

Health and Literacy Working Together: A Health Literacy Conference for New Readers & Health Professionals

By Helen Osborne, President of Health Literacy Consulting

“Health and Literacy Working Together,” was a conference unlike any other. Held in Des Moines, Iowa on September 10- 11, 2004, new readers (adults who are learning to read) and health providers (doctors, nurses, public health specialists, and others who communicate health information) met as equal partners -- together finding ways to improve health understanding.

This conference was needed because all patients -- including those who struggle to read -- have to understand health information. But they often don't. Research shows there sometimes are large gaps between what health providers communicate and patients understand. These gaps can affect people's health, such as when patients take too much medicine because they cannot read prescription labels.

Health literacy is a term that refers to this type of health communication. It is often defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Healthy People 2010).

Communicating health information in ways people can understand is a challenge. And Archie Willard, a man who learned to read when he was 54 years old, is doing something about it. One way was by having this year's New Readers of Iowa conference be a forum for patients and healthcare providers to focus on health literacy together. Organized by new readers along with members of the Iowa Health System, this conference aimed to:

- Help new readers develop confidence to speak up about health literacy problems
 - Build strong partnerships between new readers and health professionals
 - Provide a way for providers and new readers to find health literacy solutions together
- (To learn more about planning this conference, read the interviews with Willard, Eitzen, and Abrams at the end of this article.)

Conference speakers included Pat Blackwell, Ed Castor, Archie Willard, and other new readers who talked about their struggles as non-readers. They shared painful times as when classmates, teachers, family members, and health professionals teased them or set very low expectations. Some spoke of poor self-esteem. Rebecca, for example, remembered when she couldn't read and “sometimes felt like the stupidest person on earth.”

New readers also talked about their successes. Ed said that he learned to read because “I'm somebody who wouldn't quit.” He spoke of recently being honored for his volunteer work by the president of the United States. Steve said that learning to read “opened many doors” for him, including his job as an alcohol and drug counselor. Larry spoke about the joy of learning to read and how much pleasure he gets making words from the letters in a

Stop sign. Gerry, still learning to read, is proud of helping her grandson with pictures and words. As she said, “I always wanted to be a teacher and now I am.” (To learn more, go to the interviews with new readers Willard, Eitzen, Blackwell, and Kapp at the end of this article.)

Other conference speakers focused on literacy programs. Marcia Tait, senior vice president of ProLiteracy Worldwide (the largest non-profit, non-governmental literacy organization in the world) gave an international perspective. She said that more than 900,000 people around the world lack even basic reading skills.

Marty Finsterbush, executive director of VALUE (Voice of Adult Learners United for Education) talked about literacy efforts within the United States. Sharing his experiences as a new reader, Finsterbush encouraged others to take action. “This conference is successful only when you make a difference in someone else’s life.”

A panel of healthcare providers from the Iowa Health System and Iowa Medical Society Alliance then suggested ways new readers can partner with their health providers:

- Be courageous and tell your doctor that you don’t read.
- Ask your doctor to go slow so “I can do what you are telling me to do.” If your doctor won’t slow down, find someone new who will give you the needed time.
- Ask for explanations in words you understand. And if you still don’t understand, ask again. “Make us accountable to you,” said one nurse. “Don’t let us run out of the room if you don’t understand.”
- Find out exactly what you need to do. This can be taking medication correctly, eating and drinking the right foods, or getting to appointments on time.
- Take someone with you to appointments who can help listen and take notes.
- Repeat instructions back in your own words to make sure you “get it.”
- Talk with a pharmacist or doctor when you want to check about drug interactions.

And Sabrina Kurtz-Rossi, a health educator from World Education, talked about websites that have good health resources for new readers. One is the NIFL-Health Special Collection that has a lot of easy-to-read and easy-to-use health resources. (To learn more, go to <http://www.worlded.org/us/health/lincs/>)

Beyond listening to speakers, new readers also participated in two tasks. One was looking at brochures, leaflets, maps, informed consent documents and other written health materials. Here are some of the new readers’ suggestions about ways to make these materials easier-to-read:

- Limit the amount of information that is included as “too much information is not helpful.”
- Use short, simple, and familiar words. Ones like “dignity,” “expectations” and “exceeding” are hard to read. But do not eliminate all big words. “How would we learn if you get rid of them? We need to see them over and over to learn them.”
- Keep “and” and “or” out of sentences as it is sometimes better to have two short sentences instead of a long one.

- Add pictures, diagrams, and illustrations to help “get the idea in our head.” One way is to have pictures of medicine droppers or teaspoons showing how many milligrams there are in a dose of medication.
- Make important information stand out by using large print, headings, and bullet points.
- Be consistent, such as not writing the word “eight” in one place and using the number “8” in another.
- Have information available in other ways, not just in writing. This includes DVDs, videos, or objects such as teaspoons because “not everyone cooks.”
- Use brand names for common medicines such as “Advil,” “Motrin,” and “Tylenol” instead of words like “acetaminophen.”
- Use colors and arrows to help make maps easier to read. “It’s hard to fill out a questionnaire if you can’t spell or understand a map if you can’t read.”

The second task was for new readers to create a “health literacy statement.” This statement is intended as way for new readers to share their views with health providers. New readers, with help from two students at the Harvard School of Public Health, composed these two health literacy statements:

Statement #1. About Communicating with New Readers

We have always been here. We’ve always been the backbone of this country. We need help from doctors now. We need the best explanations about tests, procedures, and prescriptions and their side effects. We want to tell doctors that we need help to help ourselves and our families. Slow down and take your time. Treat us as you would like to be treated. Simplify your work so that it can be cost-efficient for both patients and doctors. Once you find out we have reading problems, you should do followups. We are human beings that need to be understood. Make sure that we understand. It’s about human respect. Yes, we lack a skill. But we’re not less than.

Statement #2. About Literacy Testing in Health Settings

A doctor’s office is no place for a reading test.

By all measures, the “Health and Literacy Working Together” conference was a great success. Just as Willard and others intended, this conference was an ideal way for new readers and health professionals to talk with, listen to, and learn from each other. Thanks for a great conference!

Ways to Learn More

By Email:

- Marty Finsterbush, finstern@netscape.net
 Sabrina Kurtz-Rossi, sabrina_kurtz-rossi@jsi.com
 Helen Osborne, helen@healthliteracy.com
 Marcia Tait, mtait@literacyvolunteers.org
 Archie Willard, millard@goldfieldaccess.net

On the Web:

- AMA Foundation's Health Literacy Toolkit, <http://www.ama-assn.org/ama/pub/category/9913.html>
- Ask Me 3, <http://www.askme3.org/>
- Harvard School of Public Health's Health Literacy Studies, <http://www.hsph.harvard.edu/healthliteracy/links.html>
- Health Literacy Consulting, <http://www.healthliteracy.com>
- NIFL-Health's Health & Literacy Special Collection, <http://www.worlded.org/us/health/lincs/>
- ProLiteracy Worldwide, <http://www.proliteracy.org/>
- World Education, <http://www.worlded.org/>

Interviews about Health, Literacy, and Health Literacy

Archie Willard: Conference organizer, health literacy advocate, new reader

HO: Why is the “Health and Literacy Working Together” conference needed?

AW: Medical people do not understand the problems that adult learners have. There are communication barriers between us. Doctors who can read and write well assume other people are at the same level.

HO: Why is it important for new readers to understand health information?

AW: There is so much we need to know. For example, I need to understand printouts about calcium and cholesterol. Is 200 too high? What is good or bad cholesterol? What is the differential between them?

I need to know what these concepts are, what the numbers mean, and what is normal or out of range. Knowing this helps me understand why I must control what I eat. The more I know, the better I can help myself and my family.

Pat Blackwell: Nurse, new reader

HO: How did you go from being a non-reader to a nurse?

PB: I quit school after 8th grade and got my GED at age 25. Then, when I was 47, I went to nursing school. Now I am a nurse working in a hospital’s progressive care unit (a step down from intensive care). The patients I treat are having or have had a heart attack. I have worked at this job for 13 years.

HO: How do you use your experience as a non-reader?

PB: I’m a “people reader,” meaning that I can spot non-readers a mile away. I can tell by their actions why they do what they do. Sometimes people cover up, are embarrassed, get mad, or become quiet. When I share that I didn’t read well until I was an adult, people share back and are less defensive.

HO: What can people do to improve health communication?

PB: I suggest that people write notes to themselves, even if they can’t spell very well. This way, they’ll be ready with questions to ask their doctor.

HO: What do you want new readers to know?

PB: I encourage others who think their situation is hopeless. I want people to know there is another way to learn to read -- they just need to keep working at it.

Gerald Eitzen: Farmer, new reader, active member of New Readers of Iowa

HO: What do you mean by “New Readers of Iowa”?

GE: The New Readers of Iowa is a close-knit group of over 100 people who help each other with self-esteem and confidence. Our goal is get the word out that there are a lot of non-readers and encourage those who cannot read to “get out of the closet” and not hide. We want people to get help at their local community college.

HO: How do you and other new readers plan the yearly conferences?

GE: A conference planning committee of about 20 -25 new readers meet in person and over the phone. We are an activist group, with conferences that have focused on education, finances, computer skills, voting, and health. Sometimes we educate outside groups, saying “We’d like to tell you what works for us.” The only financing we have comes from Iowa’s Department of Education. Since the New Readers of Iowa started having conferences in 1990, I have gone to all except one.

HO: What do you hope to accomplish at this year’s conference?

GE: We want providers to be respectful so that everyone who comes into their office feels comfortable asking questions. It’s bad when a person says that he or she can’t read, and the person at the desk says so everyone can hear, “What’s the matter? Can’t you read?”

HO: What was it like when you couldn’t read?

GE: I learned to read when I was 39. I was married 8 years before I let my wife know I couldn’t read. Even today, my parents and family don’t accept the fact that I couldn’t read.

HO: As a new reader, what is it like to go to the doctor?

GE: It’s scary to go to the doctor as there are some really rude people. There also is a lot of paperwork that is hard to understand. If the paperwork was in mechanical, not medical, terms then I’d understand.

HO: What do you think of the Internet?

GE: The computer is a scary machine. It is hard for many new readers to write emails or express themselves by typing. Before you or other health providers suggest a new reader look up information on the Internet, you might want to ask “Are you connected to the Internet?” This is a good way to find out if new readers want to learn about websites.

Douglas Kapp: Patient, new reader

HO: What was it like when you could not read?

DK: I graduated high school with mostly D's. I was in a special education class and always the "dumb kid" in school. Looking back, I assume I was dyslexic though I never was diagnosed.

HO: Being a non-reader, how did you manage at work?

DK: For many years, I was a union steward in my job at a manufacturing company. My wife knew I couldn't read, but not my employers, supervisors, or coworkers. I was on the board of UAW (United Auto Workers) for six years and no one knew I was illiterate. When I got papers to read, I might say, "I don't have my reading glasses today," "The print is too small," or "I'll take it home and look at it later."

When the economy got bad, I was laid off from this job and drove semi-trailer trucks. I drove from coast to coast, going more than 800,000 miles. Even though I never went to the same city twice, I could find places on the map by marking off streets with an "x" or check mark.

HO: How did you go from being a non-reader to learning to read?

DK: I had my first heart attack soon after I was laid off. I was unemployed, couldn't read a job application, and had no health insurance. I felt like I was at the bottom of a barrel. I went to NICC (Northeastern Iowa Community college) where I got literacy tutoring. After almost four years, my reading improved from a 4th to 7th grade level.

HO: Reading at a 7th grade level, what is it like for you in healthcare?

DK: I've now had three heart attacks and am retired on disability. I memorize words I need to know, like "catheterization." I tell my health providers that I can read, but cannot spell.

HO: How are you helping others?

DK: As a volunteer, I help nurses at the hospital review written materials. One time I took home a brochure that was written at a 17th grade level. My wife and I blacked out all the words I didn't understand and then asked the nurses if it made sense that way. Seeing how hard it is when you can't read all the words, the nurses rewrote this brochure at a 7th grade reading level.

HO: What do you want people to know about new readers?

DK: People who are perfect in reading don't know how good they have it. Illiteracy is a stumbling block, but it didn't bring me down. I'd like other new readers to be comfortable asking for help with paperwork. And I'd like hospital administrators to know that maybe half of their staff cannot read. If they find out who these people are, I hope they don't fire them. They may be your best workers, though not the best at paperwork.

Mary Ann Abrams, MD, MPH: Doctor, hospital administrator, health literacy advocate

HO: What did you learn from attending the New Readers conference last year?

MAA: Several new readers asked me same basic question, “Should I tell my doctor I have a reading problem?” My response was “Of course, that’s the right thing to do.” As a pediatrician, I knew that doctors would include the reading difficulty on a problem list, just like they do with other challenges such as diabetes.

HO: Knowing what you know now, would you still respond in the same way?

MAA: Today, I would give the same answer but in a different way. I would say, “Yes, tell your doctor that reading is a problem. But you need to know that doctors are just now learning that this is a challenge.” I would then encourage new readers to help healthcare providers understand what it means to have a reading problem. For example, I might suggest that new readers ask their provider to “Tell me twice,” “Slow down,” or “Let me ask questions.”

HO: How do you advocate for health literacy?

MAA: In addition to giving many presentations to increase awareness, we are working collaboratively throughout the Iowa Health System to address health literacy by fostering a shame-free environment and improving our written and interpersonal communication skills. Also, we are working closely with new readers and other patients to help us learn what works best to enhance health communication.