2. Inconsistency between label and dosage delivery device *(within product variability)*

- Missing necessary marking
- Superfluous markings
**HELPix ED RCT:**
Effect on Dosing Accuracy
(by Direct Observation at Follow-up)

Error in dosing defined as measuring more than +/- 20% of prescribed dose

<table>
<thead>
<tr>
<th>Category</th>
<th>Control (n=83)</th>
<th>Intervention (n=155)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ARR</td>
<td>43%</td>
<td>24%</td>
</tr>
<tr>
<td>NNT</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>p</td>
<td>0.0002</td>
<td>0.003</td>
</tr>
</tbody>
</table>

PRN (n=155)
ARR = 24%
NNT = 4
p=0.003

Daily dose (n=83)
ARR = 43%
NNT = 2
p=0.0002

Yin 2008, *Archives of Pediatrics and Adolescent Medicine*
Pediatric Liquid Medications
ACA-specific Recommendations

1. Standardize Dosing Instructions on Nonprescription Liquid Medication
2. Standardize Dosing Instructions on Prescription Liquid Medication
3. Develop Easy-to-understand Dosing Aids for all Pediatric Liquid Medication
Residency Training in Child Health

Background

- Most ACGME Competencies “allude” to health literacy
  - Interpersonal Communication
  - Professionalism

- No specific requirements for Health Literacy

- AAP Periodic Fellows Survey showed that few pediatric providers use good Health-Communication techniques (Turner 2009)

- AAP’s PediaLink Online Module in Health Literacy

www.pedialink.org/cme/healthliteracy
Welcome to the Health Literacy Course

The goal of this series is to increase awareness of health literacy among pediatric healthcare providers and its impact on the healthcare system. You will gain knowledge and skills in methods that enhance communication and patient adherence.

Your Course Progress

Evaluation has not been completed.

Course is not complete.
Case Study 1: Health Literacy and Health Outcomes

You are seeing a patient with spina bifida who has been non-adherent with appointments. Watch this video describing the mother’s experience with the healthcare system.

Mrs. Grigar, Organized Spina Bifida Support Group

The AAP gratefully acknowledges the AMA for permission to use this video clip from Health Literacy Help Your Patients Understand. American Medical Association, American Medical Association Foundation, 2003.
Pick the letters of the dispensers that most accurately measure 1 teaspoon.

(Select all that apply.)

- a.
- b.
- c.
- d.
- e.
- f.
- g.
- h.
- i.
Communication Techniques: Using Analogies

Using analogies can help you explain medical conditions to your patients and their parents. Can you relate the patient’s problem to the family’s life?

The doctor says, “Your child’s ear has fluid in it and feels clogged the way yours does when you go up fast in an elevator.”
Residency Training in Child Health

ACA-specific Recommendations

1. Make Health Literacy Training a required component of Post-graduate Training in Child Health (e.g., Pediatrics, Family Medicine, Pediatric Nurse Practitioners) (ACA Sec. 5301)

2. Improve and disseminate interactive Health Literacy Training Modules for pediatric providers
Literacy-specific Opportunities for Child Health in the ACA

1. **To Extend Coverage to All Children:**
   Simplify the CHIP and Medicaid Enrollment Process

2. **To Improve the Quality of Child Health Care:**
   Tailor the “Medical Home Model” for Low-Literacy Parents of Children, especially those with Complex Chronic Illnesses

3. **To Improve Child Patient Safety:**
   Promote National Standards for Safe-Use Labeling of Liquid Pediatric Medication

4. **To Improve the Skills of the Pediatric Workforce:**
   Require Health Literacy Training for Post-graduate Training
Thank You

- Benard Dreyer, MD, New York University
- Shonna Yin, MD, New York University
- Teri Turner, MD, Baylor University
- Ruth Parker, MD, Emory University
- Michael Wolf, PhD, Northwestern University
- Russell Rothman, MD, Vanderbilt University
- American Academy of Pediatrics
- Academic Pediatric Association