Organizational Health Literacy: Operationalizing Healthy People 2030 Goals

Lindsay Rosenfeld, ScD, ScM, Jonathan Litt, MD, ScD, MPH, Molly Fraust-Wylie, MA, Nisha Dalvie, MD, Kelly Anne McCullagh, MD

Brandeis University, Beth Israel Deaconess Medical Center, Boston Children's Hospital Division of Newborn Medicine
Agenda

1. Setting the Stage (~20 min)

2. Frameworks for Action & Action Examples (~40 min)

3. Questions / Discussion (~30 min)
Setting the Stage: Lindsay Rosenfeld, ScD, ScM
Healthy People 2030 - Exploring Organizational Health Literacy and Optimizing Care of High-Risk Children and their Families

Frameworks for Action: Jonathan Litt, MD, ScD, MPH
Organizational Health Literacy and other Multilevel Systems Frameworks in High-Risk Pediatrics

Action Example - NICU: Molly Fraust-Wylie, MA
Family Engagement and Health Literacy in the NICU

Action Example - NICU GraDS: Nisha Dalvie, MD & Kelly McCullagh, MD
Conducting an Organizational Health Literacy Assessment in a Post-NICU Follow Through Program for High-Risk Children
Session Objectives

1. Identify Healthy People 2030 Health Literacy goals
2. Define personal and organizational health literacy
3. Explore options for organizational health literacy assessment, in context of multilevel, systems frameworks
4. Identify next steps for participant’s own work in health literacy assessment
5. Access resources for doing health literacy assessment
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Health Literacy is Health Equity

https://medium.com/wehearthealthliteracy/a-path-forward-f001f5148b45
Healthy People 2030

Health Literacy in Healthy People 2030

Health literacy is a central focus of Healthy People 2030. One of the initiative's overarching goals demonstrates this focus: "Eliminate health disparities, achieve health equity, and attain health literacy to improve the health and well-being of all.”

How does Healthy People define health literacy?

Healthy People 2030 addresses both personal health literacy and organizational health literacy and provides the following definitions:

- **Personal health literacy** is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.
- **Organizational health literacy** is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.
Individual to System

2000 Early Definition HHS

2004 Prescription to End Confusion IOM

2007 What Did the Doctor Say? Joint Commission

2010/2015 Health Literacy Universal Precautions Toolkit AHRQ

2010 National Action Plan to Improve Health Literacy HHS

2012 10 Attributes of Health Literate Health Care Organization IOM

2030 Healthy People 2030 HHS

AHRQ: Agency for Healthcare Research & Quality
HHS: U.S. Department of Health & Human Services
IOM: Institute of Medicine

History of Healthy People Health Literacy Definitions:
Factors Affecting Equitable Early Childhood Development

Policy
rules, laws, and agencies
transportation
education
healthcare

Community
business, social and community support
housing
social capital
structural racism
economic development
immigration
employment

Family
family, friends and social supports
attachment and family well-being
family structure
school

Child
activities and interactions
developmental health
personality
resiliency
Health Literacy: Interactions in Larger Context
Organizational Health Literacy: Domains for Action

I. Populations

II. Providers / health professionals / staff

III. Information

IV. Environments
Skills & Systems Mismatch

Program for the International Assessment of Adult Competencies (PIAAC)

FIGURE 1. Number of U.S. adults age 16 to 65 at each level of proficiency on the PIAAC literacy scale and those who could not participate: 2012 and 2014

Millions of U.S. adults

200

150

100

50

0

Could not participate (4.0%)
Below Level 1 (4.1%)
Level 1 (12.9%)
Level 2 (31.6%)
Level 3 (34.6%)
Level 4/5 (12.9%)

Lack many of the literacy skills necessary to use US health system

PIAAC Level Definitions: https://nces.ed.gov/surveys/piaac/litproficiencylevel.asp

Providers / Health Professionals / Staff

Photos by Jon Crispin
“I agree to pay my bill”.

“I understand that fees are due and payable on the date that services are rendered and agree to pay all such charges incurred in full immediately upon presentation of the appropriate statement.”
Environment

Photos by Jon Crispin
Time for Action

**Documented:** Significant proportions of adults in most industrialized nations have limited literacy & numeracy skills.

**Documented:** Literacy skills are linked to social factors.

**Documented:** Literacy skills are linked to health outcomes.

**Documented:** Mismatch between reading level of health materials and average reading skills of adults.

**Documented:** Health systems & health care processes have become increasingly complex.

**Documented:** 60+% of health is explained by social and environmental determinants.

**Implications:** Health Inequities  
**Action:** Remove Barriers
Stop & Check: Universal Precautions

Taking specific actions that **minimize risk for everyone**, across levels

Tackles **all literacy skills, all the time:** reading, listening, speaking, writing, calculating (numeracy)

“When we introduced this… they thought 'oh great, more responsibilities to cram into our busy day.' **But what we quickly realized is that it is not adding more, it is learning how to do things differently.** After implementing some of these tools we really felt like we were **more able to connect with our parents about the health of their child.**” (AHRQ)
Patient Tasks: Follow-Up Visit

**PRE-VISIT**
- Schedule appointment
- Request time off work
- Arrange transportation
- Bring insurance / photo ID
- Confirm appointment location & details

**VISIT**
- Fill out paperwork
- Report medications and allergies
- Summarize medical history since last visit
- Check out, pay, schedule follow-up

**POST-VISIT**
- Pick up prescriptions
- Take new medications as directed
- Call for referrals and resources
- Follow-up lab results, adjust therapies
What Is Our Goal?
Change Strategy Varies by Goal
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Frameworks and Theories

- Social Ecology
- Social Determinants of Health
- Life Course
- Race and Racism
- Functioning, Disability, and Health
- Patient / Family Engagement Health Literacy
Thinking Ecologically

Bronfenbrenner’s Social Ecological Model
Figure 1 (Niederer, et. al.)
Thinking Ecologically

Policy
Rules and laws that affect your community, your home, and the activities your child does.

Community
People, places, business, and other organizations (religious places, schools) in your neighborhood that affect the activities your child does.

Home
People in your home and the set-up of your house (rooms, furniture, toys) that affect the activities your child does.

Child
Your child has his or her own abilities and interests that affect the activities he or she does.
Thinking Ecologically

Social Determinants of Health

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https://www.cdc.gov/visionhealth/determinants/index.html
Social Determinants of Health
A Life Course Approach

“A life course approach offers an interdisciplinary framework for guiding research on health, human development, and aging.”

- Impact of early life exposures on later life outcomes
- Timing and chronicity of exposures
- Vulnerability, resilience, plasticity
- Critical/Sensitive period

Kuh, Ben-Shlomo, et al, 2003
A Life Course Approach
Levels of Racism

<table>
<thead>
<tr>
<th>MICRO LEVEL</th>
<th>MACRO LEVEL</th>
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<tbody>
<tr>
<td>INTERNALIZED</td>
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<tr>
<td>INTERPERSONAL</td>
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<tr>
<td>INSTITUTIONAL</td>
<td></td>
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<tr>
<td>STRUCTURAL</td>
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</tbody>
</table>

Adapted from the Applied Research Center & Southern Jamaica Plain Health Center, Boston, MA
Functioning, Disability, and Health

Fig. 1 Framework of Functioning, Disability and Health (ICF and ICF-CY)

[14, 15]
Patient & Family Engaged Care

Table 1 | Summary of Common Elements and Patterns Identified for Creating and Maintaining a Culture of Patient and Family Engaged Care

<table>
<thead>
<tr>
<th>Cultural Elements</th>
<th>Infrastructure</th>
<th>Practices and Tactics</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Investment and intenionality in creating a supportive and trusting workplace culture</td>
<td>• PFEC fully integrated into organizational structure and strategy—not a stand-alone initiative</td>
<td>• Environmental supports to facilitate PFEC</td>
</tr>
<tr>
<td>• Emphasis on empathy and compassion</td>
<td>• Structured communication channels developed to break through hierarchy and “level set” to promote partnership of all members (leaders, staff, patients, families)—coproduction, shared goals</td>
<td>• Practices that promote patient and family engagement</td>
</tr>
<tr>
<td>• Leadership sets the tone</td>
<td>• A measurement approach that looks beyond patient experience metrics to gauge PFEC</td>
<td>• Learning opportunities at every patient touchpoint</td>
</tr>
<tr>
<td>• Eagerness to innovate</td>
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<td></td>
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<tr>
<td>• Creation of a learning culture</td>
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</tbody>
</table>

Figure 2 | Overview and core elements for Patient and Family Engaged Care: A Guiding Framework
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Example: Applying Frameworks
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FICare (Family Integrated Care)

- Health Literacy is a tool for health equity, and inclusion of families is an essential part.

- Family Integrated Care is a model that incorporates families as equal partners in the NICU care team.

- Co-created with multidisciplinary team and co-led by 3 NICU graduate parents (1 employee, 2 given stipend for contributions).

- Pilot program in NICU, now rolled out to Special Care Nursery (SCN).
FICare: Family Co-Leads

Hailey Bull
- Born at 29 weeks 1 day, 2lb 7oz
- 81 days in the NICU

August Harrison Keith
- Born at 33 weeks 6 days, 3lbs 15oz
- 21 days in the NICU
FICare: Program Basics

• Parental involvement in all aspects of their baby’s care:
  ○ Feeding, diaper changes, bathing, providing oral medications, tracking growth / development, and decision making

• Medical rounds

• Structured parental education

• Structured staff education

• Supportive NICU environment

• Support from social work and graduate parents
Multi-Level Program:

• Creation of materials and program by multidisciplinary team
  ○ NICU staff: doctors, nursing staff, social work, graduate parents, family program manager

• Staff Education
• Parent Education
• Quality Improvement
FICare: Program Development

**Staff Education:**
- MyPath tutorial for nurses
- Audio overview
- Posted documents
- Committee meetings with staff
- 1-on-1 education in the SCN
- BAE line nursing survey

**Tool Kit Creation:**
- Curriculum for parents
- Newborn Documentation Form
- Adaptation of Rounding Guides (parents present on rounds)
- Skills checklist
- Nursing vs. Parent responsibility
- Enrollment Form

**Measures:**
- IRB Waiver
- Redcap Database
FICare: Caregiver Feedback

"I actually feel like her parent now. When we go to round, changes are being made because of things we say. Now, we know what to ask at rounds."

"Before I felt like a spectator - but now I feel like a participant in my baby’s care."
"Even when we don't know the nurse, it is nice that we can still take the lead and share the responsibilities!"

"The program helped me figure out how to tackle it at home."

"This program can given parents hope, a sense of empowerment, a sense of control, and, very importantly, confidence. NICU nurses are the super heroes here but us moms like to feel like we wear a piece of the cape, too."
FICare: Next Steps

- Iterative Process… refining, now opened to entire SCN
- Health Literacy is about Navigation
- Participation (increasing staff + family)
- Process (different ways of learning + communicating)
- Quality Improvement
FICare: Next Steps

• Document review underway
• Students reviewed some of our NICU materials and provided data
• Using input to create task force
• Create new process for family facing materials
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Health Literacy is Health Equity

**Key Domains:** Accessibility of Information, Communication, and the Environment
A Refresher on Patient Tasks...

**PRE-VISIT**
- Schedule appointment
- Request time off work
- Arrange transportation
- Bring insurance / photo ID
- Confirm appointment location & details

**VISIT**
- Fill out paperwork
- Report medications and allergies
- Summarize medical history since last visit
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- Call for referrals and resources
- Follow-up lab results, adjust therapies
Our Clinic

NICU Growth and Development Support Programs (NICU GraDS)

• Follow-through clinic attached to a quaternary-care children's hospital for infants at risk for developmental delays

• Eligibility:

- Gestational age < 32 weeks at birth

- Gestational age 32 - 36 weeks at birth AND
  - Low birth weight
  - Significant respiratory, GI, or neurologic disease
  - Social complications

- Novel genetic diagnosis with suspicion of associated delays
Interdisciplinary Approach

Program Staff

- Neonatologists
- Psychologists
- Social Workers
- Physical Therapists
Our Population

Significant racial and socioeconomic inequities in program participation.

Out of 477 families referred from an urban hospital:

- 43% of White families attended versus 33% of Black and 19% of Non-White Hispanic/Latinx families.

- Families in high child opportunity neighborhoods (CON) were nearly twice as likely to attend compared to families in low CON.
Our Goal: Address Health Inequities

• Apply equity frameworks (health literacy, racial equity, social determinants of health)
  ○ **Organizational** health literacy assessment
    ▪ SMOG, PMOSE/IKIRSCCH, PEMAT
  ○ **Environmental** health literacy assessment
    ▪ Walking Interview, HLE-2
  ○ **Qualitative** health literacy perspectives
    ▪ 4 Key Informants, 9 Staff, 5 Families
Informational Assessments

SMOG

The SMOG Readability Formula

Step 1: Take the entire text to be assessed.

Step 2: Count 10 sentences in a row near the beginning, 10 in the middle, and 10 in the end for a total of 30 sentences.

Step 3: Count every word with three or more syllables in each group of sentences, even if the same word appears more than once.

Step 4: Calculate the square root of the number arrived at in Step 3 and round it off to nearest 10.

PMOSE / IKIRSH

THE PMOSE/IKIRSH DOCUMENT READABILITY FORMULA

Readability formulas offer a useful first step in assessing print materials. However, all such formulas to date focus on print material written in prose format – materials written in full sentences and paragraph structure. Many print materials are not in sentence and paragraph format. Many health materials such as medicine labels, directions, and dose charts are in document format. Documents are print materials structured as lists, charts, or graphic displays.

PEMAT

understandability and actionability of patient education materials

grade level skills needed to comprehend prose

grade level skills needed to comprehend charts / graphs
## Summary of Informational Assessments

<table>
<thead>
<tr>
<th>Material</th>
<th>Reading Grade Level (SMOG)</th>
<th>Complexity Grade Level (Pmose / Ikirsch)</th>
<th>Usability and Actionability Percent (Pemat)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NICU GraDS Welcome Letter</td>
<td>14th</td>
<td>-</td>
<td>38% 0%</td>
</tr>
<tr>
<td>NICU GraDS Q&amp;A</td>
<td>15th</td>
<td>-</td>
<td>69% 60%</td>
</tr>
<tr>
<td>NICU GraDS Website</td>
<td>16th</td>
<td>-</td>
<td>45% 0%</td>
</tr>
<tr>
<td>Developmental Milestones</td>
<td>9th</td>
<td>4th - 8th</td>
<td>75% 83%</td>
</tr>
<tr>
<td>NICU GraDS Family Feedback Form</td>
<td>12th</td>
<td>4th - 8th</td>
<td>-</td>
</tr>
<tr>
<td>NICU GraDS Referral Contact Sheet</td>
<td>11th</td>
<td>8th - 12th</td>
<td>-</td>
</tr>
<tr>
<td><strong>AVERAGE</strong></td>
<td>12th grade level (reading)</td>
<td>5th - 9th grade level (complexity)</td>
<td>57% usability 36% actionability</td>
</tr>
</tbody>
</table>
Environmental Assessment: Walking Interview
Environmental Assessment: HLE-2

Health Literacy Environment of Hospitals and Health Centers

1) Organizational Policy & Practice

2) Physical Navigation

3) Culture and Language
Qualitative Perspectives

Facilitators to Program Participation:
- Knowledgeable and personable staff
- Interdisciplinary collaboration
- Population expertise

Barriers to Program Participation:
- Lack of systems focus
- Resources and utility not communicated well
- Poor visit efficiency
Future Work

• Assemble task force to review results and strategize for action

• Implement small tests of change leading to improvement
As a professional:

- Share something you learned – benefits and challenges
  -- Talk to one colleague
  -- Plan a lunch seminar
  -- Plan a day-long professional development training; attend conferences

- Look at one new resource
- Implement at least one new learning; try something with a family or material
- Plan a short-term action, e.g. assess one material or one small space
- Plan a long-term action, e.g. infuse a department/clinic with health literacy
As a member of an institution:

- Create plain language materials
- Strive and check for clarity/understanding (print and oral)
- Remove institutional barriers
- Make time to talk about how it is going – practice & rethink strategy
- Advocate – be a champion, find a partner: a “health literacy lens” is crucial for collaboration, patient / family engagement, and continuous quality improvement
Tomorrow, Next Week, Next Month

As a community member:

• Support education and health care
• Support community and adult education
• Support clearer signage
• Support good community and building design
• Ask questions about how literacy is being considered – is it?
• Tell everyone about the connections between literacy and health – it affects us all
Wrap-Up & Discussion

1. Explore Environment
What works, what doesn't work, for patients / participants / staff

2. Examine one commonly-used item
Website, directions to organization, application forms, discharge planning document, procedure descriptions, consent form

3. Examine Findings of #1 and #2
Choose a domain for your first action

4. Consider Your Next Action
Create short and long-term actions, then try it out (e.g. Plan-Do-Study-Act cycle)

5. Reach Out to Us!
Thank you!