

The Central Roles of Information in Health Justice, Part 2: Consumer Health Information Justice and the Connections between Health, Ability, and Literacy

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Introduction

This issue is the second of a pair of special issues of the *International Journal of Information, Diversity, and Inclusion* devoted to consumer health information behavior (CHIB). Papers in these two issues explore a range of interactions and institutions involved as people seek and use information related to issues of health. CHIB plays a major role in the health trajectories and health outcomes, encompassing information needs in conjunction with activities to access and use health information. The introductory paper to the previous special issue details the foundational concepts and goals of the two issues (St. Jean, Jindal, Liao, & Jaeger, 2019).

The heart of both of these special issues is the belief that information literacy and information professionals are essential parts of access to and understanding of the health information that is so vital to quality and length of life. Widespread disparities in access to health care and health information impact many populations worldwide. Information professionals and information institutions can play an important role in overcoming these disparities by providing access to resources, promoting health information literacy, and empowering people seeking health information.

The papers in this issue and its companion issue focus on topics of behavior central to achievement of health justice, such as information access, information needs, information provision, and health literacy, as well as CHIB itself. This special issue broadens the range of subjects being discussed to also include issues of disability. While usually treated as separate research spaces, information behavior in terms of health and disability are closely related; for a disabled person, consumer health information behavior is likely inextricably linked to information behavior related to their disability. In the overall context of information institutions, programs and resources used to provide information and meet information needs related to health will also be central to meeting information needs related to many disabilities.

The Current IJDI Special Issue

The goal of this second special issue, as well as the preceding companion issue, is to bring

together researchers who focus specifically on health justice and/or social justice within a health-related context. The central focus is on the various types of information-related factors and processes that are central to the achievement of health justice, such as the health information needs of disadvantaged and/or marginalized populations; their health information seeking and use practices; and the provision of health information to these populations. Submissions examining closely related issues, such as information access, health literacy, health communication, use/usability of consumer health information technology, patient experience, stigma, information poverty, information avoidance, etc. were also welcomed. The impetus for these twinned special issues was that much of the work in this space is currently scattered across multiple disciplines and many different journals within each of these disciplines. It is hoped that this special issue, along with its preceding companion issue, provides an opportunity for readers and researchers to come together in one space to learn about and share their work on this very important topic.

The three articles and three special section papers that comprise this second special issue explore intersections of health information and health justice in the contexts of insurance, online forums, and libraries. In fact, four of the six papers focus the myriad vibrant roles that libraries play in promoting social justice in terms of health and ability.

The first article, Emily Vardell's "Health Insurance Literacy and Health Disparities in the United States: A Literature Review," explores the literature on health insurance literacy, particularly focusing on the ways in which limited health literacy skills exacerbate health disparities. Vardell covers the important topics of health insurance awareness; health literacy and health insurance literacy measures; and the readability of health insurance materials. In conclusion, she builds on two health insurance literacy models [McCormack, Bann, Uhrig, Berkman, and Rudd's (2009) Conceptual Framework for Health Insurance Literacy and Paez et al.'s (2014) Health Insurance Literacy Conceptual Model], as well as two health insurance decision-making models [Klinkman's (1991) The Consumer Choice of Health Care Plan Framework and Sainfort and Booske's (1996) Conceptual Framework of Consumer Selection of Health Plans], to propose a model of her own, the Integrated Framework for Health Insurance Literacy. This framework is offered as a guide for future research studies exploring the connections between demographic factors on the one hand, and health coverage and health status on the other, particularly as mediated by an individual's health insurance literacy skills.

In the next article, Susan Rathbun-Grubb's "The Lived Experience of Work and Career among Individuals with Bipolar Disorder: A Phenomenological Study of Discussion Forum Narratives," reports her investigation into the ways in which people with bipolar disorder (BD) discuss work and career issues in public online support forums. Rathbun-Grubb found that 7% of the 572 posts she retrieved from four different BD forums pertained to work and career issues. Through in vivo coding, Rathbun-Grubb identified the following main themes: (1) work and career histories; (2) BD symptoms at work; (3) needs for coping at work; (4) the importance of work as a part of a healthy life; (5) disclosure of the illness; and (6) recommendations offered by other contributors to the forum. Rathbun-Grubb found that the narratives contained in these posts suggested that contributors to the forum wanted to work and have successful careers, but that their symptoms, as well as encountering stigmatization from both themselves and others in their workplace, sometimes negatively impacted their ability to succeed in the workplace. She further notes the potential danger of sharing and disclosing in the workplace versus turning to the relative safety of online mental health forums for seeking and providing both empathy and advice.

The third and final research article, “Food Justice in the Public Library: Information, Resources, and Meals,” Noah Lenstra and Christine D’Arpa describe the many ways in which U.S. public libraries participate in the food justice movement. Lenstra and D’Arpa identify four overarching categories of food justice activities at U.S. public libraries: (1) Distributing food at the library (e.g., summer meal programs, such as California’s “Lunch at the Library” initiative); (2) Teaching and enabling community-based agriculture (e.g., gardening classes; seed exchanges); (3) Teaching how to cook, prepare, and eat healthy foods (e.g., cooking and nutrition classes, such as the Sonoma County Public Library’s “Healthy Living at your Library” and Free Library of Philadelphia’s “Culinary Literacy Center”); and (4) Supporting existing food justice efforts in their local communities (e.g., Wilton Public Library’s program offered in collaboration with the local Women, Infants, and Children (WIC) office, “Snacks in Stacks”; Miami (OH) Public Library’s nutrition demonstrations at local farmers markets). Within each of these categories, the authors describe in detail some of the many ways in which public libraries are contributing to food justice through the programming they offer to their local communities. In conclusion, Lenstra and D’Arpa call for further research into public libraries’ and librarians’ contributions to the food justice movement, both in the U.S. and abroad, as well as enhancements to library and information science (LIS) curricula to better prepare students to participate in, and lead, the health justice movement within and across the diverse communities they will serve.

The three special section papers all examine programs in libraries designed to promote inclusion in terms of health and ability for different populations who frequently are underserved in terms of health information. Each of these papers represents one of the many unique ways in which libraries can simultaneously promote empowerment with information and inclusion in society.

“Back to the Future: Library Book Clubs for Individuals with Intellectual Disability (ID)” by Matthew Conner and Leah Plocharczyk explains the context for library services for individuals with intellectual disabilities, providing a case study and preliminary data on new efforts in the field. Focusing on public libraries, school media centers, and academic libraries—libraries that are connected with the educational system—this article identifies gaps in attention to supporting individuals with intellectual disabilities, who may have difficulty using library services and accessing its collections. By comparing data between the case study and similar book clubs at public libraries throughout the nation, the article develops a profile of what these book clubs are doing and how successful they are.

The second special section paper, “Targeting Autism in Libraries: A Comprehensive and Collaborative Training Program for Librarians” by Ruth V. Small, Suzanne Schriar, and Mary Pelich Kelly reports findings from grants from the Institute of Museum & Library Services. The Targeting Autism program is a multi-institutional collaboration created to provide free training to the librarians of the State of Illinois on providing quality services and programs to patrons with autism. In partnership with Dominican University and Syracuse University and in collaboration with dozens of autism-related organizations, the program has offered in-person annual forums, group workshops, follow-up individualized coaching, and self-paced, online in-depth training to the librarians in Illinois and beyond.

The final section paper is “Give us vision, lest we perish: Engaging Disability at the National Library of Jamaica” by Abigail Henry, Nicole Prawl, Beverly Lashley, and Dionne Moiten. This paper details a program by the National Library of Jamaica to promote accessibility to all members of the nation, regardless of disability or physical limitations. This paper discusses a 2018 initiative to enhance engagement of persons with disabilities through a sign language

training initiative for staff, which is part of a wider initiative to improve accessibility at the National Library of Jamaica for both staff and users. With a workforce that includes employees with disabilities, the National Library of Jamaica has, for some time, been engaged in the work of improving inclusion and engagement of persons with disabilities.

Moving Forward

Hopefully, the combination of papers in these two special issues will help to build a larger discourse about and explorations of the breadth and boundaries of consumer health information behavior. In the introductory article to the preceding special issue, we suggest that one of the future frames for considering these issues could be framing them in terms of equity and inclusion, an idea which we labelled consumer health information justice. Regardless of the contours that this area of discourse ultimately follows, issues of consumer health information behavior will remain an essential area of study, as people will always need to access and understand information about their health. A soon-to-be published special issue of this journal—guest edited by Dr. Kim Thompson of the University of South Carolina—will delve further into issues of disability.

References

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