

The Jenny McCarthy Conundrum: Public Libraries, Popular Culture, and Health Misinformation

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Abstract

Throughout the United States, public libraries are important resources for all types of information and serve a variety of information needs. One of these areas is health information provision; in fact, public libraries were widely identified as institutions providing support for patrons with questions on the Affordable Care Act. Yet, not all public libraries are equipped to provide this type of support. Moreover, there seems to be an inherent tension between collecting popular literature that may provide dangerous misinformation with regard to health and access to high quality, authoritative resources. Collection development tools and policies aren't standardized across libraries, and often staff are not trained to provide health information. Researchers visited randomly selected public libraries in three eastern U.S. states and posing as a patron asked: do vaccines cause autism. Public library staff referred to print materials to answer the question in half of all visits; 69% of the time, the print resource did not provide a credible answer. The sometimes conflicting roles of popular literature provider and authoritative health information provider have implications for library practice, public health and provision of high quality health information in communities throughout the nation.

Background

Supporting a literate, educated populace has been identified as a core function of public libraries in the United States. This function has been approached in a variety of ways. For instance, the origins of small, mostly rural public libraries can be traced to the traveling library, "a collection of books lent to a community for general reading."¹ The primary purpose of the traveling library wasn't to provide access to reference information, but to provide moral and cultural support for far-flung communities.² The majority of materials lent were fiction, with very few nonfiction titles. These origins likely continue to influence how some libraries view their mission for information provision. Additionally, over half of all public libraries are managed by non-MLIS level directors.³ Thus, approaches to collection development and information provision vary, with little standardization.

Approximately one in five public library visits involves a reference transaction.⁴ Not much data is available that delineates specific subjects, but studies do report health information seeking and provision are taking place.^{5,6} Library users have stated they found valuable health information in public libraries that affected health care decisions.^{7,8} Thus, whether they choose to provide health information or not, public library staff will likely be addressing patrons' health queries. Research has shown, though, that not all public library staff are willing to provide health information and few are trained to evaluate medical information.^{9,10}

To determine a baseline for better understanding health information resource provision in public libraries, a series of unobtrusive reference visits were completed in 78 total libraries across three states (Upstate NY, Delaware and North Carolina) to randomly selected public libraries from 2010-2014. A researcher, posing as a patron, approached the library staff and asked for information on whether vaccines cause autism.

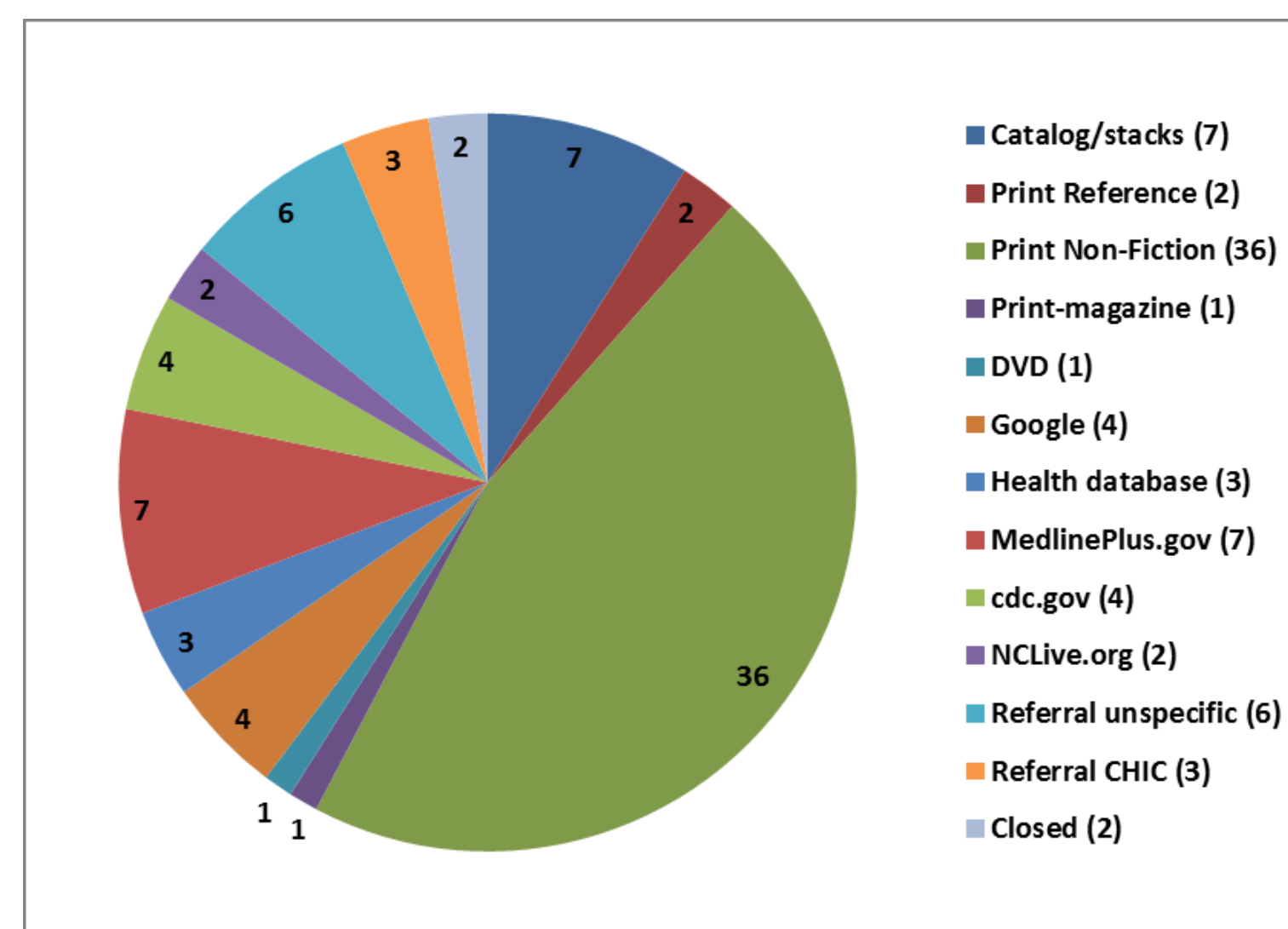


Figure 1 - First resource library staff provided during all visits



In all visits, each resource was examined to determine if it answered the question with timely, accurate, up-to-date information, in keeping with current medical literature.

Resource	Visits (n=78)	Answered question with auth. information?
Catalog/Stacks	7	No=7
Print Reference	2	No=2
Print Non-Fiction	36	No=25; Yes=11
Print Magazine	1	Yes=1
DVD	1	No=1
Google	4	No=4
Health database	3	Yes=3
MedlinePlus.gov	7	Yes=7
cdc.gov	4	Yes=4
NCLive.org	2	Yes=2
Referral not specific	6	No=6
Referral CHIC	3	Yes=3
Closed	2	No=2
Total	78	Answered=31 Didn't Answer=47

Table 1 – First resource provided in all visits and whether it answered the reference question

In half of all visits, staff referred to a print resource

- 69% of time, print resource did not answer the question

Eight visits across all states, one anti-vaccine book: *Evidence of Harm* (D. Kirby)

- 20% of all occasions where print was provided
- Reviewed in *New York Times Sunday Review of Books* (4/17/05)
- Received the "Investigative Reporters and Editors 2005 Award for Outstanding Investigative Reporting"
- Finalist for the New York Public Library Helen Bernstein Book Award for Excellence in Journalism
- From review in the *British Medical Journal*:

*"The only value of this woefully one sided account of the mercury and autism controversy is the insight it offers into the way that credulous journalists have contributed to the public nuisance and private distress caused by antivaccine campaigns."*¹¹

Other anti-vaccine books were provided

- According to one staff member when providing one of Jenny McCarthy's books: *"She knows a lot about this subject, she's pretty much the expert."*
- From the foreword to McCarthy's publication, *Mother warriors*, Jay Gordon, M.D. states: *"Vaccines can cause autism"* (2008, p. xiii, italics original).¹²

Table 2 - Print materials provided during visits and whether the resource answered the query

Print Resource	All Visits	Answered question with auth. information?
Bruni, M. (1998) <i>Topics in Down Syndrome</i>	1	No
Bock, K. (2007) <i>Healing the new childhood epidemics</i>	3	No
Buckley, J.A. (2010) <i>Healing our autistic children</i>	1	No
Good Housekeeping (1979) <i>Family Health & Med. Book</i>	1	No
Grandin, T. (1986) <i>Emergence, labeled autistic</i>	1	No
Grandin, T. (2005) <i>Animals in translation</i>	1	No
Grandin, T. (2013) <i>The autistic brain: Thinking across the spectrum</i>	2	Yes
Holmes, D.L. (1998) <i>Autism through the life span</i>	1	No
Kirby, D. (2005) <i>Evidence of harm</i>	8	No
Loehr, J. (2009) <i>The vaccine answer book</i>	1	Yes
Mayo Clinic (1990) <i>Family Health Book</i>	1	No
McCarthy, J. (2009) <i>Healing and preventing autism</i>	3	No
Miller, N. (2002) <i>Vaccines: are they really safe and effective</i>	1	No
OASIS (2001) <i>Guide to Asperger Syndrome</i>	1	No
Offit, P. (2008) <i>Autism's false prophets</i>	1	Yes
Offit, P. (2011) <i>Vaccines and Your Child</i>	2	Yes
Ozonoff, S. (2002) <i>Parent's guide to Asperger's syndrome and high functioning autism</i>	1	Yes
Park, A. (2008) <i>How safe are vaccines? Time</i> , 171(22).	1	Yes
Powers, M. (2000) <i>Children with autism: a parent's guide</i>	1	No
Robledo, S.J. (2005) <i>The autism book</i>	1	Yes
Romm, A.J. (2001) <i>Vaccinations: A thoughtful parent's guide</i>	1	No
Schreibman, L. (2009) <i>The science and fiction of autism</i>	1	Yes
Sears, R. (2010) <i>Autism book</i>	1	No
Volkmar, F.R. & Wiesner, L.A. (2009) <i>A practical guide to autism</i>	1	Yes
Wiseman (2006) <i>Could it be autism?</i>	1	No
Young, L. (2010) <i>Everything parent's guide to vaccines</i>	1	Yes
Total occurrences - Print that answered question	12	12
Total occurrences - Print that did not answer question	27	
Total Print	39	
Total Visits	78	

Implications for Practice

According to WorldCat (April 15, 2014), "non-credible" sources are widely held

- Over 1400 locations hold Kirby's book
- Combined, over 5000 locations hold McCarthy's 3 NY Times' best-selling publications
 - Holdings show the ubiquitous nature of the effect of the NY Times' bestseller lists
- Library books are collected and shared through consortia
 - if 1 member has an item with misinformation, it can reach many patrons via ILL

What can be done to guard against health misinformation?

- Federal and state training initiatives for public library staff, such as WebJunction's ongoing series: *Health Happens in Libraries*
- The regional National Network of Libraries of Medicine regularly offer webinars and courses on all kinds of topics related to health information and librarianship
- Readily available, free tools for providing authoritative, high quality consumer health information, such as: MedlinePlus.gov; cdc.gov; and state websites, e.g. in North Carolina: NCLive.org and NCHearthinfo.org
- Consideration given to where items are physically shelved
- Up-to-date and robust collection development policies and practices

Ongoing challenges

- Collection development tools and use of non-expert reviewers
- Improving and investigating methods for increasing knowledge of authoritative health information resources
- Ensuring that public library staff are aware of opportunities and have wherewithal to participate

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