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Empowering Women in Underserved Communities: Using CBPR Approaches to Improve Health Literacy and Community Capacity

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Et al.

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Introduction to health literacy

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March 3, 2017

What is health literacy?

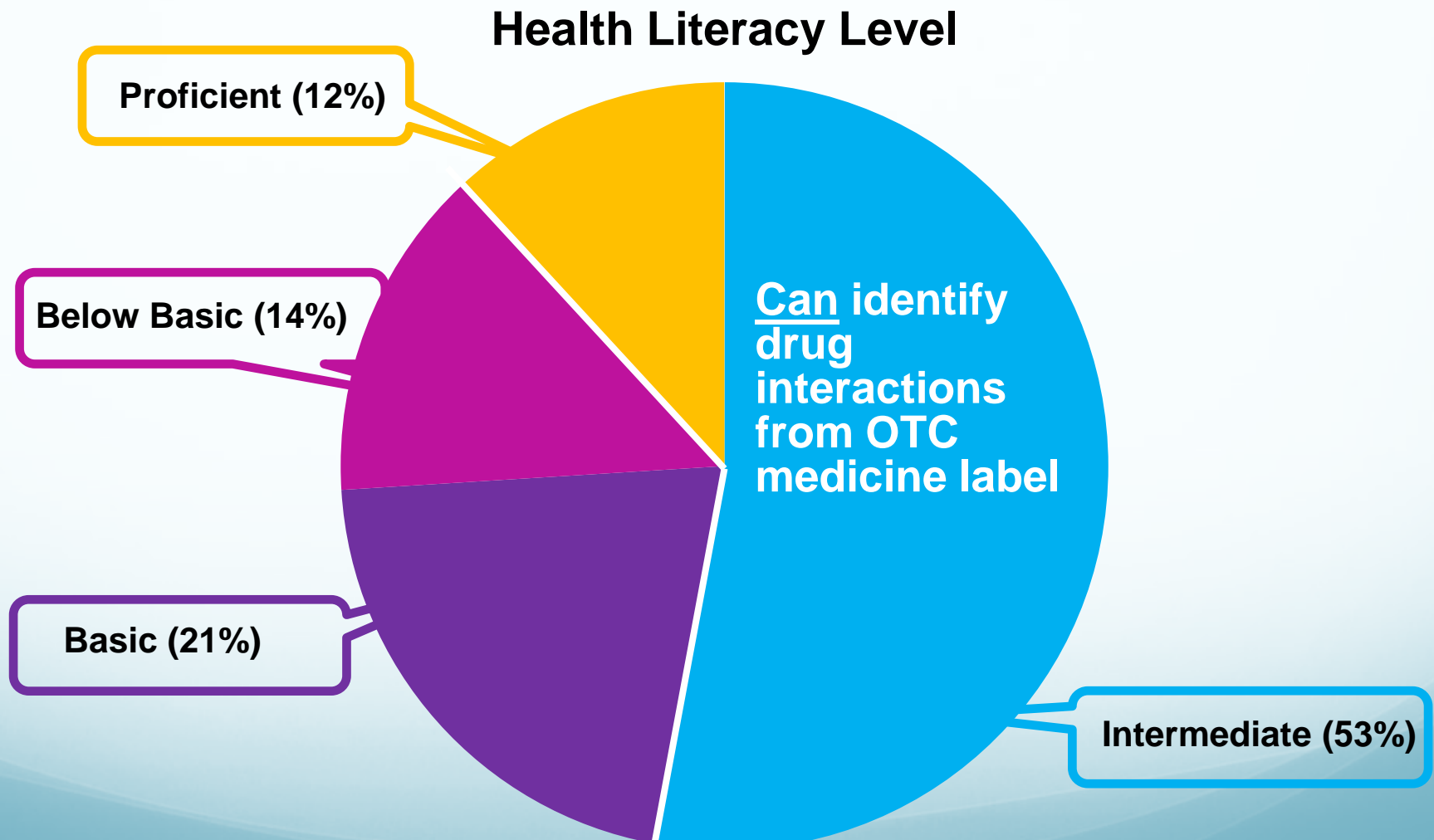


Many definitions

- 17 provided in Sorenson et al 2012!
- “The ability to understand, communicate, and use health information to function effectively in the health care system” (Nutbeam, 2000; Parker, Ratzan, & Lurie, 2003)
- “A set of skills used to organize and apply health knowledge, attitudes, and practices relevant when managing one’s health environment” (Massey et al., 2012)
- “The knowledge, skills and abilities that pertain to interactions with the healthcare system” (Ishikawa & Yano, 2008)

Who does it impact?

National Assessment of Adult Literacy (NAAL), 2003





Groups most impacted

- Older adults (cognitive declines)
- Non-native English speakers
- Minority populations
- Low income groups

BUT you can't tell who has low health literacy...

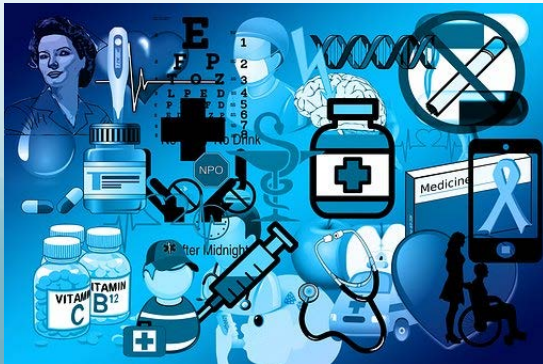
(National Network of Libraries of Medicine, n.d.)

Skills *and* environment

Health system/
Information
environment

Health
Literacy

Individual skills



Measurement

Most common tools

- Most often used
 - Rapid Estimate of Adult Literacy in Medicine (REALM)
 - Test of Functional Health Literacy in Adults (TOFHLA)
 - Newest Vital Sign (NVS)
 - Self-report

Why does it matter?

Consequences

Research has linked health literacy problems with:

- inappropriate health care service use (using care you *don't* need or not getting care you *do* need)
- poorer skills in taking medication appropriately, interpreting medication labels (Berkman et al., 2011)
- worse health outcomes and greater mortality risk (U.S. Department of Health and Human Services, n.d.; Weiss & Palmer, 2004)

Consequences

Difficulty or frustration with:

- accessing and using health care (and appropriate services)
- interacting with providers
- managing chronic conditions and personal health
- Searching for health information

(Kutner et al., 2006; Manganello et al., 2016; VonWagner et al., 2009)

Ecological approach

Ecological model

Socio-Ecological Model



National Action Plan to Improve Health Literacy (DHHS, 2010)

“seeks to engage organizations, professionals, policymakers, communities, individuals, and families in a linked, multi-sector effort to improve health literacy.”

Individual level

- Consider how age, race, gender, language, cultural background, cognitive and physical abilities relates to one's health literacy
- Health literacy may fluctuate over time (increase and then decrease)
- May also 'change' in different situations (i.e., emergency situation)



Komenaka et al. (2015)

- Investigation of the relationship of health literacy and screening mammography
- Routine health literacy assessment was performed using Newest Vital Sign to 1,664 women at least 40 years of age at a breast clinic from January 2010- April 2013
- Of all sociodemographic variables examined, health literacy had the strongest relationship with use of screening mammography



Skeens et al. (2016)

- Identifying health literacy levels of parents of infants in a NICU and preferences for who they want to provide them with education
- Mothers with babies in the NICU were available to complete the survey with a mean age of 26 years
- Rapid Estimate of Adult Literacy in Medicine indicated a low level of health literacy and that one on one discussions with a physician were the preferred source of health information for 80% of participants

Interpersonal level

- Patient/provider communication
- Communication about health with families
 - Some families have collective decision making
 - Caregivers for other family members (elderly, disabled)
- Communication with others in social networks
 - Includes online forums, social media, etc.
 - Can be helpful if others have higher health literacy, but what if they have lower health literacy?



Fry-Bowers et al. (2013)

- Determine whether maternal health literacy and maternal perception of health care provider interpersonal interactions predict maternal perception of quality of pediatric ambulatory care received
- 124 low-income Latina mothers of children 3 months to 4 years
- Speaking with clarity, explaining results fully and working with the mother to determine a child's plan of care is most predictive of whether she feels her child is receiving high quality pediatric care

Organizational level

- Health and related organizations
 - How hard is it to get services?
 - Navigate around the website?
 - Find your way around the facility?



- 10 Attributes of a Health Literate Organization
 - Published in 2012
 - https://nam.edu/wp-content/uploads/2015/06/BPH_Ten_HLit_Attributes.pdf

10 Attributes

1. Has leadership that makes health literacy integral to its mission, structure, and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
3. Prepares the workforce to be health literate and monitors progress.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.



Cafiero et al. (2013)

- Nurse practitioner intention to use health literacy strategies in practice were investigated
- Through a questionnaire it was found that intentions to use health literacy strategies in practice was strong
- Increasing NP's knowledge of health literacy and facilitating its use could support improved patient outcomes



Horowitz et al. (2014)

- 26 Maryland community-based dental clinics conducted health literacy environmental scans to identify institutional characteristics and provider practices that affect dental services access and education
- Assessed user friendliness, accessibility, signage, facility navigation, educational materials, and patient forms
- Many similarities were found with respect to clinic traits and websites
- Providers who had taken communication skills course were more likely than those who had not to use recommended communication techniques
- Patient materials were written at too high of a reading level



Community level

- Libraries, adult education
- Build partnerships across organizations
- Community health workers
- Health literacy of a community
 - <http://healthliteracymap.unc.edu/#>

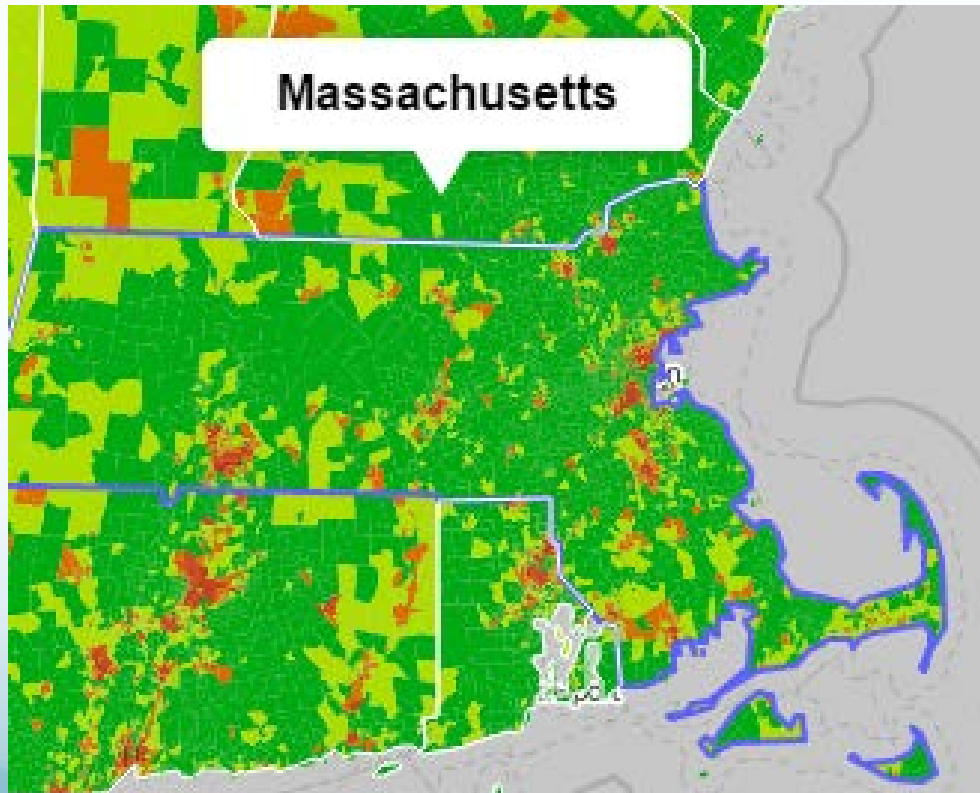



Health literacy map

Map Information

Health Literacy Levels

- Quartile 4 (highest)
- Quartile 3
- Quartile 2
- Quartile 1 (lowest)





Carroll, Smith, & Thomson (2015)

- Parents as Teachers (PAT) Health Literacy Demonstration project assessed the impact of integrating data-driven reflective practices into the PAT home visitation model to promote maternal health literacy
- 8 parent educators used the Life Skills Progression instrument to tailor the intervention to each of the 103 parent-child dyads
- The use of an empowerment model of health education, skill building, and direct information support enabled parents to better manage personal and child health



Sentell et al. (2013)

- Study sought out to determine if community health literacy had an independent relationship with individual self-reported health beyond individual health literacy
- 11,779 individuals within 37 communities from data using the 2008 and 2010 Hawaii Health survey
- Survey found both individual and community health literacy are significant, distinct correlates of individual general health status

Policy level

- Health education in schools
 - Do standards relate to health literacy?
- Policies that impact health organizations and insurance companies
- Plain Writing Act 2010: Requires federal agencies to use “clear Government communication that the public can understand and use” (PlainLanguage.gov, n.d.)
- Little research focus on studies looking at links between policies and health literacy

Psychological Empowerment



What is it?

- “A process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation.” (WHO, 2009)
- “There are many definitions, with most relating in some way to patients conceived as self-determining agents with some control over their own health and healthcare, rather than as passive recipients of healthcare.” (McAllister et al, 2012)
- Emphasis on self-efficacy



Intersection with health literacy

- Review article by Crondahl & Karlsson (2016)
 - Only 5 articles found that mention both HL and empowerment
- Key ideas
 - Empowerment is the goal of health literacy per Nutbeam (2000) (seen as an outcome)
 - HL is educational tool that can lead to empowerment per Mogford et al. (2011)
 - HL must evolve beyond the basics to provide someone with a greater sense of self-efficacy, power, and knowledge about using resources

Nutbeam (2000)-double check defs

- Functional Literacy-**not enough to lead to empowerment**
 - Basic skills in reading and writing, enabling for function in everyday situations
- Interactive Literacy
 - Be able to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances.
- Critical Literacy-**most crucial for empowerment**
 - Be able to critically analyze information, and to use this information to exert greater control over life events and situations



Schulz & Nakamoto (2016)

- One does not necessarily lead to the other
 - “A person might have adequate skills and understanding (health literacy) yet lack power and the motivation to take control (empowerment)
 - “A person with the motivation and power (self-esteem and control) to behave and act according to his or her own decisions does not necessarily have the skills or knowledge required to do so”

Schulz & Nakamoto (2016)


- **HIGH health literacy & HIGH empowerment =ideal**
- HIGH health literacy & LOW empowerment =dependent for help
- LOW health literacy & HIGH empowerment =dangerous situation
- LOW health literacy & LOW empowerment =high needs

NEXT

- Will see some examples of empowerment in intervention work and learn more about how it is related to health literacy


QUESTIONS





Rapid Estimate of Adult Literacy in Medicine (REALM)

- A medical word recognition test that can be offered to teens and adults (Davis et al., 1993)
 - A test of word recognition (66 words that are common medical terms) (Nielsen-Bohlman, Panzer & Kindig, 2004)
 - Read words aloud
 - Scores are converted into grade levels
 - Teen test takes 2-3 minutes
 - Adult test takes less than 5 minutes



Test of Functional Health Literacy in Adults (TOFHLA)

- Reading comprehension test (Parker et al., 1995)
- Provides an assessment of functional literacy
- Takes 18-22 minutes to administer
- Widely used in healthcare settings
- 50-item reading comprehension and 17-item numerical ability test
- Also S-TOFHLA (short version) that takes 7 minutes
(Nielsen-Bohlman, Panzer , & Kindig, 2004)
- A Spanish version exists

S-TOFHLA

- Short test of Functional health Literacy in Adults
- Your doctor has sent you to have _____ xrays.
 - A. stomach
 - B. diabetes
 - C. stitches
 - D. germs

Newest Vital Sign (NVS)

- Weiss et al., 2005
- Give people a nutrition label for a container of ice cream
- Ask questions about it that get at both reading comprehension and numeracy
- Only 5-6 questions

Self-report questions

- 3 item screener (always, often, sometimes, occasionally, never)
 - 1) How often do you have problems learning about your medical condition because of difficulty understanding written information?
 - 2) How often do you have someone help you read hospital materials?"
 - 3) How confident are you filling out medical forms by yourself?



Harrington et al. (2015)

- Parent health literacy may impact children's health outcomes such as asthma control
- Study assessed 281 children (6-12 years) with asthma and their parents at a single outpatient visit
- Lower parent health literacy was associated with worse asthma control and less asthma knowledge



Milford et al. (2016)

- First and second year medical students were trained through a series of didactics and then partnered with Head Start children, parents, and staff to help educate and set goals with families
- The 12 participant responses showed that medical student attitudes about the importance of health literacy were ranked highly both pre and post intervention
- Providing medical students with service learning with individuals with low health literacy increased students knowledge and skills confidence regarding health literacy and communication



Related concepts

- Patient activation (Hibbard & Greene, 2017)
 - “the skills and confidence that equip patients to become actively engaged in their health care”
 - “emphasizes patients’ willingness and ability to take independent actions to manage their health and care”

- Patient engagement
 - Includes activation
 - Patients working with providers to improve health
 - “a broader concept that combines patient activation with interventions designed to increase activation and promote positive patient behavior” (Hibbard & Greene, 2017)



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Empowerment Theory CBPR in Intervention Research

Janine M. Jurkowski, PhD, MPH

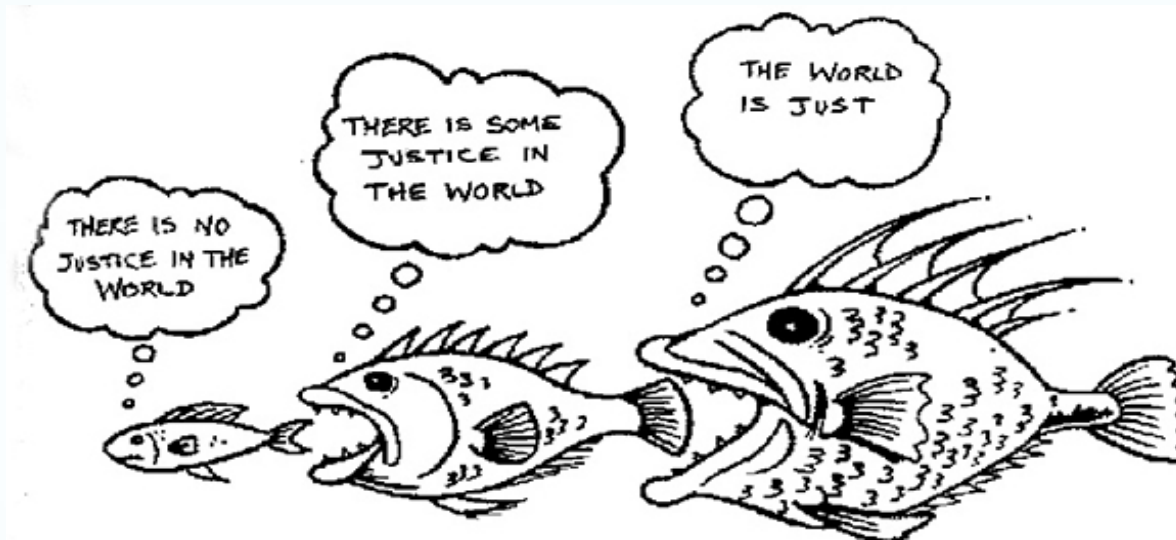


COMMUNITIES
FOR
HEALTHY LIVING

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Health Literacy related to Empowerment process

- Empowerment typically a process- have control over changes processes within which they are involved
- Empowerment as an outcome-Control over determinants that contributes to one's quality of life. Self-determination-agency- Important to have social determinants perspective
- Psychological, organizational and community empowerment (aligns with Ecological Model)
- Health Literacy related to cognitive empowerment- Psychological; fosters capacity and sense of agency



How do you think
empowerment relates to
CBPR?

Empowerment relates to CBPR

- Empowerment is inherent in CBPR
- In order to have equity- people need to be able to bridge social divides, gain knowledge and skills to participate as equals in research process
- Self-efficacy, and advocacy for participation
- Combines knowledge with action– need skills and knowledge for action
- Trust and communication



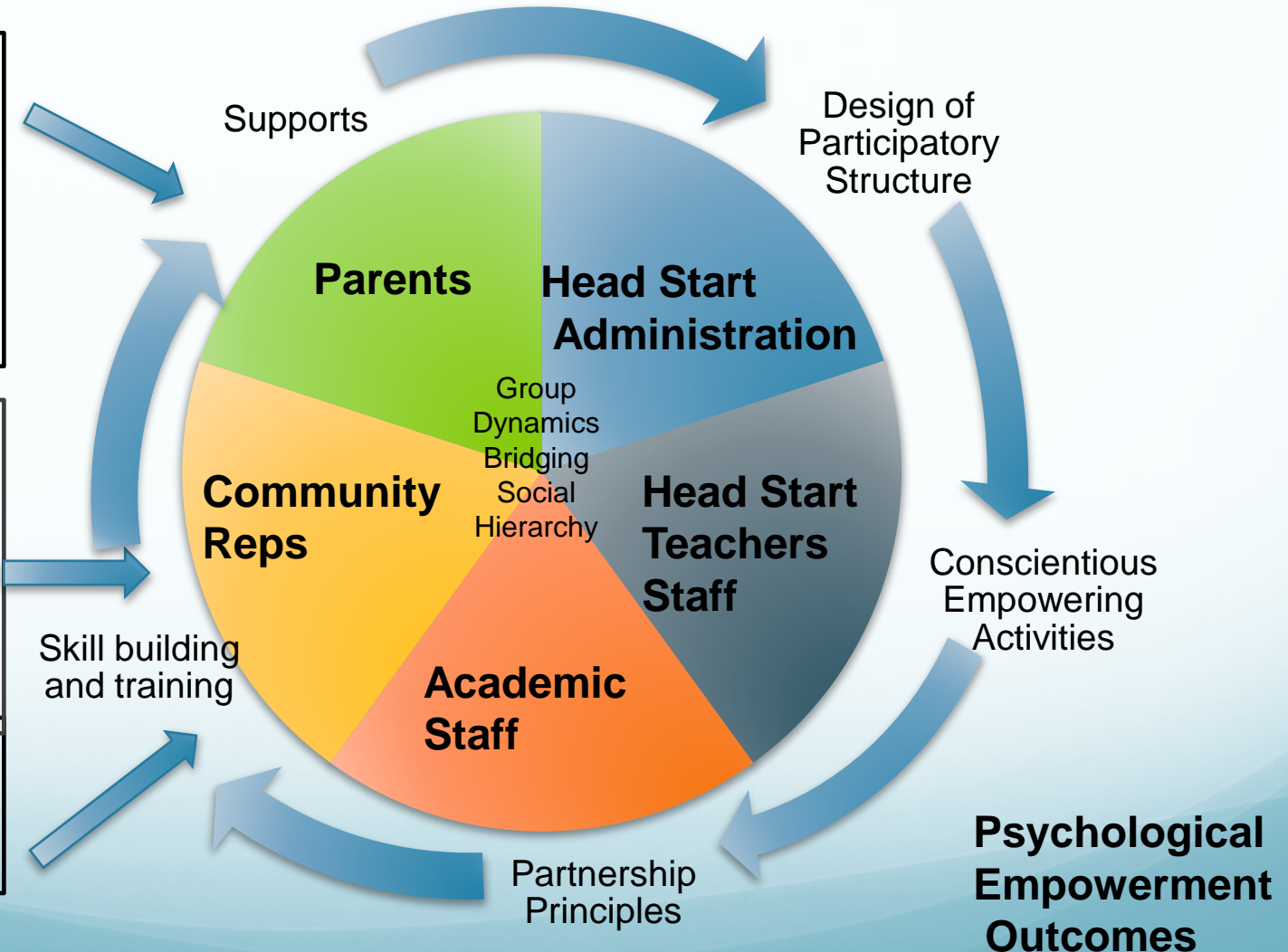
Communities for Healthy Living CBPR Approach

Setting the Stage involves Empowering Processes

CAB members' unique experiences, knowledge, skills, culture

Partner agencies' culture, grant budget and other resources

Grant budget
Participatory Infrastructure



CBPR Principles & Empowerment Theory in CHL

CBPR Principle	Empowerment Theory
Build on Strengths and Assets	<p>Cognitive Empowerment- Critical Awareness- of strengths when so often problem focused; societal determinants to avoid individual blame – <u>Critical Literacy</u></p>
Facilitate collaborative partnerships	<p>Resource Empowerment (combination of relational and cognitive) Mobilizing networks; resource linkages</p>
Co-learning and empowering process that attends to social inequalities	<p>Relational Empowerment- Collaborative Competence- low SES may not have experience collaborating in professional setting; bridging social networks</p> <p>Cognitive Empowerment- <u>Health Literacy</u>, Skill development</p>
Health addressed from a positive and ecological perspective	<p>Cognitive Empowerment- Understanding causal agents</p>
** Expertise (not a principle)	<p>Cognitive Empowerment- Professionals used to having specialty, parents not always see themselves that way</p>

Communities for Healthy Living (CHL)

(Kirsten Davison, PI)

- Childhood obesity prevention multi-faceted intervention, RCT
 - Peer-co-led Parent's Connect for Healthy Families, social media campaign, nutrition counseling, Health status letters
- Developed and piloted using a parent-centered CBPR process
 - Upstate, NY 5 Head Start Centers in Rensselaer County
- CBPR still Specific Aim
- Family Ecological Model and Empowerment Theory informed intervention
- Priority Population- Parents with children in Head Start
 - Upstate- African American and White
 - Boston- Families living in poverty, immigrants
African Americans and Latinos
 - Parents from Nepal, Dominican Republic, China, Haiti

CBPR to Tailor Evidence-Based CHL Intervention

- Empowerment Theory guiding intervention
- Parents Connect program completely revamped
 - Empowerment Theory explicitly throughout program
- Other intervention components modified so that fits with different agencies (organizational members important)
- Implementation process engaging Head Start agency
- Soft pilot

Expected Psychological Empowerment Outcomes of Intervention

- Parents will gain critical awareness of neighborhood and other social and environmental determinants that influence childhood obesity.
- Parents will learn how to work with a diverse group parents to gain social support to support child health
- Parents will gain communication skills and confidence to bridge social hierarchy to gain resources

How CBPR Resulted in a Non-Traditional the Childhood Obesity Intervention Parents Connect

1. Child Development
2. Behavioral Health
3. Mindfulness and Stress Reduction
4. Parenting Styles and Skills
5. Health Family Relationships
6. Neighborhoods and Health
7. Parent Advocacy

* Risk Factors and Behaviors for Childhood Obesity embedded in context of topic- diet, physical activity, screen time and sleep

Parents Connect Framework

- Shared leadership
- Active learning with Adult Learning Theory
- Empowerment Theory
 - RELATIONAL
 - COGNITITVE*
 - EMOTIONAL
 - RESOURCE
 - Self-efficacy*
- *Aligns with health literacy and critical literacy

Parents Connect Objectives Related to Empowerment

- Parents will gain critical awareness of childhood obesity related health behaviors
- Parents will gain critical awareness of the influence of behavioral health, temperament, parenting styles, neighborhood resources and environment on childhood obesity related health behaviors
- Parents will gain skills and experience bridging cultural and professional divides to build professional and personal relationships to support child health
- Parents will gain competence in communication skills to support bridging social hierarchy to support child health
- Parents will learn to mobilize resources within Head Start and within their community to support child health
- Parents will gain knowledge and learn skills in to mobilize networks and advocate for themselves and their families

DRAFT

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Mpower: Empowering Mothers for Health

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- What do the images have in common?
- What do we know about these women and their children?

What We Know

- Caregivers/mothers
- Shared values, beliefs, norms and behaviors
- Barriers/concerns

What We Want to Know

- Caregivers/mothers **living in poverty**
- **Influence of a global society**
- Barriers/concerns
- Shared **vs. culture-specific** values, beliefs, norms and behaviors



United States of America

United Kingdom

Ghana

Australia

- 1 Netherlands
- 10 Austria
- 20 Ghana
- 29 Liechtenstein

Background

The *Mpower* project responds to the United Nations General Assembly call to:

Promote health literacy in parents and empower women as a global strategy to reduce non-communicable diseases (NCDs).

Maternal Health Literacy (MHL)

*... **cognitive and social skills** which determine the **motivation and ability of mothers** to gain access to, understand, and use information in ways that promote and maintain **their health** and that of their **children**.*

Maternal Health Literacy (MHL)

- MHL is a **personal and community asset** vs. a risk.
- Improvement measured as change that demonstrates **skill development** (actions, practices, behaviors).
- Reading proficiency (*functional literacy*) **useful, but not sufficient.**
- This definition **opposes dominant opinion in US** medical centers and much of the literature, which views health literacy more narrowly.

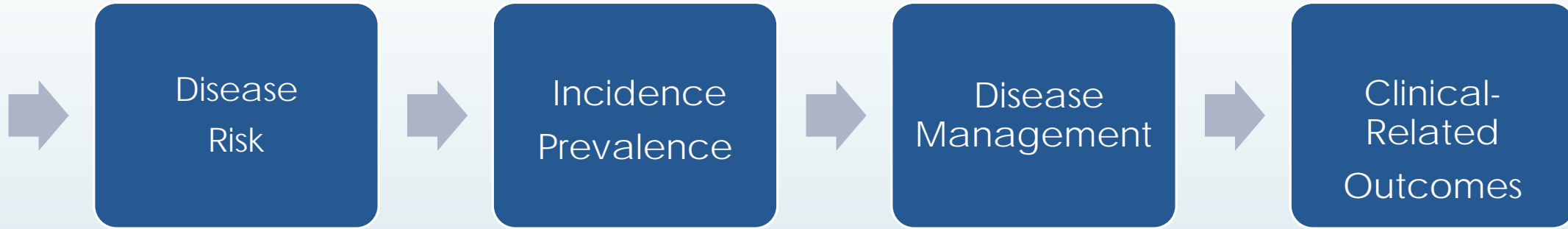
Traditional Health Literacy Research (simplified view)

Demographics

- Education*
- SES
- Race/ethnicity
- Age

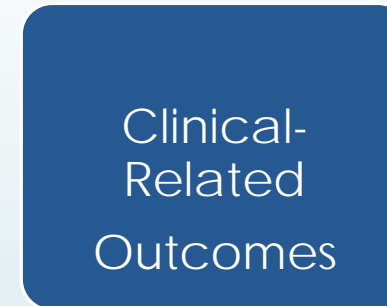
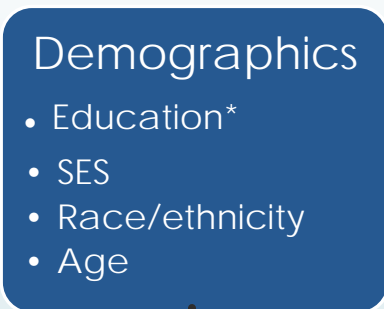
Other Factors

- Heredity
- Lifestyle
- Occupation



*Education often used as a proxy for HL.

Traditional Health Literacy Research (simplified view)



Poor health literacy:

- Impedes provider–patient **communications**
- Affects the ability to **access and navigate** the health service system
- Associated with poorer **medication adherence**
- Exacerbates existing child **health disparities**

- Pregnancy complications
- LBW infants
- Maternal depression
- Feeding practices (including less BF)
- Overall MCH
- Health care costs

Despite global recognition of the importance of maternal health literacy, significant gaps exist:

- Study outcomes are primarily **individually-oriented**.
- Most studies are **clinically-based**.
- **Intervention studies are limited**, especially community-based interventions customized to diverse low-literacy populations.
- Few studies emphasize **skill development or empowerment** of women in poverty.

The *Mpower* project will purposefully address gaps in the field of health literacy research by:

- Using an innovative community-based participatory approach (**novel research strategy**).
- Focusing on *critical health literacy* skills, empowerment, and health literacy for health protection and promotion (**expanded focus**).
- Identifying both women and their communities as units of analysis (**broader target audience**).

Why CBPR?

CBPR is a promising approach to overcome limitations of previous research efforts.

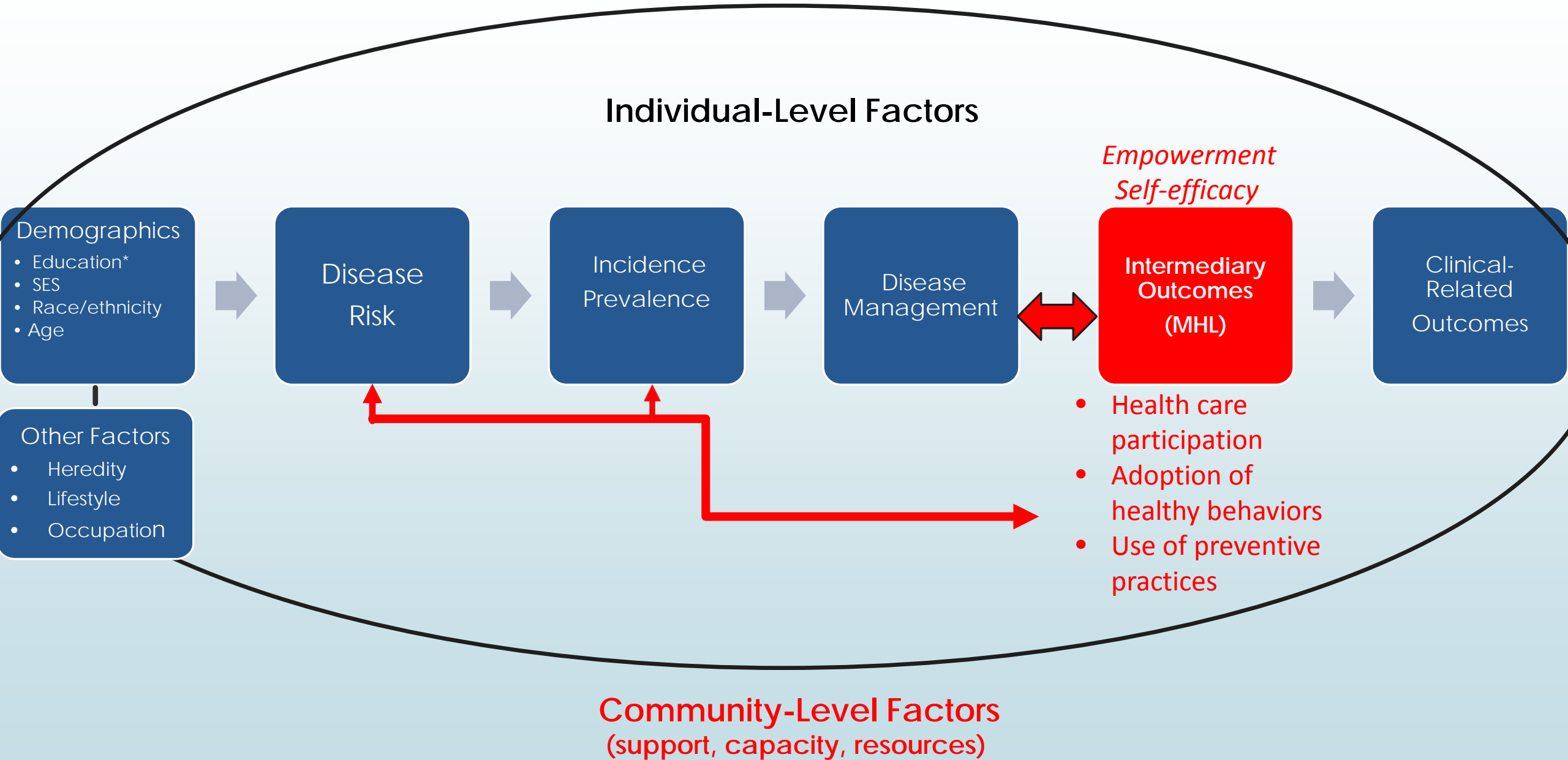
- CBPR built on the premise that **people who engage in unhealthy behaviors are in the best position to know what will enable them to change their behaviors.**
- CBPR “***equitably involves... community members, organizational representatives, and researchers in all aspects of the research process.***”

Why Empowerment?

*Empowerment is the process of **enhancing the capacity** of individuals or groups **to make choices** and to transform those choices into **desired actions and outcomes**.*

*Central to this process are actions which both build **individual and collective assets**, and improve the **efficiency and fairness** of the organizational and institutional context which govern the use of these assets.*

Expanded View of Health Literacy Research



	Traditional (health-related) Literacy Research	Expanded View of Health Literacy Research
Focus	Disease treatment and health care	Health promotion
Definition of Health Literacy	<ul style="list-style-type: none"> • <i>Functional health literacy</i> (reading and writing) • Health-related focus • Deficit model – HL viewed as a risk 	<ul style="list-style-type: none"> • <i>Interactive & critical HL</i> – access information, make meaning of it, and act on it • Socio-cultural focus • Asset model - HL viewed as a personal and community asset
Purpose	Reduce literacy demands of information and system-level barriers to improve clinical outcomes	Develop skills and motivation to use information for health; increase control over modifiable determinants of health (increasing HL = empowerment strategy)
Target Audience	Individuals/patients	Individuals and communities
Setting	Clinical	Community
Research Strategy	RCT, few intervention studies	Community-Based Participatory Research (CBPR)
Measurement	<p><i>Functional health literacy</i> measures -- reading and word recognition tests</p> <p>Ex: TOFHLA, WRAT, REALM, NVS, etc.</p>	<p>Measure what mothers do regarding health with skills, information and support they receive</p> <p>Life Skills Progression (LSP) instrument - Positions MHL as a latent construct indirectly measured by changes in intermediary health outcomes; progression is an indicator of increasing skill and autonomy</p>
Outcomes	Direct clinical outcomes (e.g., medication adherence, diabetes control, blood pressure, etc.)	Intermediary health outcomes (health care participation, adoption of healthy behaviors and preventive practices, etc.)

Maternal Health Literacy (MHL)

- A means and an outcome of actions.
- Aimed at promoting **empowerment** and **participation** of people in their communities and of people in their health care.
- *...addressing [this issue] requires a **whole-of-society approach** ... to improve ... health literacy of **individuals and communities** and to make **environments** easier to navigate in support of health and well-being.*

Improving MHL, and in the process empowering disadvantaged mothers, can:

- **Reduce disparities** by enabling mothers to better reduce risk.
- **Maximize protective factors.**
- Make the most of the **benefits of accessible health and social services.**
- **Achieve healthy outcomes** for themselves, their community, and their children later in life.

Your Turn

1. What do you anticipate might be some of the **challenges** of using a CBPR approach in MHL research globally?
2. How would you address these challenges (**possible solutions**)?

Anticipated Challenges

Potential Solutions

Mistrust among community members

Work with local health care providers/caregivers

Recruitment issues

Purposeful selection of pregnant women in two sites:

- Ghana
- U.S. (Seattle, WA)

Lack of familiarity among project team re:

- *Critical health literacy*
- Empowerment
- CBPR

Training Workshop #1

- Introduce a curriculum framework
- Stimulate discussion on how to incorporate CBPR into MHL research

Culture-specific issues

Training Workshop #2

- Identify culturally-sensitive data collection and communication strategies.

Methods – Long Term

- A **mixed methods** prospective cohort design.
- **Four sites:** Ghana, UK, Australia, and US.
- In a **facilitated group process**, mothers of children aged 0-3 will **design an intervention** to address an aspect of maternal-child health in their community.
- Their **action plans** will inform development of a global strategy and methods for adaption across cultures.

Long Term Goals

- **Increase understanding** of factors influencing HL capacity.
- Facilitate **development of MHL skills**.
- **Identify key components** to inform development of a global strategy.
- **Identify methods** for adapting these components across cultures.
- **Increase recognition** of MHL and empowerment as foundational to health worldwide.
- **Expand** health literacy research.

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