

Incorporating Concepts of Health  
Literacy into **State** Prevention,  
Wellness and Healthcare Programs:  
**Successes and Challenges**

---

Linda Neuhauser DrPH  
University of California, Berkeley  
IOM Roundtable on Health Literacy  
Washington DC  
September 15, 2009



# Challenges...

**Scale up** HL efforts for population impact

Identify **strategies** that lead to success

Two decades of research provides solid evidence about the importance of health literacy and “clear communication” issues. However, it has been hard to move from successful pilots to larger-scale, sustainable initiatives. One problem is that there is limited information about detailed approaches that can lead to success.

# Why State-Level HL?

## Advantages for HL efforts linked to:

- State laws, regulations and policies
- Leaders of HL-relevant programs
- Government and philanthropic budgets
- Health provider and cultural networks
- Media

Often state-level decision-making is necessary to create and sustain large-scale health literacy initiatives.

# Health Research for Action



- ◆ Research translated → interventions, policy
- ◆ User-centered design
- ◆ Public and private partners
- ◆ Large-scale, multi-media communication
- ◆ Relevant to users' literacy, language & culture
- ◆ Local, state, national, international
- ◆ Resources have reached 30 million households

The UC Berkeley Health Research for Action center has developed over 15 statewide initiatives in CA and in other states (and overseas) that leverage state or foundation funds, and involved the participation of government, professional networks, communities, academia, media and philanthropy. Health topics include: wellness, parenting information, choosing and navigating health care plans, disability issues, falls prevention and activity for older adults, care-giving, environmental health, etc. Media include print, Internet, audio, video, and special formats in Braille and adapted to American Sign Language.

## State-Level Communication Challenges

- Engaging diverse stakeholders
- Defining key communication issues
- Designing communication relevant to users' literacy, language, and culture
- Planning feasible statewide implementation
- Measuring outcomes
- Extending communication to other states

At the outset, it is often difficult to identify and get “buy-in” from state-level stakeholders. Education about health literacy, and specific examples of how state-level communication could be improved are helpful to engage key partners. Understanding the diversity of potential users and their communication barriers is an important early step. Communication design is often de-linked from the distribution plan; this can result in implementation problems. If outcomes are not measured, decision-makers will usually not commit to long-term investment of a large-scale communication initiative. Typically, statewide initiatives do not move beyond that state. Potential developers in other states do not usually have access to detailed information about such models.

## Steps to Create Statewide “Clear Communication”

1. Define **audiences** & communication goals
2. Set up **advisory group**: users & stakeholders
3. Identify issues from **formative research**
4. Draft content: **HL design principles** & **user input**
5. **Usability** test – until it works
6. **Co-design implementation** plan
7. **Evaluate**, revise, and **extend** to other states

These strategies differ from those used in traditional health communication in which experts have tended to broadcast generic information to audiences. We have found that these seven approaches are key to creating and extending successful statewide initiatives to improve health literacy. At the beginning, it is important to identify and partner with stakeholders (from multiple sectors and disciplines) who will play a key role in the initiative. Advisory groups are an excellent way to set up a collaborative process. An emphasis on formative research to examine what might facilitate or hinder the value of the communication for diverse groups is a critical step. Likewise, multiple health literacy design principles should be identified as “standards” early on. However, these principles are only a proxy for the complex factors related to “clear communication.” Therefore, user-centered design should be the foundation to communication development. This participatory process involves iterative rounds of usability testing by representatives of the intended beneficiary groups. Representatives should include members of subgroups who can cover literacy, language, and disability issues related to the communication. After the communication is created and tested in one language (typically English), it should be adapted, rather than literally translated, into other languages with attention to linguistic variations. It is important for the advisory group and other partners to develop the implementation plan during the creation of the communication resources—each will influence the other. For example, a statewide resource about using health plans will likely need to include county level supplemental information. Evaluations should be designed and presented to be beneficial to all stakeholder audience. Multiple formats (scientific manuscripts to one-page media advisories) will likely be needed. When the communication initiative is extended to another state, the seven steps should be repeated, but the process can be done much faster than the initial one.

## Case 1: The CA Kit for New Parents



Challenge: How to reach 500,000 new parent families and their service providers with effective, affordable parenting education? Studies in California showed that most parents (especially those who had language or other informational barriers) did *not* believe they had access to the information they needed to give their young child the best start in life. National studies found similar results. The above CA Kit was developed using participatory and clear communication processes. It has printed and DVD materials, including a Parents Guide developed by the UC Berkeley Health Research for Action center.

## Creating the CA Parents Kit (1)

1. Defined **audiences**: parents & stakeholders
2. Convened **advisors**: parents & stakeholders
3. Conducted **formative research**
4. Drafted content: [HL design principles & user input](#)

The “co-designers” included thousands of diverse parents (from multiple literacy levels, socio-economic levels, cultures, and with a variety of disabilities), and hundreds of providers, state and local decision-makers, experts from professional networks (like pediatric and childcare associations), media, etc.

## Health Literacy – Clear Communication Design Principles

- Readability (computerized testing)
- Cultural relevance & format: SAM measure
- Linguistic adaptation rather than translation
- Web usability guidelines (DHHS criteria + others)

User-centered design goes beyond these principles

During the formative research and participatory design processes, parents and providers identified many problems with past parenting information (high reading level, poor translation quality, lack of practical advice, lack of referrals to local services, etc.) that were addressed in the Kit development. Readability was set between 4<sup>th</sup>-8<sup>th</sup> grade depending on the particular printed resource. When the Kit was adapted into Spanish and 3 Asian language, parents wanted many cultural as well as linguistic changes to the content.

## Creating the CA Parents Kit (2)

5. Conducted **usability** tests and revised prototypes; adapted resources into 5 languages
6. Co-designed statewide **implementation plan**
7. **Evaluated**, revised, & **extended** Kit to 4 other states

As partners developed the statewide implementation plan, it was clear that the Kit would need some customization for each of CA's 58 counties. The final decision was to have each county develop local referral materials and have the choice to add small items to the Kit (outlet safety covers, toothbrushes, etc.). The Kit package was developed to accommodate these additional materials.

## Getting the Kit at WIC



Each of the state's 58 counties set up a commission to oversee the local Kit distribution planning and implementation. There are thousands of distribution sites in the state, including this one at a Women, Infants and Children's program for expectant and new parents.

## Statewide CA Kit Evaluation



- 3 year longitudinal study
- 87% usage rate (95% for Spanish-speakers)
- Parents improved knowledge & practices
- Revisions to Kit and its distribution strategies

Also--positive results in other state Kit evaluations

The positive evaluation findings have been critical for state decision-makers to commit to a long-term investment in the Kit in CA and in other states. Evaluation findings have also been important to identify areas in which these communication resources and their distribution strategies could be improved. In California, evaluation recommendations resulted in motivating the state to have Kits produced in 3 additional languages (Chinese, Vietnamese and Korean), use DVDs rather than videos, package the materials in smaller suitcase-sized boxes, and have more Kits distributed to parents before, rather than after the birth of the baby. The second to last slide in this presentation gives a reference to a published paper about the Kit evaluation.

## Extending Kit Information to 4 States



Examples of customized Parents Guides produced by UC Berkeley's Health Research for Action center, and included in parents kits in 5 states

## Kit Distribution in Arizona



A nurse provides the Arizona Parents Kit to a new mother at a delivery hospital in Phoenix. Kits are now available to most new parents in the state.

## Case 2: The CA Medicaid Access Guide

---

Intended for 600,000 seniors and people with disabilities on Medicaid: English, Spanish & Chinese

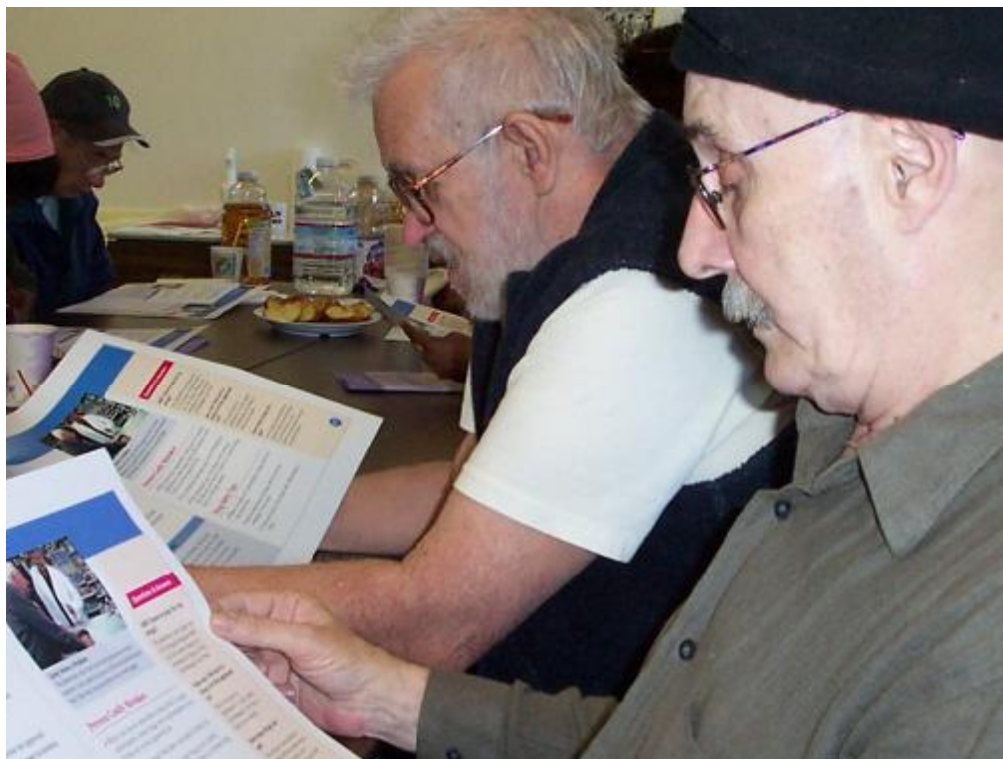
Beneficiaries have a poor understanding of information about Medicaid and about using healthcare services

Low health literacy is a major problem for this population. Most statewide materials for them are written many grade levels above their reading skills, and are not carefully co-designed with the participation of members of this population.

## Steps to Design CA Medicaid Guide (1)

1. Defined consumer & professional **audiences**
2. Identified communication issues from **formative research**
3. Convened **advisors**: consumers, providers, policy-makers
4. Drafted content using **design principles & user input**

We found many health literacy relevant communication barriers among sub-groups of seniors and people with disabilities who would be the intended beneficiaries of the Medicaid guide. The advisory group includes representatives from the state Medicaid office, health plans, consumers, academics, and professional groups. Their advice and review of multiple drafts of the guide, and participation in developing the implementation plan, has been invaluable.

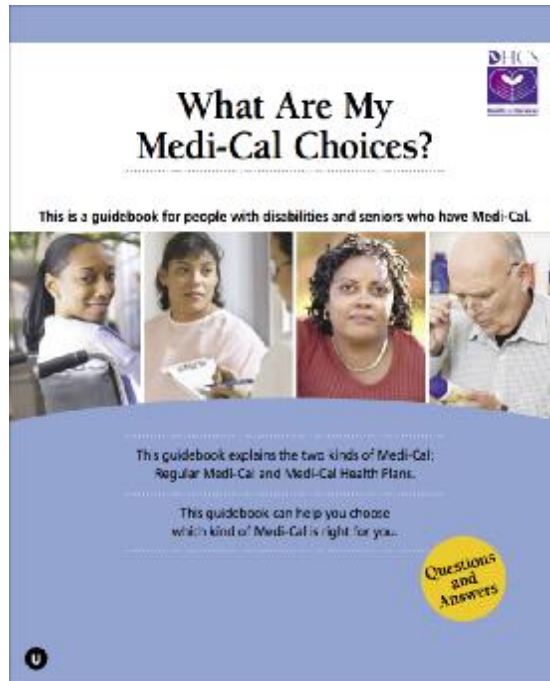


The photo shows Medicaid beneficiaries (who are seniors or people with disabilities) engaged in critiquing a draft of the Medi-Cal guide. Medicaid beneficiaries participated in 5 rounds of usability testing and re-design before the final guide was produced. The fine nuances of their recommendations were very important. For example, participants who were deaf and hard-of-hearing specified how a photo should be set up to show the correct positions of a deaf or hard-of-hearing patient, a provider, and translator during a medical visit (the original photo in the draft prototype was incorrect).

## Steps to Design CA Medicaid Guide (2)

5. Conducted 5 rounds of **usability tests**
6. **Adapted** content in Spanish and Chinese
7. Guide produced and mailed to 60,000 consumers
8. **RCT study** of guide use, understanding, satisfaction

The process to develop Spanish and Chinese versions included participants with a diversity of linguistic variations in those languages. The resulting Spanish guide uses a “neutral Spanish” that is understandable to people who may come from a variety of countries such as Mexico, Puerto Rico, or El Salvador. The Chinese version uses traditional characters as recommended from research about Chinese languages spoken in CA, and by participants in the design process who spoke either Cantonese or Mandarin.



The guide is produced in English, Spanish and Chinese. It was awarded the Institute for Healthcare Advancement's 2008 National First Place Award for Health Literacy (published materials category)

## CA Medicaid Guide: RCT Results

---

High usage: 77%

High satisfaction: 98%

Intervention group significantly increased

- Knowledge
- Confidence
- Intended behaviors

Newer findings show that the guide is associated with increased selection of managed care health plans—a major goal of California’s Medicaid program. The research design had to be adapted to address health literacy barriers of the participants. For example, a special “informed consent” process was used to ensure that people interviewed over the telephone could confirm that they understood what they were consenting to in the interview. Likewise, we added a “fatigue break” during the interview to accommodate the needs of participants who needed to stop during an interview. These processes were pilot-tested with the participants before the survey.

## Ideas to Advance Statewide HL

- Examine and describe models: **IOM report?**
- Include state-level guidance in the HHS National Action Plan to Improve Health Literacy
- Establish statewide partnerships, like:  
Health Literacy Missouri & Midwest Collaborative

Information about statewide health literacy efforts is limited in the scientific literature. A national report (such as by IOM) about such models, including detailed strategies to develop these initiatives, would be very useful. The US Department of Health and Human Services is creating a National Action Plan that could be used as the basis for a Surgeon General's National Call to Action to improve health literacy. This would also be a critical resource offering guidance about statewide health literacy initiatives. The Missouri Foundation for Health's "Health Literacy Missouri" program and their leadership in pulling together a collaborative of Midwestern states around health literacy issues, is an excellent model.

## References

---

Neuhauser L, Constantine WL, Constantine NA, Sokal-Gutierrez K, Clayton L, Desai M, Sumner G, Syme SL. 2007. Promoting Prenatal and Early Childhood Health: Evaluation of a Materials-Based Intervention for Parents. *American Journal of Public Health*, 97(10): 813-819.

Neuhauser L, Rothschild B, Graham C, Ivey S, Konishi S. (in press; e-pub October 2009). Participatory Design of Mass Health Communication in Three Languages for Seniors and People with Disabilities on Medicaid. *American Journal of Public Health*.

These two references give details about the design and outcomes of the CA Kit for New Parents and the CA Medicaid guide.

# Thanks

---

Linda Neuhauser

[lindan@berkeley.edu](mailto:lindan@berkeley.edu)

UCHealthAction.org

