Promoting Individual and Community Health at the Library

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Contents

List of Figures and Tables vii
Acknowledgments ix

CHAPTER 1
Introduction 1

CHAPTER 2
Public Libraries and Consumer Health:
A Historic Perspective 15

CHAPTER 3
Health Information Provision in Public Libraries 33

CHAPTER 4
Health Programming in Public Libraries 53

CHAPTER 5
Reaching Out to the Community:
Opportunities for Wider Engagement 75

CHAPTER 6
Looking Ahead: Future Opportunities 93

CHAPTER 7
Onward and Upward 111

Index 123
FIGURES

2.1 Relationship of patient-provider interaction, self-care, health literacy, and health information 18
4.1 “Get Walking at Your Library” promotional poster 60
4.2 “Read & Reach” coloring page by Suzanne Bloom 63
5.1 Community constellation of potential health outreach collaborators 77
5.2 Local health department (LHD) partnership relations (adapted from NACCHO, 2016) 79
6.1 Endcap in public library displaying poster from local public health department 95
6.2 Bulletin board in North Carolina public library displaying health department information 100
6.3 Health brochures display and book drop that acts as food drop in public library in hurricane-prone region 104
7.1 Triad of health information provision 114

TABLES

1.1 Acronyms related to health agencies 9
4.1 Sample Health Observances (U.S. Dept. of Health and Human Services) 66
Introduction

*A library is a place that is a repository of information and gives every citizen equal access to it. That includes health information. And mental health information. It’s a community space. It’s a place of safety, a haven from the world.*

—Neil Gaiman

THE INFORMATION AGE HAS USHERED IN A LEVEL OF EXPECTATION for volumes and quality of information unimaginable in any previous era. In spite of most Americans having smartphones and Internet access, recent decades have recorded increased usage of public libraries, with millions of people per year using their local libraries for health information. Many libraries have dramatically stepped up their provision of health information in order to meet these demands and patron expectations. This volume covers the strategies used by libraries to improve people’s access to and use of health information, whether to address an individual’s acute information need, to improve the community’s ability to understand health information, or in some cases to lead programs and efforts to improve people’s health.

In communities throughout the world, public libraries offer all types of support beyond access to books and information. From citizenship classes to early literacy initiatives to maker spaces to wide arrays of program provision, libraries provide not only resources and space; they are full of opportunities that support individual fulfillment and community progress. As longtime literacy providers and advocates, public libraries are expanding services to incorporate all types of literacies, such as
financial and digital literacy. Because they provide access to health information in a variety of ways, health literacy is yet another area where public libraries can offer support for individuals and communities.

**Health Literacy**

From their inception, public libraries have served as venues for all types of literacy activities and instruction. As educational organizations, they have a long history of supporting lifelong learning; libraries provide classes, tutoring, and individual training. Much of the programming in libraries is centered on literacy, such as storytime programs, book discussion groups, and summer reading programs. Many libraries also provide outreach to organizations such as Head Start and local day care centers, extending their influence and literacy training beyond the library’s walls and into the community.

Literacy is not only restricted to a person’s ability to read; there are other types of literacies that contribute to an individual’s capacity to function. These can include information, digital, computer, technology, media, cultural, multicultural, visual, and financial literacy. Another type of literacy has a significant impact on individuals’ well-being—health literacy. The unique aspects of health information contribute to the challenges related to health literacy, however. Medical science progresses rapidly, and health information can overwhelm even persons with advanced literacy skills. In addition, what has been learned often becomes outdated or forgotten, or is incomplete. Health information can be misrepresented or misunderstood, and is often provided in a stressful or unfamiliar situation, and so is difficult to retain.

**Health Literacy Defined**

Ratzan and Parker (2004) developed the definition of health literacy adopted for use by the U.S. Department of Health and Human Services for *Healthy People 2010*: “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services to make appropriate health decisions” (Institute of Medicine, 2004, 4). This and other early definitions of health literacy set the stage for
studying the concept, but they have been characterized as somewhat lim-
ited in that they were focused on individual skills (Six-Means, 2017). Over
time, the definition of health literacy has been extended to include health
care personnel and expanded to include abilities, such as to communicate
and use information (Centre for Literacy); in addition, shared responsi-
bility for health literacy has been ascribed to clinicians, institutions, and
health care systems (Koh and Rudd, 2015).

In 2012, a systematic review of the health literacy field was con-
ducted in which researchers identified 17 definitions of health literacy
and 12 conceptual frameworks (Sorensen et al., 2012). These were inte-
grated to provide the following definition which points to the centrality
of health information: “Health literacy is linked to literacy and entails
people’s knowledge, motivation and competences to access, understand,
appraise, and apply health information in order to make judgments and
take decisions in everyday life concerning healthcare, disease preven-
tion and health promotion to maintain or improve quality of life during
the life course” (Sorensen et al., 2012). The U.S. Department of Health
and Human Services (2017) now states: “The primary responsibility for
improving health literacy lies with public health professionals and the
healthcare and public health systems. We must work together to ensure
that health information and services can be understood and used by all
Americans. We must engage in skill building with healthcare consumers
and health professionals. Adult educators can be productive partners in
reaching adults with limited literacy skills.” This description of health lit-
eracy points to a responsibility for those who work in the information
field, namely librarians, to embrace their role in health literacy promo-
tion, not only in health care systems, but in the community as well (Six-

**Background**

Health literacy requires a basic knowledge of health topics. People with
limited health literacy often lack such knowledge or have misinformation
about the body and the nature and causes of disease, and they may
not understand the relationship between lifestyle factors (e.g., diet and
exercise) and various health outcomes. Health literacy also requires or
includes numeracy skills for things such as interpreting test results,
calculating cholesterol and blood sugar levels, measuring medications, and understanding nutrition labels. In addition, choosing between health plans and comparing prescription drug coverage requires numeracy skills for calculating premiums, co-pays, and deductibles.

Although more than 90 million American adults have low health literacy, the health effects of low literacy and illiteracy have been referred to as “the silent epidemic” (Marcus, 2006, 339). Only 12 percent of adults have proficient health literacy, which means that approximately 9 out of 10 adults may lack the necessary skills to manage their health and prevent disease. Thirty million people (14 percent of adults) lack even basic health literacy. These adults are more likely to report their health as poor (42 percent), and are more likely to lack health insurance (28 percent) than adults with proficient health literacy (Kutner, Greenberg, Jin, and Paulsen, 2006).

According to the U.S. Department of Health and Human Services, health literacy is dependent not only on individual factors, but on systemic factors in health care as well. These include:

- Communication skills of lay persons and professionals
- Lay and professional knowledge of health topics
- Culture
- Demands of the health care and public health systems
- Demands of the situation/context

Low health literacy can affect people’s ability to navigate the health care system, such as locating providers or services and filling out complex forms. It may also make it difficult to share personal information (e.g., health history) with providers, to engage in self-care and chronic-disease management, and to apply the mathematical concepts that are needed to understand probability and risk. The population groups who are at higher risk for low health literacy include

- Older adults
- Racial and ethnic minorities
- People with less than a high school degree or GED certificate
- People with low income levels
- Nonnative speakers of English
Introduction

- People with compromised health status
- Rural populations

**Costs of Low Health Literacy**

Nearly half of all Americans are estimated to be functionally illiterate in terms of dealing with health care issues (Dickenson et al., 2014). In the United States, the cost of not meeting health literacy needs is estimated to be between $106 and $238 billion annually, or between 7 and 17 percent of all personal health care expenditures (Vernon, Trujillo, Rosenbaum, and DeBuono, 2007). Low literacy has been linked to higher hospitalization rates and less frequent use of preventive services; both of these are associated with higher health care costs. The costs are not just monetary; however; low health literacy skills often lead to poor health consequences. Patients with low literacy are 1.5 to 3 times more likely to experience a poor outcome, as determined by morbidity measures, intermediate disease markers, health resource utilization, and general health status (DeWalt et al., 2004).

Elderly individuals with lower health literacy comprehension are more likely to have poorer mental and physical health. Inadequate health literacy in this population has also been linked to higher risk-adjusted rates of cardiovascular death and an increased risk of hospital admission as well (Baker et al., 2002; Baker, Parker, and Williams, 1998; Baker et al., 2007). Besides poor health outcomes, low literacy affects compliance and self-care capability. Numerous examples in the medical literature outline the negative effects of inadequate literacy. Low levels of the understanding of chronic diseases, such as diabetes and hypertension, have been linked to low literacy. In one study, 94 percent of patients with diabetes and adequate functional health literacy could identify the symptoms of hypoglycemia, compared to only 50 percent of patients with inadequate literacy (Williams, Baker, Parker, and Nurss, 1998). Findings such as these warrant attention, since individuals’ misunderstanding or ignoring of early disease signs can result in delayed care, with the consequences of poorer health outcomes and increased costs.

Treatment can also be adversely affected. Among asthma patients, inadequate literacy has been strongly correlated with improper metered-dose inhaler utilization (Williams, Baker, Honig, Lee, and Nowlan, 1998).
Patients with low literacy are often unable to understand prescription drug warning labels as well (Davis, Wolf, and Bass, 2006). Preventive care is another area that can be adversely affected by low literacy levels. In Louisiana, a study of low-income women showed that 39 percent of those with a third-grade reading level did not know what a mammogram was for, as compared to only 12 percent of women with a reading level at or above the ninth grade level (Davis et al., 1996).

Inadequate literacy can produce negative effects at all levels of encounters in the patient-care process. With an increasing emphasis on patient-centered care, individuals with inadequate literacy levels will face increasing challenges. As the adverse consequences of low literacy with regard to health status become better known, the health care community is responding. A relatively easy and cost-effective response is to simplify print materials for patients (Lee, 1999; Wilson, 2000). Tailored educational approaches have also been found to help patients to learn and remember self-management skills in asthma treatment, and to improve outcomes for diabetes management (Paasche-Orlow et al., 2005; Rothman et al., 2004).

EMPOWERING PATRONS

A distraught mother comes to the circulation desk at a small, rural public library in New England. She is checking out books on autism; in fact, it looks like she has most of the books in the collection piled on the counter. She tells the clerk at the desk that she is trying to find a cure for her son’s condition; she will do anything to help him. A few weeks later she returns, and optimistically reports that she will no longer need the books. She received an invitation to attend a weekend-long seminar in Utah, where a new cure for autism is being introduced. It is a relatively new therapy, but so far, it looks like it has a 100 percent success rate. The seminar will cost $25,000, all expenses included. If she takes out a second mortgage, she should be able to swing it. She is worried, though, and before she borrows the money, she would like to know a little more about the new therapy.

The circulation clerk refers her to the reference librarian. When the mother sits down at the reference desk, she explains her quandary. When the librarian asks for more information, the mother hands her the
solicitation she received in the mail. The librarian then goes online to the National Library of Medicine’s PubMed website. She explains a bit about the MEDLINE resource and the necessity for using authoritative health information sources, and performs a search on the reported therapy. When she finds no results, she tries finding synonyms, and performs more searches using a wider variety of keywords. She explains that if this therapy was effective, it is highly likely there would be some reports in the medical literature. The mother considers carefully, thanks the librarian, and says rather forlornly, “I guess I won’t be making that trip.” In the years that followed, it became clear that the solicitation was nothing more than blatant and unethical false advertising. The encounter between the reference librarian and the mother provided the necessary information to save not only money, but time, effort, and inestimable emotional duress.

**Role of Librarians**

A fundamental component of improving health literacy is the transmission of health information (Nutbeam, 2000). Thus, librarians have a central role to play in addressing this social challenge. No matter the type of setting where a patron may be seeking health information, the librarian’s role is to make easily and readily understood information available (Martin and Wathen, 2008). Public libraries have been identified as logical partners in promoting health literacy efforts. Not only do public libraries provide free access and ensure confidentiality, they are also located in almost every neighborhood, and are generally well connected to other community resources. In 2009, approximately 28 million patrons used public library computers for locating information on a variety of health issues, such as specific diseases and medical conditions, medical procedures, diet and nutrition, and finding doctors and health support groups (Becker et al., 2010).

The 2014 Digital Inclusion Survey reports that 58 percent of public libraries help patrons find health information online, close to 60 percent help patrons find health insurance resources, and 48 percent help patrons understand specific health topics (Bertot et al., 2014). At the Libraries for the Future Building Partnerships conference, public libraries were
characterized as gateways to electronic access for the underserved. At that same conference, keynote speaker and literacy expert Rudd (2009) stated: “Libraries are the only public institution that says to its users: ‘we trust you.’ The importance of that philosophy in promoting health literacy—particularly among the underserved—cannot be underestimated.”

Organizations such as the American Library Association (ALA), the Public Library Association (PLA), and the Medical Library Association (MLA) also recognize the potential role librarians can play and are involved in efforts to promote health literacy (American Library Association, 2009; Deutsch, 2017; Hogan-Smith, 2004). The PLA used the opportunity of National Public Health Week in April 2017 to highlight public libraries’ work in advancing health and health literacy. The Health Information Literacy Research Project, an undertaking by the MLA, and funded by the National Library of Medicine, studied the health science librarian’s role as health literacy educator (Shipman and Funk, 2009). These advocacy and study efforts are appropriate steps and indicate recognition in both the medical and public library fields of the importance of engaging in health literacy efforts, and the need for librarians to become involved.

Public libraries already support health literacy in a number of ways, including the provision of free access to the Internet, consumer health collections, native language resources, reference assistance, and training for patrons and community members on how to find authoritative, high-quality health information. Organizations across the country are building coalitions and engaging in outreach activities to improve health literacy in their communities, since community-based educational outreach will be key to addressing this important issue (Pomerantz, Muhammad, Downey, and Kind, 2010; Nutbeam, 2008). Partnerships provide forums for reaching new and larger audiences, sharing resources, creating new tools, expanding services, and increasing funding opportunities (Libraries for the Future, 2009). Given the complexity of issues surrounding health literacy, these efforts will require collaboration not only across disciplines but across institutions as well. It is clear that a national, integrated effort is necessary to determine what strategies and approaches work for communicating health information to patients, no matter what their educational level, reading ability, culture, or language is (Baker, 1999).
Tools

Two federal agencies, the Agency for Healthcare Research and Quality and the Centers for Disease Control and Prevention (CDC), have extensive resources for promoting health literacy. The health literacy sections on both their websites provide information, tools, and links on research, practice, and evaluation. The CDC site also has a section on libraries and health literacy, a list of health literacy activities by state, and provides a weekly health literacy e-mail update. The National Library of Medicine’s (NLM) consumer health site, MedlinePlus, also has numerous resources on the topic.

ACRONYMS IN THE HEALTH FIELD

As with most professions and specialties, the health care field is rife with acronyms, a veritable alphabet soup. Table 1.1 includes a sample of some of the agencies and organizations involved in health information and their accompanying abbreviations. It is by no means an exhaustive compilation, but includes organizations that have been referred to in this volume and those that might be referred to by library patrons, or encountered during reference transactions in the public library setting.

TABLE 1.1
Acronyms related to health agencies

<table>
<thead>
<tr>
<th>ACRONYM</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACA</td>
<td>Affordable Care Act (shortened from Patient Protection and Affordable Care Act)</td>
</tr>
<tr>
<td>AHIP</td>
<td>Academy of Health Information Professionals (MLA)</td>
</tr>
<tr>
<td>AHIP</td>
<td>America’s Health Insurance Plans</td>
</tr>
<tr>
<td>AHRQ</td>
<td>Agency for Healthcare Research and Quality</td>
</tr>
<tr>
<td>AMA</td>
<td>American Medical Association</td>
</tr>
<tr>
<td>AMIA</td>
<td>American Medical Informatics Association</td>
</tr>
<tr>
<td>CAPHIS</td>
<td>Consumer and Patient Health Information Section (MLA)</td>
</tr>
</tbody>
</table>

(cont.)
TABLE 1.1  Acronyms related to health agencies (cont.)

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare &amp; Medicaid Services (previously known as Health Care Financing Administration)</td>
</tr>
<tr>
<td>DHS</td>
<td>Department of Homeland Security</td>
</tr>
<tr>
<td>DHHS</td>
<td>Department of Health and Human Services</td>
</tr>
<tr>
<td>DIMRC</td>
<td>Disaster Information Management Research Center (NLM)</td>
</tr>
<tr>
<td>FEMA</td>
<td>Federal Emergency Management Agency</td>
</tr>
<tr>
<td>IMLS</td>
<td>Institute for Museum and Library Services</td>
</tr>
<tr>
<td>IOM</td>
<td>Institute of Medicine (now National Academy of Medicine)</td>
</tr>
<tr>
<td>MLA</td>
<td>Medical Library Association</td>
</tr>
<tr>
<td>NACCHO</td>
<td>National Association of County and City Health Officials</td>
</tr>
<tr>
<td>NAM</td>
<td>National Academy of Medicine (formerly Institute of Medicine)</td>
</tr>
<tr>
<td>NCCIH</td>
<td>National Center for Complementary and Integrative Health (NIH)</td>
</tr>
<tr>
<td>NCHS</td>
<td>National Center for Health Statistics</td>
</tr>
<tr>
<td>NHIS</td>
<td>National Health Interview Survey</td>
</tr>
<tr>
<td>NIH</td>
<td>National Institutes of Health (for list of Institutes and Centers of the National Institutes of Health, see nih.gov)</td>
</tr>
<tr>
<td>NLM</td>
<td>National Library of Medicine</td>
</tr>
<tr>
<td>NN/LM</td>
<td>National Networks of Libraries of Medicine</td>
</tr>
<tr>
<td>ONC</td>
<td>Office of the National Coordinator for Health Information Technology</td>
</tr>
<tr>
<td>PHS</td>
<td>Public Health Service</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>

In a Nutshell

Since public libraries missions’ have long been intertwined with literacy promotion, it makes sense for public librarians to become involved in collaborative efforts to improve health literacy. In the words of one health literacy expert, “Improving health literacy in a population involves more than the transmission of health information, although that remains a fundamental task. Helping people to develop confidence to act on that knowledge and the ability to work with and support others will best be achieved.
through more personal forms of communication, and through community based educational outreach” (Nutbeam, 2008, 2077). Public libraries are the perfect setting for these empowering interactions to take place.

Besides literacy activities and initiatives, there are countless ways that public libraries are addressing local health challenges. The chapters that follow will address specific aspects of public libraries with regard to individual and community health promotion and efforts. Chapter 2 discusses the role of public libraries and consumer health from a historic perspective. Chapter 3 more specifically addresses health information provision in public libraries and highlights appropriate, trustworthy resources. Chapter 4 describes health programming in the library and offers some examples. Chapter 5 explores how the public library can reach out and engage with the broader community around health initiatives. Chapter 6 talks about future organizational opportunities for public libraries in the arena of community health and resilience. Chapter 7 addresses ethical and cultural sensitivity and discusses opportunities for incorporating and sustaining health initiatives through training and capacity-building.

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Introduction


INDEX

A
access
to health information, 33–36
to health information as individual right, 19
to health information via Internet, 20
library health information provision, 50
acronyms, 9–10
advertising, 67
See also promotion
Affordable Care Act, 107, 118
age, 20
Agency for Healthcare Research and Quality, 9
agreements, 78
ALA
See American Library Association
Albrecht, Steve, 119
American Association of the Deaf & Blind, 106
American Heart Month, 68–71
American Hospital Association, 17–18
American Institute for Conservation of Historic and Artistic Works (AIC), 106
American Library Association (ALA)
bicycling webinar, 88
Committee on Work with Foreign Born, 118
disaster planning tools, 106
on evaluation of resources, 37
Guidelines for Library Services for People with Mental Illnesses, 83
on opioid problem, 119
on role of librarians in health literacy, 8
RUSA guidelines for health information, 35–36
on use of public libraries, 16–17
American Red Cross, 81, 106
Ancker, Jessica S., 21
apps, 44–45
Arbuthnott, Alexis E., 46
Arnott Smith, Catherine, 47–48
ASCLA (Association of Specialized and Cooperative Library Agencies), 83
assessment
community health assessment, 89–90
of Have a Healthy Heart Month program, 71
of health promotion activities, 67–68
Association of Specialized and Cooperative Library Agencies (ASCLA), 83
asthma, 5–6
Aurora, Colorado, 105

B
Baker, David W., 5, 8
Baltimore, Maryland, 59, 105
Barbash, Fred, 21
Bascom, Elva L., 25
baseline data, 68
Bass, Pat F., 6
Bateman, Patti, 105
Becker, Samantha, 7, 21
Berry III, John N., 105
Bertot, John Carlo, 7, 53
Better Brothers, 79
Bibel, Barbara, 115, 116
“Big Rigs” program, 84
“Bikes and Libraries: Pedaling toward Innovative Outreach, Health and Sustainability” webinar (ALA), 88
Bloom, Suzanne, 63
book display, 70
Boston Public Library, 16
Boston Women’s Health Collective, 17
Brody, Erica R., 39–40
Brown, Jerry, 21–22
businesses, local, 87–88

C
California, 21–23
California Pacific Medical Center, 25–26
Canada, 43
cancer support groups, 79
CAPHIS
See Consumer and Patient Health Information Section
caregivers, 42–43
Carolina Health Assessment Research Tool (CHART), 61
Case Western Reserve University’s School of Library Science, 25
Castillo, Mariano, 104
Centers for Disease Control and Prevention (CDC)
on community health assessment, 89
disaster preparedness and response resources, 102
disease outbreaks/public health notifications, 95–96
Ebola outbreak and, 97, 98
health data resources of, 90
on obesity, 62
on public health, 78
as recommended source for general health information, 39–40
tools for health literacy, 9
for up-to-date health information, 44
website for current health information, 39
Centre for Literacy, 3
CHA (community health assessment), 89–90
Charbonneau, Deborah H., 49
CHART (Carolina Health Assessment Research Tool), 61
checklist, 41
CHI
See consumer health information
children
health promotion resources for health programming, 54–56
Internet sources for parents/caregivers, 42–43
physically active storytime activities, 62–63
whooping cough at storytime, 75–76
Children’s Hospital of Philadelphia (CHOP), 93–94
Children’s Museum of Manhattan (CMOM), 54–55
Chiochios, Maria E., 105
CHIPS (Consumer Health Information Program and Services), 26
CHIS (Consumer Health Information Service), 50
CHIS (consumer health information specialization), 112–113
CHOP (Children’s Hospital of Philadelphia), 93–94
Christie, Chris, 97, 98
CHSI (Community Health Status Indicators), 90
Cincinnati Public Library, 25
classification, of health information, 47
Clemmons, Nakia S., 21
Clifton, Shari, 112
cclimate change, 102
clubs, local, 87
CMOM (Children’s Museum of Manhattan), 54–55
collaboration
future collaboration by public libraries, 109
organizational cooperation, 93–94
for provision of health information, 24–25
public libraries as research incubators, 108
See also cooperation; partners/collaborators
collection, 37–39
colleges, partnership with, 86
The Common Sense Book of Baby and Child Care (Spock), 17

Community
- Community Health & Literacy Center, 93–94
- disaster preparedness and response, 100–106
- health data, for guiding health programming, 64
- health information resources, 88–91
- health programming in public libraries, examples of, 59–62
- partners/collaborators, identification of, 76–82, 84–88
- public libraries as anchor institutions in, 75
- public libraries as program providers for, 53
- use of public libraries, 16–17

Community clubs, 87
Community forums, 76–77
Community Health & Literacy Center, 93–94
Community health assessment (CHA), 89–90
Community Health Information Network, Massachusetts, 25
Community health information resources, 88–91
Community Health Status Indicators (CHSI), 90
Community organizations, 78
Community-based education outreach, 8, 10–11
Computing skills, 21
Confidentiality
- See privacy

Consumer and Patient Health Information Section (CAPHIS)
- consumer health information policy statement, 19–20
- first policy statement of, 18
- list of health websites, 38
Consumer health, history of, 17–19
Consumer health information centers, 25–27
Consumer health information (CHI)
- CAPHIS policy statement on, 19–20
- provision of by public libraries, 24–28
- public libraries and, 19–21
- statewide approach to, 27–28

Consumer Health Information Program and Services (CHIPS), 26
Consumer Health Information Service (CHIS), 50
Consumer health information specialization (CHIS), 112–113

Cooperation
- cooperative extension agencies, 86
- cooperative extension websites, 43
- organizational, 93–94

See also collaboration; partners/collaborators

Cosgrove, Tracey L., 25–26
Costs, of low health literacy, 5–6

County Health Rankings and Roadmaps (Johnson), 91
Count of Los Angeles Public Library, 26
Crandall Public Library, Glen Falls, New York, 26–27
Credibility markers, 49
Criminal justice system, 85
C.S. Mott Children’s Hospital, 22
Cultural competency, 116

Cultural Diversity in Health and Illness (Spector), 117
Cultural sensitivity, 116–117
Cuomo, Andrew, 97–98

D
Dahl, Linda, 117
Danforth, Liz, 63
D’Avanzo, Carolyn E., 117
Davis, Catherine L., 63
Davis, Jackie, 67
Davis, Terry C., 6
DeBuono, Barbara, 5
DeBuono, Barbara, 5

dedicated health information centers, 25–27
Delaware, 27–28, 112
Delaware Academy of Medicine, 27–28
Delaware Division of Libraries, 27–28
Dempsey, Kathy, 67
Deutsch, Laurence, 8
DeWalt, Darren A., 5
Diabetes, 5
Dickenson, Nancy, 5
Dickerson, Lon, 103
digital divide, 20
Digital Inclusion Survey (Bertot et al.), 7
Disaster Distress Helpline, 106
Disaster Information Management Resource Center (DIMRC)
  definition of “disaster,” 100
  disaster planning tools, 106
  disaster preparedness and response resources of, 101
  opioid problem, resources for, 119
disaster preparedness and response
  disaster plans, 106
  human-made disasters, 104–105
  natural disasters, 102–104
  overview of, 100–102
disclaimers, 49–50
disease outbreaks
  Ebola risks from West Africa, 96–99
  public libraries’ role in information dissemination, 94–96, 99–100
diseases, 5
Disneyland, measles outbreak at, 21–23
displaced persons, 105
displays, 59, 70
Ditzion, Sidney H., 15–16
diversity, 66–67
Dixon, Jessica, 21–23
Doctors without Borders (MSF), 96–99
Downey, Stacey, 8
Dugan, Maeve, 20, 21
Duke University, 113

E
EatPlayGrow, 54–55
Ebola, 96–100
education
  about mental illness, 82–84
  in disaster preparedness, 101
  health information training, 111–113
  patient health information education, 19–20
Edwards, Christine, 46
eHealth literacy, 117
elderly individuals, 5
electronic discussion lists, 44
embedded librarians, 27–28
emergency medical services personnel, 84–85
ethics, 115–116
evaluation
  See assessment
Evidence Based Library and Information Practice (EBLIP) (journal), 114–115
evidence-based practice (EBP), 113–115
exercise, 62–63

F
Facebook, 67, 70
faith-based organizations, 87
Farlow, John W., 24
Farmville Public Library, Farmville, NC, 59–62
federal agencies
  disease outbreaks/public health notifications, 95–96
  health data resources from, 90–91
Federal Emergency Management Agency (FEMA), 101–102, 103
federal government, 101
Ferguson, Missouri, 104–105
fire department, 84–85
Fitbit
  Farmville Public Library’s health program, 60
  in Have a Healthy Heart Month program, 69, 70
  personal information-seeking with, 118
5K and fun run event, 61
Flaherty, Mary Grace
  on Consumer Health Information Center, 26–27
  on embedded health librarians, 27, 28
  on ethics of health information provision, 115–116
Farmville Public Library and, 60, 61
  on health-related reference questions, 35
  on Lyme Disease treatments, 46
  on print health-reference materials, 38
  on public libraries for access to health information, 21
Ford, Anne, 118–119
Ford, D., 104
Fox, Susannah, 20
Funk, Carla J., 8
future opportunities
  disaster preparedness and response, 100–106
disease outbreaks/public health notifications, 94–96, 99–100
Ebola risks from West Africa, 96–99
organizational cooperation, 93–94
patron assistance, 106–107
public libraries as research incubators, 107–108
summary about, 109

G
gaiman, neil, 1
gartenfeld, ellen, 25, 49
“get walking at your library” program, 60
gillaspy, mary l.
on consumer health movement, 17
on dedicated health information centers, 26
on shift to patient-centered care, 19
good research questions (grq), 36–37
Goodchild, Eleanor Y., 26
governmental agencies, 85
grants, 28
Greenberg, Elizabeth, 4
Grier, Persko L., Jr., 27
Guidelines for Library Services for People with Mental Illnesses (American Library Association), 83

H
hand washing, 95, 96
Have a Healthy Heart Month, 68–71
Hawkins, E. R., 25
Head Start, 81
Health Affairs (journal), 107–108
health agencies, acronyms related to, 9–10
health care community, library relationships with, 76
health care organizations, partnership with, 79–80
health check tools, 56
Health Happens in Libraries, 54
health information
community health information resources, 88–91
consumer health information relationships, 18
provision of by public libraries, 24–28
Health Information Literacy Research Project, 8
health information provision
apps, limitations of, 45
cultural sensitivity, 116–117
current information, 43–44
ethics and, 115–116
evidence-based practice, 113–115
historic perspective, 33–34
importance of, 50
librarian training for, 111–113
misinformation/classification, 46–47
present day, 34–36
privacy/liability, 48–50
recommended Internet sources for parents/caregivers, 42–43
recommended sources for general health information on Internet, 39–40
research questions, 36–37
resources, evaluation of, 37–39, 41–42
triad of, 114
vaccination, neutrality about, 47–48
health literacy
acronyms in health field, 9–10
background on, 3–5
consumer health information relationships, 18
definition of, 2–3
empowering patrons, 6–7
librarians, role of, 7–8
library literacy programming, 2
library mission of improving, 10–11
library support/services, 1–2
low health literacy, costs of, 5–6
tools for, 9
health programming
evaluation of, 67–68
examples of, 59, 62
Farmville Public Library, Farmville, NC, 59–62
ideas/objectives for, 64–66
increase in programs, 53–54
National Health Observances, program using, 68–71
physically active storytime activities, 62–63
program opportunities across diverse groups, 66–67
health programming (cont.)
  promotion/marketing, 67
  resources for, 54–58
  summary about, 71
health promotion resources, 54–58
health screenings, 61
healthfinder.gov, 39, 66
Healthy Library Initiative, 94
Healthy People 2010 (Institute of Medicine), 2
HealthyChildren.org, 40
heart disease, 68–71
Hesketh, Kathryn R., 63
Hogan-Smith, Catherine, 8
homeless shelters, 81
Honig, Eric G., 5
Horrell, Lindsey N., 108
Horrrigan, John B., 21
hospitalization, 5
Hu, Linden T., 46
Huber, Jeffrey T.
  on consumer health movement, 17
  on dedicated health information centers, 26
  on shift to patient-centered care, 19
human-made disasters, 104–105
Hundal, Savreen, 47–48
Hurricane Katrina, 103
Hurricane Sandy, 103

I
  ideas, for health programs, 64
  imedicalapps.com, 44
  immigration departments, 81
  income, 20
  insanity, 99
  Institute of Medicine, 2, 18–19
  Institute of Museum and Library Services (IMLS)
    on health programming attendance, 53
    on library visits per capita, 16–17
    on reference transactions, 34
  Internet, access to health information via, 20–21
  Internet resources
    eHealth literacy, 117
    evaluation of, 38–39
    for health programming in public libraries, 54–58
  misinformation/classification, 46–47
  recommended sources for general health information, 39–40
  recommended sources for parents/caregivers, 42–43
  internships, 112

J
  Japan, 103
  Jensen, Eric, 63
  Jeon, Eunjoo, 45
  Jerath, Maya R., 115–116
  Jin, Ying, 4
  Joint Commission on the Accreditation of Healthcare Organizations, 18
  Jones, Dee, 63
  Journal of Consumer Health on the Internet, 44
  juvenile detention centers, 85

K
  Kaplan, Karen, 21, 38, 45
  Kaplan, Samantha J., 47–48, 115–116
  Keselman, Alla, 47–48
  Kim, Hyun-Young, 45
  Kind, Terry, 8
  Kindig, David A., 19
  Koh, Howard K., 3
  Kortum, Philip, 46
  Kutner, Mark, 4

L
  Lee, Paul P., 6
  LEP (limited English proficiency), 116–117
  Let’s Move program, 55–56
  Lewis, Stephen P., 46
  liability, 48–50
  librarians
    cultural sensitivity of, 116–117
    ethics of health information provision, 115–116
    evaluation of health information resources, 41–42
    evidence-based practice, 113–115
    as health information interlocutor, 120
    health information reference transactions, 35–36
    health information training, 111–113
    health programs/opportunities for, 62
natural disasters and, 103
cnumber of patrons assisted by, 17
 patrons, empowering, 6–7
research questions, 36–37
role in health literacy, 3, 7–8
libraries
California Senate Bill Number 277 and, 22–23
commitment to public health, 91
health literacy, mission of improving, 10–11
health literacy, role of librarians in, 7–8
literacy programming, 2
privacy/liability and, 48–50
support/services of, 1–2
vaccination issue, 47–48
See also public libraries
Libraries for the Future Building
Partnerships conference, 7–8
Library Bill of Rights (American Library Association), 83
library consortia, 112
Library Journal, 24, 49
Library of Congress, 106
library organizations, 112
Library Services and Construction Act, 25
lifelong learning, 2
limited English proficiency (LEP), 116–117
literacy
eHealth literacy, 117
kits for newborns, 59
library support/services for, 1–2
types of, 2
See also health literacy
local businesses, partnership with, 87–88
local clubs, partnership with, 87
local health departments
CHAs, performance of, 89–90
disease outbreaks/public health notifications, 95
partnerships with, 78–79
local service organizations, 87
Longo, Jean Marie, 112
Los Angeles County Carson Regional Public Library, 26
Los Angeles County Harbor General Hospital Regional Medical Library, 26
Louisiana, 6
Luther, Michael E., 21
Lyme disease, 46
M
Mahdy, Jasmine C., 46
Malachowski, Margot, 53
Malone, Tara, 112
Marcus, Erin N., 4
marketing
See promotion
Martin, Carolyn, 119
Martin, H. J., 7
McCarthy, Jenny, 47
McCaul, Michael, 97
McCloskey, Donna J., 116
McCook, Kathleen de la Peña, 16, 118
McPherson library branch, Philadelphia, 118–119
measles, 21–23
medical libraries, 24, 25, 108
Medical Library Association (MLA)
CAPHIS, first policy statement of, 18
CAPHIS list of health websites, 38
Consumer and Patient Health Information Section of, 40
c consumer health information specialization, 112–113
disaster information specialization offered by, 101
e-mail discussion list, 44
resources for evaluation of health information, 42
on role of librarians in health literacy, 8
“What Did My Doctor Say?” tool, 42
Medical Subject Headings (MeSH), 20
MEDLINE, 33–34
MedlinePlus
access to medical research with, 113
disease outbreaks/public health notifications, 95
“Find a Library” feature of, 26
function of, 34
on health challenges of ethnic/racial groups, 67
health literacy resources, 9
as recommended source, 39, 42
as resource for health programming, 56
MedlinePlus (cont.)
resources for evaluation of health information, 42
as starting point for health research, 39
as trusted resource, 46
for up-to-date health information, 44
Mended Hearts, 79
mental illness, 82–84
MeSH (Medical Subject Headings), 20
Michal, Natalie J., 46
Miller, David, 59–62
Min, Yul Ha, 45
Minnesota Department of Health, 89
misinformation
about disease outbreaks, 94–95
health information provision in public libraries, 46–47
vaccination issue, neutrality of library, 47–48
Miura, Taro, 103
MLA
See Medical Library Association
Monaghan, Elizabeth Michaelson, 34–35
Morgan, Anna U., 107–108
Mosby’s Pocket Guide to Cultural Health Assessment (D’Avanzo), 117
movie night, 59
Muhammad, Abdul-Ali, 8
Murray, Susan, 26, 27
MyHealthapps.net, 40

N
National Association of County and City Health Officials (NACCHO), 78–79, 89
National Center for Complementary and Integrative Health, 42
National Center for Health Statistics (NCHS), 90
National Center for Post-Traumatic Stress Disorder, 106
National Center for Rural Health Works, 89
National Health Council, 25
National Health Observances (NHOs)
example of health programming using, 68–71
sample of, 66
as starting point for health programs, 65
National Institute on Aging, 40
National Institutes of Health Library, 90
National Institutes of Health (NIH), 54–55
National Institutes of Mental Health, 82
National Library of Medicine (NLM)
on consumer health information, 20
disaster preparedness and response resources, 101
disease outbreaks/public health notifications, 95
health promotion resources from, 56–57
MEDLINE, introduction of, 33–34
MedlinePlus, 9, 113
National Network of Libraries of Medicine, 57–58
PubMed, 7, 34
National Network of Libraries of Medicine (NNLM)
guidelines for health information, 36
membership in, 57–58
as recommended source for general health information, 40
National Park Service, 85
National Standards for Culturally and Linguistically Appropriate Services, 116
natural disasters, 102–104
NCHS (National Center for Health Statistics), 90
NEDCC (Northeast Document Conservation Center), 106
New Hanover County Public Library, North Carolina, 28
New York, flooding in, 105
New York Public Library, 67
NHOs
See National Health Observances
Nielsen-Bohlman, Lynn, 19
NIH (National Institutes of Health), 54–55
NIH MedlinePlus (journal), 44
NLM
See National Library of Medicine
NNLM
See National Network of Libraries of Medicine
Norman, Cameron D., 117
North Carolina School of Information and Library Science, 101
Northeast Document Conservation Center (NEDCC), 106
numeracy skills, 3–4
Nurss, Joann R., 5
Nutbeam, Don
  on community-based education outreach, 8, 10–11
  on transmission of health information, 7
O
Obama, Michelle, 55–56
obesity, 62–63
objectives
  evaluation of health programs and, 67–68
  for Have a Healthy Heart Month, 68–69
  for health programs, 64–66
Office of Minority Health, 116
Offit, Paul, 47
Oklahoma, 112
online resources
  See Internet resources
opioid addiction, 118–119
organizational cooperation, 93–94
organizations
  library relationships with organization leaders, 77
  partnerships for community-based education outreach, 8
  public health departments, 78–79
Our Bodies, Ourselves (Boston Women’s Health Collective), 17
outcomes, 68
outreach
  community health information resources, 88–91
  library commitment to public health, 91
  partners/collaborators for, identification of, 76–82, 84–88
  to patrons with mental illness, 82–84
  public libraries as anchor institutions in community, 75
  summary about, 91–92
  whooping cough at storytime, 75–76
Owens, Donna Marie, 59
P
Paasche-Orlow, Michael K, 6
PAL (Police Athletic League), 85
Palm Beach County Library System, 50
Panzer, Allison M., 19
parents, 42–43, 63
Park, Hyeoun-Ae, 45
Parker, Emily D., 62
Parker, Ruth M., 2, 5
parks and recreation departments, 85
Partners in Information Access for the Public Health Workforce, 90
partners/collaborators
  colleges/universities, 86
  for community-based education outreach, 8
  cooperative extension agencies, 86
  faith-based organizations, 87
  fire, police, emergency medical services personnel, 84–85
  governmental agencies, 85
  health care organizations, 79–80
  local businesses, 87–88
  local clubs, 87
  local health department partnership relations, 79
  local service organizations, 87
  other library organizations, 86
  public health departments, 78–79
  schools, 85–86
  senior centers, 80
  social service agencies, 80–82
  support groups, 80
  working relationships, establishment of, 76–78
patient education, 19–20
patient-centered care, 19
patient-provider interaction, 18
Patient’s Bill of Rights (American Hospital Association), 17–18
patrons
  cultural sensitivity in health information provision, 116–117
  empowering, 6–7
  ethics of health information provision, 115–116
  guidelines for health information reference transactions, 35–36
  with mental illness, 82–84
  patron assistance by public libraries, 106–107

alastore.alapro
patrons (cont.)
  privacy/liability, 48–50
  promotion of library health program, 67
Patterson, R. S., 24
Paulsen, Christine, 4
pedometers
  in Have a Healthy Heart Month program, 70
  as prize, 64
  for public library program, 60
Pew Internet and American Life Project, 17
Pew Research Center
  health data resources of, 91
  on health information at public libraries, 21
  on Internet use for health information, 20
PHAB (Public Health Accreditation Board), 89
Philadelphia, Pennsylvania, 93–94
Phill, Jo, 112
physically active storytime activities, 62–63
PIDCPhila, 94
Pifalo, Victoria, 25
Pima County Public Library, Arizona, 53
PLA (Public Library Association), 8, 101
Planetree Health Resource Center, 25–26
planning stage, 68
poison control centers, 81
Police Athletic League (PAL), 85
police department, 84–85
Pomerantz, Karyn L., 8
press release, 67, 70
Pressley, Tara, 82–84
preventive care, 6
print reference collections, 38
prisons, 85
privacy
  ethics of health information provision, 115–116
  health information provision in public libraries, 48–50
  health information reference transactions and, 35, 36
  patron assistance with health information and, 107
  website about protection of health information, 40
programming
  See health programming
promotion
  of Have a Healthy Heart Month program, 69–70
  for health programming in public libraries, 67
  See also outreach
public health, 78
Public Health Accreditation Board (PHAB), 89
public health departments, 78–79
public health notifications
  Ebola risks from West Africa, 96–99
  by library about disease outbreaks, 94–96, 99–100
Public Health Service, 25
public libraries
  disaster preparedness and response, 100–106
  disease outbreaks/public health notifications and, 94–96, 99–100
  as essential community resources, 120
  health literacy efforts, 10–11
  health literacy, role of librarians in, 7–8
  health programming in, 53–54
  patron assistance by, 106–107
  as research incubators, 107–108
  See also future opportunities; health information provision; health programming
public libraries/consumer health
  consumer health, history of, 17–19
  consumer health information, 19–21
  health information provision and, 24–28
  measles at Disneyland/Senate Bill Number 277, 21–23
  public libraries in U.S., 15–17
  summary about, 28
Public Library Association (PLA), 8, 101
PubMed, 7, 34
Purcell, Kristen, 21
Q
  “quantified self;” 117–118
quarantine, 96–99
R
Rainie, Lee, 20, 21
Ratzan, S. C., 2
"Read & Reach: A Resource Promoting Physical Activity in Children's Storytimes" website, 63
Ready Kids, 102
Ready.gov, 101–102
recovery, 82–84
Reference and User Services Association (RUSA), 35–36
reference transactions, 34–36
refugees, 105
relationships
See partners/collaborators
research questions, 36–37
resources
community health information resources, 88–91
for disaster plans, 106
disaster preparedness and response resources, 101–102
evaluation of, 37–39, 41–42
evidence-based practice, 113–115
for general health information on Internet, 39–40
for health programming in public libraries, 54–58
Internet sources for parents/caregivers, 42–43
Richards-Kortum, Rebecca, 46
Richman, Larry, 65
Robert Wood Johnson Foundation, 90–91
Roberts, Les
on Ebola outbreak, 96–99
on health-related reference questions, 35
on public libraries for access to health information, 21
Rose, Joel, 103
Rosenbaum, Sara, 5
Rosenfeld, Kat, 105
Rothman, Russell L., 6
Round Health, 44
Rubenstein, Ellen
on challenges of CHI provision, 28
on health information provision by libraries, 24, 111, 112
Rudd, Rima, 3, 8
rumor, 105
Rural Health Networks, 81
RUSA (Reference and User Services Association), 35–36
Russell, Katherine, 59
S
Sackett, David L., 113
Sanchez, Edgar, 46
schools, partnership with, 85–86
search, 36–37
security, 40
self-care, 18, 20
self-monitoring, 97–99
self-tracking tools, 117–118
Senate Bill Number 277, 21–23
senior centers, 80
Shaia, Kathryn L., 45
Shera, Jesse H., 15–16
Shipman, Jean P., 8
Simon, Darran, 119
Six-Means, Amy, 3
Skinner, Harvey A., 117
Slagle, A. D., 25
"SMART," 64–65
SMART Life Study, 108
"SMARTER," 65
social media, 67, 96
social service agencies, 80–82
Sorensen, Kristine, 3
Spatz, Michele
accessibility of health information, 17
on ethics, 115, 116
on Planetree Health Resource Center, 25–26
Spector, Rachel E., 117
Spencer, Craig, 98
Spock, Benjamin, 17
Stafford Disaster Relief and Emergency Assistance Act, 103
state health departments, 90
state library agencies, 112
Stewart, Adam, 103
stigma, 82–84
storytime, 62–63, 75–76
Substance Abuse and Mental Health Services Administration, 82
support groups, 79
surveys, 71
Suzuki, Shiho, 103
Swan, Melanie, 117–118

T
Taveras, Elsie M., 63
technology, 117–118
terminology, 9–10
Thieriot, Angelica, 25–26
Timm, Donna F., 63
Tobey, John A., 24
Tominaga, Mana, 88
tools, for health literacy, 9
Tox Town, 56–57
tracking devices, 117–118
training, 88, 101
trans-institutionalism, 83
treatment, 5–6
Trujillo, Antonio, 5
Turnock, Bernard, 89
Twitter
library use of, 70
MedlinePlus and, 44
for promotion of library programs, 67

U
universities, partnership with, 86
University of Alberta Libraries, 114–115
University of Pennsylvania, 94
Urban Health Councils, 82
U.S. Bureau of Education, 16
U.S. Census Bureau, 90
U.S. Department of Health and Human Services
definition of health literacy, 2, 3
on health literacy factors, 4
Healthfinder.gov, 39
National Health Observances, 65, 66
National Standards for Culturally and Linguistically Appropriate Services, 116
on recovery from mental illness, 82
U.S. Department of Labor, 25
U.S. Food and Drug Administration, 44

V
vaccination
library neutrality about, 47–48
measles outbreak at Disneyland/Senate Bill Number 277, 21–23
whooping cough at storytime, 75–76
Van Aalst, Maarten K., 102
Vannier, Edouard, 46
Vartan, Starre, 107
Vernon, John, 5
veterans support networks, 81
Viral Hemorrhagic Fever (VHF) database, 99
Vnuk, Rebecca, 38

W
walking, 60–62, 64
Wathen, C. Nadine, 7
We Can! (Ways to Enhance Children’s Activity & Nutrition) program, 55
Weak, Emily, 88
website
of AHRQ/CDC, 9
CAPHIS list of health websites, 38
for promotion of library programs, 67
PubMed, 34
See also resources
weeding, 38
West Africa, Ebola outbreak, 96–99
“What Did My Doctor Say?” tool (MLA), 42
Wheaton Public Library, Wheaton, Maryland, 26
White, Mary, 36–37
whooping cough, 75–76
Williams, Mark V., 5
Wilson, Feleta L., 6
Wolf, Michael S., 6
Wood, M. Sandra, 38
Woodson, Diedra E., 63
World Economic Forum, 102
World Health Organization (WHO), 63, 97
Wormser, Gary P., 46

Y
Yemm, Graham, 65

Z
Zichur, Kathryn, 21