

Health Literacy & Plain Language: What It Is and How You Can Help

Applying the Principles of Universal Design to
Serving Survivors with Disabilities & Deaf
Survivors Training

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Health Literacy

Health literacy is defined in terms of skills.

- *Healthy People 2010* defines health literacy 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.”
- The *American Medical Association Council of Scientific Affairs* defines functional health literacy as “the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient.”
- Personally, I think of health literacy as a shared responsibility between patients (or anyone receiving health information) and providers (or anyone on the giving end of health communication). Each must communicate in ways the other can understand.



Health Literacy —When Patients and Providers Truly Understand One Another

Health Literacy Facts & Figures

Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy

This nationwide survey asked 19,000 adults to perform reading tasks in three health domains: clinical, prevention, and navigation of the healthcare system. There were four levels of task difficulty:

- **Below basic.** One of the tasks was to circle the date of a medical appointment.
- **Basic.** One of the tasks was to read a clearly-written booklet and then give two reasons why someone with no symptoms should be tested for this condition.
- **Intermediate.** One of the tasks was to determine a healthy weight using a BMI graph.
- **Proficient.** One of the tasks was to use a table to calculate an employee's share of health insurance costs.

Overall, adults scored at: 14% below basic, 22% basic, 53% intermediate, 12% proficient. Significant differences include:

- Older adults (65 years, or over): 59% scored at basic, or below
- Black adults: 58% scored at basic, or below
- Hispanic adults: 66% scored at basic, or below
- People with less than/some high school education: 76% scored at basic, or below

Other recent reports and research:

- "70% of patients with low literacy correctly stated the instructions 'take two pills by mouth daily' but only 35% could demonstrate the number of pills to be taken daily." (Davis, 2006)
- "60% of the people could not correctly calculate the number of carbohydrates in ½ bagel when the serving size is a whole bagel." (Rothman, 2006)
- "The safety of patients cannot be assured without mitigating the negative effects of low health literacy and ineffective communications on patient care." (JCAHO, 2007).
- "Low health literacy presents a risk to patients, providers, and the U.S. health care system as a whole." (AMA Foundation, 2007)
- "Low health literacy is a major source of economic inefficiency in the U. S. healthcare system. An initial approximation places the order of magnitude of the cost of low health literacy in the range of \$106 - \$238 billion annually. This represents between 7-17% of all personal healthcare expenditures." (Vernon, 2007)

Individual Learning Needs

People have difficulty with health literacy for many reasons, including: a complex healthcare system in which patients are seen by multiple providers in a variety of settings, the often stressful conditions in which health information is communicated, and the varied learning needs and abilities of patients and their families. Learning needs include:

Literacy

Literacy is more than just the ability to read and write. As defined in the 2003 US National Assessment of Adult Literacy (NAAL), literacy is the set of skills needed to use “printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential.” NALS asked nearly 20,000 adults in the United States to perform a variety of word-based tasks. Findings showed that:

- 33% of the adults in the US are at a basic or below basic level for prose literacy (continuous text)
- 34% are at a basic or below basic level for document literacy (non-continuous text)
- 55 % are at a basic or below basic level for quantitative literacy (numbers and calculations)

Age

Older adults, those who are 65 years and over, make up more than 12% of the US population. Many people in this age group have difficulty learning due to limited literacy, disease, chronic illness, drug interactions, social changes, stress, or anxiety.

Disability

People with limited vision or hearing may have problems learning because they have one less way to receive information. When people gradually lose these skills, they may be unaware of their diminished abilities and unfamiliar with other ways of communicating.

Language

Language refers to the words we use. About 20% of the US population speaks a language other than English at home. Besides English, more than 325 languages are spoken. It can take anywhere from two years to a lifetime to become fluent and have the language skills needed for complex concepts such as “how” and “why.”

Culture

Culture is the context in which people understand words. Culture includes people’s values, beliefs, traditions as well as language. Even people from the same country or region may not share the same point of view.

Emotion

People may have difficulty listening and remembering when they are scared, anxious, or overwhelmed. Given the right set of circumstances, everyone can have trouble understanding health information.

Writing in Plain Language

Content and organization

- Differentiate between “need to know” and “nice to know” information
- Organize information from the reader’s point of view
- Provide ways to learn more including non-written options (hotlines, groups, and such)

Words

- Use common 1-2 syllable words
- Define unfamiliar, yet necessary, words/terms
- Be consistent, using the exact same wording each time
- Avoid or explain acronyms, jargon, idioms, and needlessly “stuff” words

Sentences

- Write short sentences (up to about 15 words), each with only one idea
- Use an active voice, identifying who is doing the action
- Avoid conditional if/then sentences

Numbers

- Appreciate that many people have difficulty with quantity, time, risk, calculations
- Avoid numbers that are very big (over 100) or very small (less than 1)
- When possible, present data in absolute terms (5 out of 10) v. relative (twice as many)
- Convey concepts using pictures, stories, metaphors, and other non-numeric ways

Tone

- Speak directly to the reader, using “you” and “your”
- Frame information in positive, yet honest, ways
- Consider your reader’s logic and life experience
- Give specific instructions, not assuming readers know exactly what to do

Format, Layout, and Graphics

- Use headers to identify new sections and topics
- Create short bulleted lists, chunking similar items together
- Have “adequate” white space so pages do not look crowded
- Use at least 12-point type, with combined upper and lower case letters
- Line up (justify) the left margin, but not the right or center
- Include graphics to show key ideas or actions
- Encourage reader interaction

Confirm Comprehension

- Appreciate the limitations of reading grade level assessment tools
- Get feedback twice from your intended audience
- Consider using check-lists such as *SAM* (Doak, Doak, and Root)

Simplifying Words and Terms

Use everyday words to explain these terms:

Service recipient/consumer

Domestic violence

Sexual assault

Multidisciplinary collaboration

Intake/admission

Adhere to policies, procedures, program rules

Recommended grievance solution

Simplifying Sentences

Restate these sentences so that they:

- include no more than about 12 – 15 words
- have only one main idea
- use everyday words

“The XYZ Shelter will not be liable for any damages to person or property or for loss by theft or damage occurred by acts, omission, or neglect by any person except as to agents acting intentionally wrongful.”

“You have the right to request an order from superior court to file a petition requesting any of the following orders for relief; an order restraining the abuser from battering the victim and other family members, an order directing the abuser to leave the household, an order preventing the abuser from entering the residence, school, business, or place of employment of the victim, an order awarding the victim custody of a minor child or children, an order restraining the attacker from molesting or interfering with minor children in the custody of the victim, an order directing the party not granted custody to pay support of minor children if that party has a legal obligation to do so, an order directing the defendant to make specified debit payments coming due while the order is in effect, and/or an order directing either or both parties to participate in counseling.”

Our finding that women with and without disabilities do not differ substantially on maintaining a healthy weight was based on a body mass index analysis (weight in kilograms divided by height in meters squared). The average body mass index of women with disabilities was 26 kg/m² (the standard for normal is 20-25 kg/m²). About the same percentage of women with and without disabilities were in the various obesity categories (23% versus 28%); however, significantly more women with disabilities were in a lower BMI category (20% versus 11%).

Useful Feedback Questions

Attractiveness

Does the material attract and hold the attention of the target audience?

- Can you tell me what you like about the (pamphlet, video, title, color,...)?
- Are the people in the material attractive to you?
- In general, do you like the pictures? What would you tell the artist to change?

Understandability

Does the reader understand the ideas presented and can s/he tell what the message is in her/his own words?

- What do you think is the most important idea in this pamphlet?
- What is the pamphlet asking people to do?
- Are there any words you think people might not understand?
- What does this (specify) mean what it says _____? How do you do that?

Personal Relevance

Can the reader relate to the message and/or pictures and apply them to her/his own lifestyle?

- Is that something you would be likely to do?
- Do the people in the pictures look like anyone you know?

Acceptability

Is the message offensive or annoying? Is the message perceived as being important or true?

- Do you think it is important for people to know about _____?
- Is (the message) something people you know would be likely to (do, remember, think is important,...)?
- In your opinion, who is the pamphlet for?
- Is there anything in the pamphlet that is hard to believe?

Overall Impressions

- Can you tell me how this can be improved?
- Is there anything you don't like, even if you don't know how you would change it?
- Take a look at the pictures. In general, do you like the pictures? What would you like the artists to change?
- Do you think we left out anything that should be included?

Adapted and reprinted with permission from: Brandes W (editor). Literacy, Health and the Law. Health Promotion Council of Southeastern Pennsylvania, Inc. Philadelphia. 1996.

To Learn More: Health Literacy & Plain Language

- *Clear Language & Design*, Reading Effectiveness Tool, <http://www.eastendliteracy.on.ca/clearlanguageanddesign/readingeffectivenessstool>
- Davis TC, et al, 2006. "Literacy and Misunderstanding of Prescription Drug Labels." *Annals of Internal Medicine*, 145(12):887-894.
- Doak C, Doak L, and Root J, 1996. *Teaching Patients with Low Literacy Skills*. J.B.Lippincott Company, Philadelphia. Available online at <http://www.hsph.harvard.edu/healthliteracy/doak.html>
- Fadiman A. 1997. *The Spirit Catches You and You Fall Down*. Noonday Press: NY.
- *Harvard School of Public Health, Health Literacy Studies*, <http://www.hsph.harvard.edu/healthliteracy/links.html>.
- *Health Literacy Consulting* at www.healthliteracy.com. Includes the full text of Helen Osborne's articles, tips, links, and a free "What's New" monthly e-newsletter.
- *Health Literacy Month* at www.healthliteracymonth.org. Worldwide campaign to raise awareness about the importance of understandable health information.
- *Health Literacy Out Loud podcasts*, www.healthliteracyoutloud.com
- Institute of Medicine, Nielsen-Bohlman L, Panzer AM, Kindig DA (ed) 2004. *Health Literacy: A Prescription to End Confusion*. The National Academies Press: Washington, DC.
- Mayer GG, Villaire M, 2007. *Health Literacy in Primary Care: A Clinician's Guide*, New York, NY: Springer Publishing Company.
- *National Assessment of Adult Literacy (NAAL)*, <http://nces.ed.gov/naal>
- *National LINCS*, a service of the National Institute for Literacy. Includes NIFL-Health (a health literacy listserv), <http://www.nifl.gov/mailman/listinfo/Healthliteracy>
- Osborne H, 2004. *Health Literacy from A to Z: Practical Ways to Communicate Your Health Message*. Sudbury, MA: Jones & Bartlett. <http://www.jbpub.com/catalog/0763745502/>
- *Plain Language Action & Information Network*, includes "Writing User-Friendly Documents," <http://www.plainlanguage.gov>
- *Plain Language Association International (PLAIN)*, <http://www.plainlanguagenetwork.org>
- Schwartzberg JG, VanGeest JB, Wang CC (ed), 2005. *Understanding Health Literacy: Implications for Medicine and Public Health*. AMA Press.
- *Readability Studio* (software to assess readability), <http://www.oleandersolutions.com/readabilitystudio.html>
- Rothman RL et al, "Patient Understanding of Food Labels: The Role of Literacy and Numeracy." *American Journal of Preventive Medicine*, 2006;31(5): 391-398.
- Schriver KA. *Dynamics in Document Design*, 1997. New York, NY: Wiley Computer Publishing.
- Williams R. *The Non-Designer's Design Book*, 1994. Berkeley, CA: Peachpit Press.

In Other Words...Working With Lawyers to Make Health Information Clear

By Helen Osborne, M.Ed., OTR/L

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I often lead plain language workshops, teaching clinicians and other health communicators how to convey health messages more clearly. Plain language goes beyond simple words and short sentences. It includes organizing information from the reader's perspective, setting a tone that invites readers to read, using words that readers already know or clearly defining new ones they need to learn, and making messages visually appealing with formatting such as bold type, bullets, and large font.

Almost always, participants "get" what to do and leave my workshops with the skills they need to begin writing health documents in plain language. But before they go, someone invariably asks, "What can we do about those lawyers?" This question may be about mandated, multi-syllabic, complicated regulatory documents, such as *HIPAA* or informed consent. Or relate to their organization's document approval process in which lawyers routinely nix materials written in plain language.

To address these concerns, I spoke with Joseph Kimble, who is a law professor at Thomas Cooley Law School in Lansing, Michigan. He also is a champion of plain language and author of numerous articles and a book called *Lifting the Fog of Legalese*.

Getting beyond the stuffy uncertainty of legalese

Kimble acknowledges that many lawyers object to plain language, saying it is not sufficiently precise or does not offer an organization adequate legal protection. He says, however, these objections are myths. Plain language does not change the meaning, Kimble says. In fact, it tends to make the meaning clearer.

In Kimble's opinion, traditional legal writing may cover up all sorts of uncertainties. For instance, when a statement reads "refer to information herein," does that mean that additional information can be found on the same page, within a certain section, or somewhere in the entire document? It would be much clearer and more precise to say, "To learn more, go to page x."

Kimble says that the myth of precision was exposed many times during his work in redrafting the *Federal Rules of Civil Procedure* and the *Federal Rules of Evidence*. The process of putting them in plain — or plainer — language revealed lots of inconsistencies and ambiguities.

Another myth, according to Kimble, is that traditional legal language is needed to protect an organization if a case is brought against it. "Nonsense," says Kimble. He says that if a

plain language version of information has the same content and substantive meaning, then an organization will get exactly the same protection.

Kimble is forthright in his criticism of traditional legal writing, or "legalese." He says that documents do not need stuffy words such as "thereof" and "pursuant to." While acknowledging the need for certain legal content, Kimble firmly believes most information can be explained in ways ordinary citizens can understand. To Kimble, "plain language means writing clearly and effectively for your readers."

Working with lawyers to make health information clearer

The good news is that there are ways clinicians can work with lawyers to produce clear, simple, and understandable health documents. Kimble offers this example of what to do when lawyers deny approval to a plainly written document:

If the lawyer insists on certain wording, you (the plain language writer) should ask why. Find out if particular wording is required by statute or regulation. Ask for its citation number in the [Code of Federal Regulations](#) (or whatever other source the lawyer is referencing) and then look up the requirements. You can usually do this without assistance from a lawyer.

In Kimble's experience, most statutes and regulations don't set out a template or give exact words that have to be repeated verbatim. If the statute states, "Document must include the following language," then you're stuck with it, he says. But if instructions are more general, such as "Must notify the consumer that..." without requiring specific language, Kimble says you can convey the concept in plain language so long as you include the required substance.

Here are some other ways clinicians can work with lawyers:

- **Create a team.** Writing an understandable document takes a team of subject-matter experts, a plain language writer, and likely readers. For official healthcare documents, subject-matter experts should include clinicians (who ensure medical content is correct) and lawyers (to confirm legal accuracy). The writer should be skilled in plain language and serve as an unceasing advocate for readers. As well, the team should include one or more readers to review each draft and determine whether documents truly are understandable and useful.
- **Write in plain language.** Writing in plain language is a skill like any other, says Kimble. It not only includes using simpler words and shorter, less contorted sentences but also presenting information in ways that engage readers. An example is using the pronoun "you" rather than "the health plan participant."
- **Consider adding a simply written summary.** Many legal or regulatory documents are long and complex. Kimble doesn't see any problem in also offering a plainly written summary, so long as:
 - It is clearly titled, "This is a summary only."
 - Content is reasonably accurate and not misleading.
 - The Summary refers to the full document.

- **Define only those words that need defining.** Look critically at words and don't define unnecessarily, says Kimble. Readers may already know what key terms mean. Show close variations with parentheses. An example: "*Co-payment*" (*sometimes called 'co-insurance' or 'co-pay'*).¹ If uncertain about which words to define, test them with intended readers or at least get an opinion from outsiders. For instance, Kimble might ask non-lawyers what a word such as "negligent" means and how they would define it. If their answers are incomplete or incorrect, then he would define it for non-legal readers.
- **Format documents to improve readability.** Good document design encourages readers to look at documents and helps them focus on important information by using formatting such as headings, bullet points, and white space. Kimble says readers can feel defeated and discouraged, as if they don't have a chance at understanding, when a page looks like an imposing legal document.

Lawyers, like health professionals, are becoming increasingly aware of the need for and benefits of plain language. But the change is slower than Kimble would like. "Legal writing is not as bad as it used to be, but much of it still is pretty bad," he admits. On the bright side, Kimble sees more and more law schools and legal organizations committed to plain language.

Ways to learn more:

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- Kimble J. *Lifting the Fog of Legalese: Essays on Plain Language* (Carolina Academic Press, 2006).
- Kimble J. "Answering the Critics of Plain Language," *5 Scribes J. Legal Writing* 51 (1994–1995), <http://www.plainlanguagenetwork.org/kimble/critics.htm>

The Center for Plain Language defines plain language this way: "A communication is in plain language if the people who are the audience for that communication can quickly and easily find what they need, understand what they find, and act appropriately on that understanding."

Plainlanguage.gov is a federal group working to improve communication from the government to the public. Its website states, "No one technique defines plain language. Rather, plain language is defined by results—it is easy to read, understand, and use."

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