Faculty Publications

2023

Finding and Using Federal Information Relevant to People with Disabilities

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Published In

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Introduction

As of 2019, approximately 13.2 percent of the U.S. population had a form of disability (Institute on Disability 2020, 3). There are many types of disabilities and impairments, including mobility-related, learning-related, communication-related, vision-related, and hearing-related. These disabilities may fall into the category of "visible" or "invisible" disabilities (Schomberg and Highby 2020). This ubiquity implies that most librarians in all types of libraries are serving patrons with disabilities every day, though they may not realize it.

People with disabilities often face enormous challenges across all aspects of life, and federal laws, regulations, and policies such as the Americans with Disabilities Act (ADA) often cut across all these aspects. Federal government information that pertains to persons with disabilities is often scattered across multiple agencies, presenting a challenge not only to patrons with disabilities themselves but also to librarians who may not be familiar with these resources. Consequently, the purpose of this chapter is to familiarize librarians with key resources for people with disabilities in the domains of healthcare, employment, and education, along with a brief overview of significant legislation in this area.

Key Legislation

Any overview of disability rights information would be remiss without first examining the premier federal law mandating equal rights and opportunities for people with disabilities: the Americans with Disabilities Act of 1990 (Pub. L. 101-336, 104 Stat. 327). Originally enacted in 1990 and subsequently revised in 2008, the ADA prevents discrimination against people with disabilities in areas such as employment, public services, and public accommodations. The

purpose of the ADA is to protect the rights of people with disabilities to participate in all areas of society, whether that may mean obtaining equal compensation from their employer as would a person without disabilities; receiving services from the government (including a public education); or obtaining services from commercial facilities, such as hotels and restaurants, without obstacles. However, while the ADA broadly protects the rights of people with disabilities to receive services from, and to be employed by, entities within the public and private sectors, Congress passed additional legislation to thwart discrimination in the areas of healthcare, education, and employment.

The Education of the Handicapped Act Amendments of 1990 (Pub. L. 101-476, 104 Stat. 1103) guarantees "a free appropriate public education" to children with disabilities, including special education services (104 Stat. 1112). This Act (104 Stat. 1141-42) renamed the Education for All Handicapped Children Act of 1975 (Pub. L. 94-142; 20 U.S.C. 1400) as the Individuals with Disabilities Act (IDEA). The 1990 amendments also provide for early childhood education intervention services for children and toddlers with disabilities. Finally, the Act allows for grants to state education departments, institutions of higher education, and related nonprofit organizations to support research for, and development of, special education services.

In 1973, Congress passed the Rehabilitation Act of 1973 (RHA) (Pub. L. 93-112, 87 Stat. 355) to establish affirmative action policies for organizations contracting with the federal government to employ individuals with disabilities. With major implications for the employment of people with disabilities, section 504 of the RHA expanded workplace protections for individuals with disabilities, particularly in instances of discrimination by employers in receipt of federal funds. The following year saw passage of the Vietnam Era Veterans' Readjustment Assistance Act of 1974 (Pub. L. 93-508, 88 Stat. 1578), which the Department of Labor enforces

to ensure equal employment opportunities for disabled veterans. Several decades later, the Workforce Innovation and Opportunity Act of 2014 (Pub. L. 113-128, 128 Stat. 1425) came about to engineer competitive integrated employment opportunities for individuals with disabilities.

RHA also offers protections for individuals with disabilities within the context of health care, as section 504 regulates all programs and services provided to individuals with disabilities through the use of federal funds, including those conducted by the U.S. Department of Health and Human Services (HHS). Similarly, section 508 of RHA mandates the accessibility of information technology used by programs in receipt of federal funding, including health care records created and maintained by HHS.

Beyond these pieces of legislation, the federal government implemented many other laws to protect individuals with disabilities. These areas include: transportation, voting rights, telecommunications, architectural barriers, and the civil rights of "institutionalized" people. This includes individuals within government-operated mental health facilities, correctional facilities, pretrial detention centers, and juvenile detention centers. These legislative acts and associated public services and programs merit further analysis from the library community. Two good sources for this information include ADA.gov, administered by the Department of Justice, and the Library of Congress's research guide, "Disability Law in the United States: A Beginner's Guide," https://guides.loc.gov/disability-law.

ADA.gov offers information and technical assistance on the Americans with Disabilities Act of 1990, including the full text of the regulations, the ADA's standards for accessible design, significant cases pertaining to the ADA, and technical documents concerning ADA requirements for small businesses and local governments. The newly available beta site, https://beta.ada.gov,

offers a link on the home page for users to file an ADA complaint. This user-friendly beta version also offers a "topics" page, which includes in-depth sub-pages relating to service animals, accessible parking, mobility devices, and communication technologies for people with disabilities. As an additional helpful resource, the Library of Congress's "Disability Law in the United States: A Beginner's Guide," LibGuide features publications within the Library of Congress about disability law, links to federal law, links to regulatory agencies' websites, and federal publications about the use of service animals. This LibGuide also includes publications relevant to disabled veterans and legal reference materials relating to disability law.

Health Information

There are two key organizations that are essential for disability information in a health context: the National Library of Medicine (NLM), part of the National Institutes of Health (NIH), and the Centers for Disease Control and Prevention (CDC). The NLM and the CDC in turn are both part of HHS.

MedlinePlus, https://medlineplus.gov/, is the NLM's consumer health portal, useful in all libraries but especially in public libraries. MedlinePlus has a clean, accessible interface that showcases authoritative health information without problematic outside influences from, for example, pharmaceutical companies. Articles on MedlinePlus tend to follow a standard format. First, they summarize the topic in plain language and then link out to other, reliable sources for patrons to read.

For example, the article "Disabilities," https://medlineplus.gov/disabilities.html, contains a summary, a "Start Here" section that links to the CDC, scholarly sources such as clinical trials, journal articles, and resources for children. Articles vary in their ratio of scholarly- to non-

scholarly content, but there are many parent-friendly, jargon-free sources related to diagnosing and assessing disabilities at an early age.

PubMed, https://pubmed.ncbi.nlm.nih.gov/, is the official NLM portal for citations and abstracts of medical literature, often with links to full text from PubMed Central (PMC), https://www.ncbi.nlm.nih.gov/pmc/. It works similarly to many other library databases that librarians use but has some unique features. An advanced search lets the user "[a]dd terms to the query box," which can then be combined with Boolean operators. A useful feature of PubMed is that any NIH-funded research since April 7, 2008 must be made freely available in PubMed Central, NLM's full-text archive, twelve months after publication (National Institutes of Health 2021), with some copyright-related exceptions. This policy makes much recent medical scholarship freely available to all librarians and patrons which might otherwise be behind a paywall.

Using the advanced search, patrons can choose from a range of article types, such as clinical trials, randomized control trials, and systematic reviews. An even more effective way to search PubMed for information relevant to people with disabilities is by using the Medical Subject Headings (MeSH), an NLM-developed controlled vocabulary similar to the Library of Congress Subject Headings. This specialized system is helpful for mapping problematic terminology about disabilities to more current terminology.

Users can access the MeSH Database from the PubMed home page and then type in a search term. An initial search took the increasingly outdated term "Handicapped" and redirected it to the more current term "Disabled Persons." The PubMed Search Builder allows the user to construct a search using additional MeSH terms. For example, after searching for the phrase "Disabled Persons," the user checks the search result box for "Disabled Persons." On the right-

side of the screen, the user will locate "Add to search builder." The user ~~then~~ has the option to select which Boolean operator to use; PubMed defaults to "AND." Selecting "AND" and clicking the button "Search PubMed" populates the "PubMed Search Builder" box with "Disabled Persons [Mesh]." Next, the user conducts a search for another MeSH term "Mental Health." The user can click on the heading "Mental Health" to explore its nuances or add the term to the Search Builder from the results list. This action results in the search "('Disabled Persons' [MeSH]) AND 'Mental Health' [MeSH]. After finalizing their selection, the user clicks "Search PubMed" to find relevant articles. Search results using MeSH are very similar to those from a keyword search, but they are more precise, especially given the wide range of terminology on the subject of disabilities.

As with the NLM's resources, the CDC's website, https://www.cdc.gov/, contains a mixture of material for both the expert (e.g., historical data on Lyme disease) and the layperson (e.g., a COVID-19 quarantine and isolation calculator), and its content is useful for all library types. When a user is searching for a disability or topic, the search bar is a good place to start. Users can find lots of valuable information, but it is not always easy to find the consumer-friendly landing page for a specific disability or topic this way. Consequently, the CDC has an A-Z list of many common disabilities under its "Diseases and Conditions" tab, including specific conditions such as ADHD (attention-deficit hyperactivity disorder) and autism as well as broader categories like "Developmental Disabilities." These landing pages contain a wealth of information. For ADHD, the "Data and Statistics" page contains easy-to-parse statistics on the condition while providing librarians with links to the original surveys that collected the data. However, not all conditions or topics have their own CDC A-Z landing page. In these instances, using the search bar is the most effective strategy.

While it is possible to find information on some disabilities using the "Diseases and Conditions" menu on the CDC home page, a better option is to start with the A-Z entries "Disabilities and Health" or "Developmental Disabilities." Both provide information from the National Center on Birth Defects and Developmental Disabilities (NCBDDD), https://www.cdc.gov/ncbddd/index.html. Part of the NCBDDD's mission is to help children with developmental disabilities and adults with disabilities, so they have some pertinent information.

Clicking "Disabilities and Health" from the CDC index will display the NCBDDD's "Disability and Health Promotion" webpage. The "Disability & Health Overview" webpage discusses what disabilities are, how they affect people, and useful infographics on the topic. Their discussion of disability inclusion is a wonderful primer for people who may never have considered the topic before, and it explains how people with disabilities should be treated with dignity. The Data and Statistics page is great here as well, which includes state-by-state summaries and statistics.

The Developmental Disabilities landing page, https://www.cdc.gov/ncbddd/developmentaldisabilities, contains a wide range of information for a variety of audiences. Parents can learn about typical developmental milestones for children up to age five. This information is crucial; whether children attain these milestones, experience delays, or do not reach them at all is the basis for accurate diagnosis of these disabilities. In addition, users can download fact sheets, infographics, posters, and multimedia content such as the "All Things ADHD" podcast at https://www.cdc.gov/ncbddd/adhd/materials-multimedia/index.html. The NCBDDD collects a range of disability-related content from across the CDC, but their annual report, https://www.cdc.gov/ncbddd/aboutus/report/, has some

excellent summaries of what the Center is doing to help children with developmental disabilities. The report is written in plain language and contains links to reliable sources such as academic journal articles and advocacy groups like as the Tourette Association of America, making it excellent for students, researchers, and the public.

Finally, the NCBDDD's Disability and Health Data System allows users to find in-depth disability statistics by state. For example, clicking on Florida breaks down the state data by a wide range of indicators, such as demographics, barriers to care, and disability estimates. Users can see how many adults are out of work, unable to work, and employed. Data can be downloaded in PDF and CSV formats. The data at this time covers 2016-2019; more updates are expected in the future.

Education Information

Educational opportunities for students with disabilities have improved markedly since the 1960s when Congress began to pass a series of legislation to improve outcomes for this group (Center on Education Policy 2020b). Ensuring that children and college students with disabilities have access to a quality education is a key concern for many parents. Fortunately, the U.S. Department of Education offers a wide range of resources for those who want to learn about this population and the issues they face.

Public education in the United States is composite in character, with federal, state, and local entities all playing a part in its operation (Center on Education Policy 2020a). Despite its democratic aspirations, public education excluded several groups, including students with disabilities (Center on Education Policy 2020b). Section 1414 of IDEA outlines the creation of individualized education programs (IEPs) for students with disabilities, to be implemented at the local level. This legislation provides information about rights for children with disabilities and

their parents, such as the right to an initial educational evaluation; the right to an IEP team consisting of parents, teachers, and other stakeholders; and the right to IEP team meetings (20 U.S.C. 1414). For more information, the IDEA website, https://sites.ed.gov/idea/, links to the Department of Education's Office of Special Education and Rehabilitative Services (OSERS), with reports, publications, policy, newsletters, topical listservs, and other resources. The IDEA website is useful in a wide range of libraries but especially public and school libraries, where parents and educational staff can learn more about IEPs and how they may apply in a given situation.

The ADA applies to K-12 education, small businesses, and a host of other organizations. This is documented in the *Code of Federal Regulations* as "Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities" (28 CFR Part 36). However, ADA accommodations are also common in public and private colleges and universities, where services received under IEPs in K-12 education may not apply. Although the Department of Justice ultimately enforces the ADA, it is possible to find education-specific information on the law, along with many other education-related topics, through the Education Resources Information Center, or ERIC.

ERIC, https://eric.ed.gov/, is the Department of Education's citation and abstract database of journal literature, reports, and other education-focused scholarship. As with PubMed, ERIC contains selected full text. However, unlike PubMed, the Department of Education does not have an open access mandate in the way the NIH does, so although ERIC is comprehensive, researchers must often find the full text from another source.

ERIC uses a single box for both basic and advanced search, employing fields, filters, quotes, and other limiters on one line. Researchers can search for peer-reviewed and/or full-text articles by checking the boxes. Once a relevant article is found, they can use the descriptors, or subject terms, to find more articles. It is worth noting that ERIC covers education in foreign countries in addition to education in the United States. In the case of the ADA, it is possible to compare efforts to accommodate students with disabilities in different countries. ERIC is free to use but is most useful in an academic setting, where patrons may have access to the cited paywalled journal citations they come across.

The National Center for Education Statistics (NCES), https://nces.ed.gov/, is a clearinghouse for a range of educational statistics, surveys, and assessments. The Center's data cover all levels of education from preschool to postsecondary. It is possible to find information on students with disabilities across a wide range of instruments, but there are two key surveys that stand out.

The NCES's *Condition of Education*, https://nces.ed.gov/programs/coe/, is an annual snapshot of the state of education in the United States. Its Students with Disabilities page, https://nces.ed.gov/programs/coe/indicator/cgg, contains detailed statistics about students with disabilities from ages 3 to 21, such as a breakdown of what disabilities are most common among students served by the Individuals with Disabilities Education Act (IDEA). To make it as readable as possible, NCES alternates text with charts and graphs and allows users to manipulate the findings by race/ethnicity, sex, disability type, and other categories.

A more concise version of the *Condition of Education* can be found in *Fast Facts*, available from the "Menu" button on the NCES home page. *Fast Facts* frames this issue in a question-and-answer format, asking, "How many students with disabilities receive services?"

and answers the question with text and tables. There are many more surveys, charts, and graphs at NCES, but these two products will meet the needs of most patrons with questions about disabilities, while researchers will have the opportunity to delve into copious amounts of data on this topic.

Workplace Discrimination Information

The two federal entities which enforce federal workplace anti-discrimination laws are the Equal Employment Opportunity Commission (EEOC) and the Department of Labor. Pertinent to people with disabilities, the EEOC enforces Title I of the Americans with Disabilities Act of 1990 (ADA) and sections 501 and 505 of the Rehabilitation Act of 1973 (RHA) (U.S. Equal Employment Opportunity Commission n.d.). The EEOC also enforces federal anti-discrimination laws against employers who do not receive federal financial assistance, whereas the Department of Labor's programs only enforce anti-discrimination laws against employers receiving federal assistance.

Within the Department of Labor, the Office of the Assistant Secretary for Administration and Management's Civil Rights Center enforces the aspects of Title II of the ADA which relate to the "programs, services and regulatory activities connected to labor and the workforce" (U.S. Department of Labor n.d.). Many types of complaints relating to employment discrimination based on disability can be filed through the Department of Labor's Civil Rights Center. However, the Department of Labor only handles discrimination complaints against employers who receive federal assistance. The Civil Rights Center website, https://www.dol.gov/agencies/oasam/centers-offices/civil-rights-center, is user-friendly and jargon-free. Halfway down the landing page, a menu to the left of the screen includes a link to a page entitled "Resources for Individuals with Questions about Filing a Discrimination

Complaint." This same menu includes links to pages about Reasonable Accommodations for Programs for Employees and Applicants with Disabilities, the Architectural Barriers Act, and Notification of Equal Employment Opportunity Violations.

The Office of Federal Contract Compliance Programs, https://www.dol.gov/agencies/ofccp, is responsible for enforcement of Title I of the ADA as it concerns federal contracts. These are some highlights of the legislation that the Department of Labor is tasked with enforcing, and an exhaustive list can be found through the Department's website. Patrons seeking to file a disability discrimination complaint against a company which contracts with the federal government may do so through the Office of Federal Contract Compliance. The link to the complaint page is easily found through the Office's home page, and this complaint page is easy to follow, jargon-free, and includes complaint forms and filing instructions available to download in PDF format in twelve different languages.

As far as data sets are concerned, the main source of departmental data of interest to librarians is provided by the Department of Labor's Bureau of Labor Statistics (BLS). The main source of labor information relating to people with disabilities is furnished by the Bureau of Labor Statistics, https://www.bls.gov/. The "Data Tools" tab on the BLS home page is where librarians will find almost any federal data needed. Here, users can find labor data by industry, by location, by a convenient menu of frequently requested data tables; or through an application programming interface (API). This is a customizable program that allows developers to create their own applications using BLS data.

An overall search of the BLS website for the keyword "disability" yields thousands of results, giving a sense of the overall wealth of employment information relating to people with disabilities within the BLS site. The resources range from recent press releases on labor force

characteristics to data on the employment status of people with disabilities, to information about employee access to disability insurance plans and many other topics in between. Disability data within the context of employment is located within the Current Population Survey Labor Force Statistics, https://www.bls.gov/cps/lfcharacteristics.htm. Articles relating to employment of people with disabilities also appear within BLS publications, such as *Spotlight on Statistics*, and these often discuss the impact of current events on labor market trends. For example, the October 2021 edition, https://www.bls.gov/spotlight/2021/labor-market-characteristics-of-people-with-a-disability/home.htm, describes the impact of the coronavirus pandemic and recovery on the labor market outlook for people with a disability.

Conclusion

Along with key pieces of legislation, this chapter discussed federal resources for people with disabilities in healthcare, education, and employment. It is important for librarians to be aware of these resources, because serving marginalized populations and to "advance racial and social justice" are core tenets of librarianship (American Library Association 2021). Additionally, many libraries are undertaking diversity, equity, and inclusion (DEI) efforts to improve the patron and employment experience (Anaya and Maxey-Harris 2017) and addressing the needs of persons with disabilities should be part of those initiatives. Having knowledgeable librarians on staff who are well versed in federal information about disability is an excellent place to start.

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