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Abstract

Public libraries are often referred to as community anchors—boundary-spanning institutions (Williams 2002) ideally positioned to inform, empower, and connect citizens in local communities. Despite American Library Association (ALA) and Institute of Museum and Library Services (IMLS) statements explicitly valuing diversity, inclusivity, and equitable access, people with disabilities (PWD) and their families are often excluded from meaningful use of, and engagement with, local libraries. For a large portion of the autism community, the library does not provide meaningful services or information beyond early childhood and can be perceived as an unsafe space for adults with autism. This article presents secondary analysis of a survey of 635 parents of individuals with autism spectrum disorders (ASD) in the state of North Carolina, as well as an intersectional analysis of race, gender, disability, and information behavior. It also discusses the implications of these findings for library planning.

Introduction

Great Need and Great Potential

Autistic people and their families make up a large and growing portion of the US populace. Research on parenting children with autism spectrum disorders (ASD) suggests that parents often have a range of unmet information needs across their children's lifespans, and that helping families meet these needs can improve social, emotional, and health outcomes. Community-based institutions (including libraries) hold enormous poten-

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tial for supporting families of people with disabilities and a range of neurodiversities, but often lack awareness of their unique needs and effective provisions of support. As a result, parents commonly experience difficulty understanding and navigating systems of care; struggle to find and secure appropriate services; experience fragmented and inadequate support; encounter underfunded, underequipped, and underinformed education and healthcare systems; and report difficulty finding trustworthy information (Carbone et al. 2010; Gibson, Kaplan, and Vardell 2017; Jacobson and Mulick 2000). Combined, these challenges contribute to family fragility, decreased well-being, and poorer quality of life for people with ASD and their families. Information seeking as a mechanism for increased agency and coping has been well recognized in the LIS literature (Chatman 1996; Harris et al. 2001; Savolainen 1995; Wilson 2000) and, though less prevalent, particularly observed in information behavior studies of parents who have children with significant health concerns and disabilities (Al-Daihani and Al-Ateeqi 2015; Gibson 2014; Jackson et al. 2008; Mackintosh, Myers, and Goin-Kochel 2005; Özyazıcıoğlu and Buran 2014).

Research Questions

This secondary analysis examined demographic distinctions among parent respondents of children with autism with regard to their information needs and source preferences. Mitigating factors were also explored to identify facilitators, inhibitors, and barriers of access. As such, the following questions guided inquiry:

- What is the nature of the relationship between identity and demographic characteristics (specifically race, income, education level, and geographic location), information seeking, source preferences, and access?
- What do the findings imply for planning equitable and inclusive library services?

About Autism Spectrum Disorders

Autism spectrum disorder (ASD) is a developmental disability and serves as an umbrella term to describe a profile of neurodevelopmental differences found in approximately 2.41 percent of individuals (1 in 41) (Xu et al. 2018). People with ASD are highly heterogeneous, exhibiting characteristics that vary in expression and fall along a wide continuum of intensity and life impact. One common trait shared by many with ASD relates to how individuals process and respond to sensory stimuli—for instance, light, sound, texture, weight, taste, and smell. While some individuals experience an oversensitivity to stimuli, others may exhibit an undersensitivity. Persistent sensory craving is also sometimes observed (Miller et al. 2009). Another marker of ASD commonly identified in early childhood is a delay in language development. As children age, many struggle with social communication and have difficulty picking up and understanding social cues. Both children and adults with ASD are more likely to experience chronic physical and mental-health conditions than individuals without ASD and individuals with other types of developmental disabilities (Weiss et al. 2018; Cummings et al. 2016). Approximately 50 percent of individuals with ASD have an intellectual disability (IQ < 70) (Charman et al. 2011). Many in the disability field have debated the general notion of intelligence and the adequacy of standardized measures used to assess the IQ of individuals with ASD (Charman et al. 2011; Dawson et al. 2007; Scheuffgen et al. 2000).

Over the last decade, ASD has received considerable attention in the research literature and mainstream media, predominately centered on etiology, curative initiatives, and therapeutic interventions to address a range of challenges experienced by individuals and their families. Less acknowledged, these challenges are not fixed or static. They can be dependent on and influenced by environment, expectations, and opportunity. Knowledge, behaviors, and skills/abilities can change over time with education, experience, and support.

The perspective of autism as a positive trait is one not often amplified in the research and practitioner literature (Riosa et al. 2017; Teti et al. 2016). Unquestionably, individuals with ASD can possess ordinary and extraordinary strengths and abilities. Strong memory, attention to detail, sustained focus, expertise in special interest areas, pragmatism, honesty, authenticity, and resiliency are some of the most frequently observed strengths or qualities reported (Carter et al. 2015; Montgomery et al. 2008). Strengths-focused research is an emerging area of study advocated by many in the disability field, with promising implications for targeted program development and shifting societal perceptions (Riosa et al. 2017; Wehmeyer and Shogren 2014; Carter 2013)

Rethinking Disability

Critical disability theory offers the LIS field a powerful, yet underutilized, mechanism to more fully examine the lived experiences of individuals with autism and their families. As a lens for inquiry, the framework rejects the lingering yet reductive medical model of disability that positions impairment central and casts individuals as deficient, afflicted, and abnormal. Critical disability theory also argues against the social model as the singular root of disablement. Subscribers of the social model assert that an individual is not disabled by his/her impairment but rather by society and its unwillingness to accommodate the wide diversity of human experience. In contrast, critical disability theory acknowledges disability as a uniquely individual, intersectional, and collective experience of both social and physiological influence and origin (Shildrick 2012).

A Note on Language

Debates around terminology—including use of the term *disability*, identity-first terminology such as *autistic*, and person-first terminology (Dunn and Andrews 2015) such as *person with autism*—are ongoing in and outside of communities of people with various disabilities and neurodiversities. During our presurvey interviews, we found that autistic teens and young adults felt strongly about the use of identity-first language, while their parents used a mix of person-first and identity-first language. We have elected to use all three of these terms in this article to reflect usage by respondents and autistic self-advocates who have embraced *disability* and identity-first language as a descriptor of a collective political and social identity (Putnam 2005; Scotch 2000), and to respect current professional norms related to person-first language (Young [2007] 2009; Dunn and Andrews 2015; Kenny et al 2016).[1]

Understanding Intersections

The face of autism research has largely been white (Heilker 2012) and focused on individuals—few studies examine how information systems and services create contexts that turn intersections between disability and other facets of identity into "vehicles for vulnerability" (Crenshaw 2016) rather than fulfilling the idealization of information as a "great equalizer" (Naisbitt 1984). This article contributes to the discussion around services for people with ASD by exploring the ways that race, income, education level, and geographic location influence the information needs and information source preferences of parents of people with ASD. We also discuss the implications of our findings for librarians, information professionals, and community-based organizations serving these families in local communities.

The Great Equalizer

Historically, different types of social and technical information systems—including education systems (Mann 1957), computing technology and the internet (Christensen 1997), and libraries (Stripling 2013)—have been regarded as tools for working toward greater social equality. American libraries have acknowledged their responsibility in this arena, citing public good, access, and diversity among librarianship's core values (ALA 2006a). In 2013, the American Library Association presented the *Declaration for the Right to Libraries*, a public document asserting the role and influence of libraries in communities and individual lives. The declaration states, "Libraries are the great equalizer. Libraries serve people of every age, education level, income level, ethnicity and *physical ability* [emphasis added]. For many people, libraries provide resources that they could not otherwise afford—resources they need to live, learn, work and govern" (ALA 2013).

Unfortunately, libraries have also reproduced many of the injustices seen in broader society, including racism (Knott 2016; Kumasi 2012) and ableism (Kumbier and Starkey 2016; Schomberg 2018).

Libraries and Disability: An Aspirational History.

While the *Declaration for the Right to Libraries* is fairly recent, Jaeger (2018) reports that the field of librarianship has long been aware of the access needs of patrons with *physical* disabilities. In 1897 the Library of Congress established a reading room with braille resources for the visually impaired (Cylke, Moodie, and Fistick 2007). In 1906, the American Library Association first established a committee to begin addressing information services and supports for individuals with disabilities. By the early 1980s, basic access standards for physical disabilities were well established across the field, including directives for physically accessible buildings, collections, and services (Jaeger 2018). In 2001, the American Library Association approved the "Services for People with Disabilities Policy." The policy underscores the life disparities and widespread discrimination experienced by individuals with disabilities and acknowledges that "libraries play a catalytic role in the lives of people with disabilities by facilitating their full participation in society" (ALA 2006b).

As a field of LIS scholarship, inquiry into the information needs, practices, and experiences of individuals with physical, developmental, and intellectual disabilities is scarce. The available research suggests that the organizational aspirations outlined in the *ALA Code of Ethics* (2008) and *Declaration of the Right to Libraries* are as yet unfulfilled for individuals with disabilities and their families. They often do not experience the same benefits as their nondisabled counterparts and often feel unwelcome and less safe in their local libraries than other library users (Gibson, Kaplan, and Vardell 2017; Pionke 2017; Prendergast 2016; Barker 2011; Sin and Kim 2008; Burke 2009; Holmes 2008).

A closer review of the LIS literature, as a whole, offers several revealing explanations. First, despite a strong and vocal history of advocacy and action within the LIS field, the efforts and lessons learned by those on the ground are not abundantly reflected in the LIS literature. Second, strategies and interventions outlined in the literature far too often lack empirical grounding and are detached from the disability research on quality of life experiences of this community. Third, much of the available literature presents only a narrow view, focused on individuals with physical, visual, and auditory disabilities. Consideration of individuals with intellectual disabilities and profound sensory sensitivities is largely absent. Finally, few studies actively solicit and incorporate the voices, perspectives, and priorities of the individuals and their families they strive to understand and support. Jaeger (2018, 59) posits that "all library activities related to disability can be enhanced by interviewing disabled people and incorporating those perspectives directly into development and refinement of such activities." One might argue that soliciting the perspectives and priorities of individuals and their families will not simply enhance library activities but is critical to ensure relevant and life-improving services, resources, and support.

Methods

Overview of Initial Study

This article describes secondary analysis of data from a 2015 survey study that examined the information needs and source preferences of parents of children with autism in North Carolina. Four research questions guided the original study:

- What information sources do parents of individuals with autism use most frequently?
- How do information sources vary by child age?
- What is the role of the internet in meeting parent information need?
- What is the role of local information sources in meeting parent information need?

Additional details on survey design (including presurvey interviews) can be found in Gibson, Kaplan, and Vardell (2017), which focused on differences in parent information needs related to their children's ages.

Sample and Recruiting

Survey participants were recruited from the autism Research Participant Registry Core (N=4200), a confidential opt-in research panel maintained by the Carolina Institute for Developmental Disabilities at the University of North Carolina. Recruiting was done via email (with a direct link to the web survey) by the Registry Core staff, and no exclusions were made for comorbidities or dual diagnoses. North Carolina does not maintain a census of people with ASD. The researchers calculated an appropriate sample using the reported ASD prevalence for the state of North Carolina in 2014 (one year prior to data collection) to estimate a population of 171,448 people with ASD in the state (CDC 2014). The researchers calculated a minimum sample size of 780 respondents using a confidence interval of 3.5 and a confidence level of 95 percent.

Of the initial 935 respondents, 644 were included as cases for the current analysis. Of the original sample, 291 cases were removed from consideration as the respondents completed the survey without providing demographic information. Analyzed cases comprised respondents who met a 95 percent survey-completion criteria. See table 1 for a summary of participant demographic data derived from the 644 cases. As noted, the survey respondents were allowed to skip questions; therefore, total responses (n) for demographic variables differ.

Table 1. Summary of participant demographic data

	Frequency	%
Gender (n=625)		
Female	548	87.70%
Male	77	12.30%
Race (n=644)		
White	530	82.30%
Black/African American	71	11.00%
Asian	10	1.60%
Native Hawaiian/Pacific Islander	1	0.20%
Two or More Races	11	1.70%
Other	21	3.30%
Ethnicity (n=620)		
Hispanic	26	4.20%
Not Hispanic	594	95.80%
Annual Household Income (n=614)		
Less than $24,999	73	11.90%
$25,000–$49,999	127	20.70%
$50,000–$74,999	116	18.90%
$75,000–$99,999	117	19.10%
$100,000–or more	181	29.50%
Education Level (n=630)		
Less than a High School Diploma	3	0.50%
High School Diploma or Equivalent	61	9.70%
Some College or Associates Degree	173	27.60%
College (BA/BS)	223	35.60%
Graduate Degree	170	27.10%
Employment Status (n=633)		
Employed: Full-Time	319	50.40%
Employed: Part-Time	100	15.80%
Stay-at-Home Parent	153	24.20%
Not Employed/Retired	61	0.10%
Parenting Arrangement (n=633)		
Single-Parent Household	80	12.60%
Two-Parent Household	457	72.20%
Separated or Divorced with Shared Parenting	46	7.30%
Other	50	7.90%
Number of Children with ASD Diagnosis (n=634)		
One Child	578	91.00%
Two Children	48	7.60%
Three or More Children	8	1.30%
Location (n=624)		
Metropolitan	555	88.94%
Not Metropolitan	89	14.26%

Survey Design

The survey was designed and administered as a confidential online Qualtrics survey that consisted of twenty-eight closed and open text questions. The first fifteen questions were designed to assess areas of specific information need and preferred information sources based on predetermined categories (see tables 2 and 3). These categories were identified during data analysis open coding of interview-response content collected in the original study. The last thirteen survey questions gathered demographic,

Table 2. Topics of information need

Physical growth and development
Behavior management
Speech and language development
Gross- and fine-motor development
Puberty
Helping your child find peers with a similar diagnosis
Helping your child relate to neurotypical peers
Sexuality and dating
Independent living
Sensory-friendly activities
Recreational activities designed for individuals with autism
Community-sponsored recreational activities designed for individuals with autism
Recreational activities designed by organizations focused on individuals with autism
Techniques or exercises to support your child's schoolwork
Administrative information about your child's school, such as IEP planning, classroom placement, or testing
Higher education, job training, employment

Table 3. Preferred information sources

Non-Internet Sources	Internet Sources
Local organizations	National organizations' websites
Therapists	Social media
Other parents of people with ASD	Local email listservs
Doctors	National online forums / email listservs
Friends and family	Other websites
Local library	

family composition, and ASD diagnosis information. This article focuses on parent responses to six questions about information sources. The first four questions asked variations on the question "Where, in the last 12 months, have you looked for information about the following topics related to your child?" See figure 1 for an example of the survey interface.

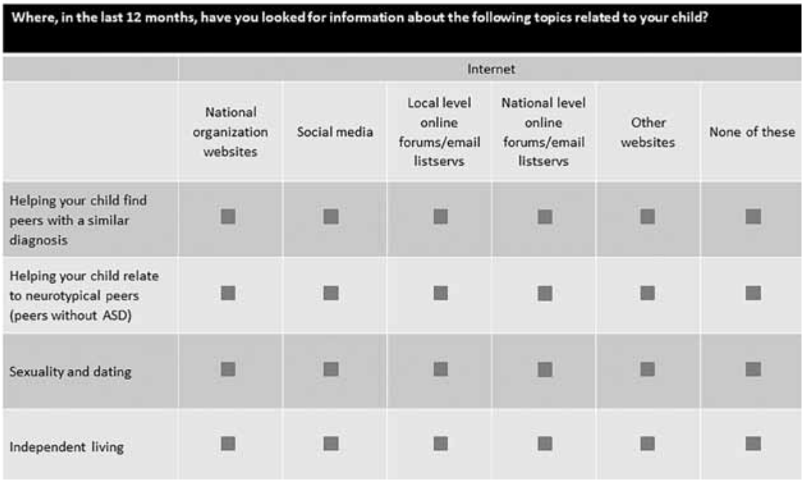
Additionally, findings will be shared on the analysis of parent responses to two open-ended questions:

- Is there any other information you'd like to share about your experiences seeking information related to your child with ASD?
- Please describe your involvement with any local and/or national parent groups or autism-related organizations such as the Autism Society of North Carolina (ASNC) or Autism Speaks!

For the purposes of the current article, the following four demographic areas were identified for aggregation and analysis: race, income, education level, and location.

Data Analysis

Quantitative data. Quantitative survey data was analyzed using SPSS. Parent responses to survey questions about recently accessed information sources



Where, in the last 12 months, have you looked for information about the following topics related to your child?

	Internet					
	National organization websites	Social media	Local level online forums/email listservs	National level online forums/email listservs	Other websites	None of these
Helping your child find peers with a similar diagnosis	☐	☐	☐	☐	☐	☐
Helping your child relate to neurotypical peers (peers without ASD)	☐	☐	☐	☐	☐	☐
Sexuality and dating	☐	☐	☐	☐	☐	☐
Independent living	☐	☐	☐	☐	☐	☐

Figure 1. Example of survey interface

and topic areas were analyzed. The use of an information source was intentionally coded "1," and the nonuse of a source was coded "0." Such coding produces a percentage/proportion of those using a source, represented as the mean. Proportions were then compared using an independent samples t-test to compare responses by race and a one-way ANOVA to compare response differences by participant income level, educational attainment, and residential location. A breakdown of categories within each of these four variables can be found in table 4. For purposes of statistical comparisons, categories yielding sample sizes less than 60 have been excluded from analysis.

Given unequal sample sizes between comparison groups, a Levene's test was necessary to assess homogeneity of variance for all comparison groups and a Tamhane's T2 post hoc was applied to test the statistical significance of variance. Significance was set at .05 (p) for all measures.

Qualitative data. Qualitative survey data was analyzed using NVivo for inductive thematic coding (Thomas and Harden 2008) of parent responses to the following two open-ended survey questions:

- Is there any other information you would like to share about your experiences seeking information related to your child with ASD?
- Please describe your involvement with any local or national parent groups or autism-related organization such as the Autism Society of North Carolina or Autism Speaks!

In order to facilitate thematic coding within and among demographic categories, we generated matrices that sorted open-ended responses from

Table 4. Independent variable categories

Variable	Survey Question	Categories
Race	Which of the following describe you?	1–White (n=530) 2–Black / African American (n=71) ~~3–Asian (n=10)~~* ~~4–Native Hawaiian / Pacific Islander (n=1)~~* ~~5–Two or more (n=11)~~* ~~6–Other (specify if you wish) (n=21)~~*
Education Level	Please select the highest level of education you have completed.	~~1–Less than a high school diploma (n=3)~~* 2–High school diploma or equivalent (n=61) 3–Associate's degree or some college (n=173) 4–Bachelor's degree (n=223) 5–Graduate degree (n=170)
Annual Household Income**	Which range contains your annual household income?	1–Poverty = Less than $24,999 (n=73) 2–Lower = $25,000-$49,999 (n=173) 3–Middle = $50,000-$99,999 (n=233) 4–Upper = $100,000 and higher (n=181)
Location	Please enter your zip code.	1–Metropolitan (n=555) 2–Not Metropolitan (n=89)

*A strikethrough category signifies the occurrence of a sample size too small to yield statistically meaningful results.

**The distribution for the annual household income level closely aligns with the income scale reported in a 2016 report by the Urban Institute's Income and Benefits Policy Center (Rose 2016).

the target questions by race, income level, geographic location, and education level. They were then open-coded for emergent themes, and resorted by code.

Findings

Race and Information Networks

The sections below highlight statistically significant differences found among groups by race (table 5), and present related qualitative responses.

White families relied more heavily on personal connections than black families. For several topics, white parents reported significantly higher reliance on personal information networks—families and friends and connections to other parents of individuals with similar disabilities—for finding information related to their children's well-being than black parents. Specifically, they relied more heavily on other parents of individuals with autism for information on physical growth and development, behavior management, and encouraging development of gross and fine motor skills. They were significantly more likely to consult their friends and family for information on puberty, the special education process, behavior management, and gross and/or fine motor skills.

Open-ended responses from white families demonstrated a broad but

Table 5. Significant differences by race for "Where do you look for information about the following topics related to your child?"

Source	Topic	%Black	%White	%Diff
Doctors	Community-sponsored recreational activities designed for individuals with autism	**15.49%**	6.04%	9.46%
	Helping your child find peers with a similar diagnosis	**21.13%**	10.19%	10.94%
	Higher education, job training, and employment	**21.13%**	10.57%	10.56%
	Recreational activities designed by organizations focused on individuals with autism	**16.90%**	5.28%	11.62%
	Sensory-friendly activities	**0.00%**	8.30%	15.64%
	Sports and/or recreational activities designed for individuals with autism	**18.31%**	5.47%	12.84%
Books / Pamphlets / Magazines	Community-sponsored recreational activities designed for individuals with autism	**16.90%**	6.79%	10.11%
	Recreational activities designed by organizations focused on individuals with autism	**16.90%**	6.42%	10.49%
	Helping your child find peers with a similar diagnosis	**15.49%**	3.96%	11.53%
	Sports and/or recreational activities designed for individuals with autism	**18.31%**	7.36%	10.95%
	Techniques or exercises to support your child's schoolwork	**28.17%**	15.09%	13.07%
Friends and family	Puberty	9.86%	**18.49%**	–8.63%
	Administrative information about your child's school, such as IEP planning, classroom placement, or testing	12.68%	**21.32%**	–8.64%
	Behavior management	16.90%	**26.60%**	–9.70%
	Gross- and fine-motor skills	4.23%	12.83%	–8.60%
Other parents with my child's special need or disability	Physical growth / Development	19.72%	**30.00%**	–10.28%
	Behavior management	25.35%	**43.40%**	–18.04%
	Gross- and fine-motor skills	14.08%	**25.28%**	–11.20%
Therapists	Behavior management	35.21%	**49.62%**	–14.41%
	Higher education, job training and employment	**16.90%**	5.09%	11.81%
Local organizations	Physical growth / Development	**23.94%**	13.40%	10.55%
	Techniques or exercises to support your child's schoolwork	**32.39%**	19.81%	12.58%
National organization websites	Sensory-friendly activities	**32.39%**	18.68%	13.72%
Other websites	Helping your child find peers with a similar diagnosis	**16.90%**	6.04%	10.86%

*Significance was set at .05.

Boldface percentages represent higher preference rates of an information source per topic area.

nuanced range of issues, and included more frequent discussion about the unmet information needs of parents of "high functioning" children. This explicit differentiation, which was not as prevalent in open-ended responses of nonwhite parents, crossed income and education levels. One high-income white mother wrote, “My child is high functioning and falls into ‘the dead zone’ of services. He doesn’t need full assistance, but would do well in a supervised social scene with other teenagers like him. Not many opportunities out there except for Miracle League Baseball.” One parent who reported an income under $25,000 wrote, “My child has aspergers and it is very hard to find resources/activities for higher functioning adults.” It was unclear whether this difference was due to the higher number of open-ended responses by white parents, cultural differences among respondents, increased variation in neurodiversity among white families, or some other reason.

Explicit claims to individualism was a strong theme among white respondents. Variations on the phrase “If you’ve met one person with autism, you’ve met one person with autism” appeared relatively frequently in this portion of the data. One mother wrote, “People with ASD diagnosis are so different, there is not a one size fits all.” Another wrote, “It’s very hard to sift through information that applies to the particular situation. A lot of bad ‘science’ is out there regarding Autism, as well as doom and gloom.”

As noted in Gibson, Kaplan, and Vardell (2017), a strong theme among black and white parents alike was the lack of information about services and activities in their local communities. One parent wrote, “As a working parent, and as a parent with neuro typical children, it can be difficult to attend local support groups. I feel like it’s extremely difficult to find information about local activities for my ASD child outside of group participation. There doesn’t seem to be a localized resource where I can search for activities or message board with other local parents of special needs kids.”

Black families relied more heavily on institutional and professional sources than white families. In contrast, black parents were significantly more likely to rely on institutional and professional sources than white families for several categories of information. They were also significantly more likely than white parents to turn to their doctors for a broad range of information, including finding autistic peers, locating sensory-friendly activities, finding sports and recreational activities, helping their child find peers with similar disabilities, and information about life after K–12 (i.e., employment and higher education).

Open-ended responses mentioned local schools and local parent organizations as valuable sources of information for this group of parents. Many responses emphasized great difficulty accessing information and resources, and advised resilience and persistence in the face of difficulty. One parent’s comment sums up a sentiment expressed repeatedly: “There is not one good source, you just constantly have to keep checking and asking around. It is very frustrating!” Beyond this emotional toll, continually having to actively seek information about accessing basic care and services takes valuable time and, sometimes, money. Respondents also expressed frustration and a sense of unfairness at neglect of their children by local government services. One mother questioned what she saw as insufficient allotment of state and local county funds to serve her child's needs, saying, "In our area __ County there doesn't seem to be many places that have sports activities other than the special olympics each year. My child would love to play football or basketball AT school but I'm guessing there just aren't enough teachers/coaches/funds to provide this for our kids. Makes me wonder where the lottery money is going."

Although the percentage of information seeking from friends, family, and other parents of children with a similar diagnosis was significantly lower among black parents than white parents, these personal connections were mentioned among black families with high incomes. One mother wrote,

> Information seems to be limited and at times, when reaching out to schedule behavioral specialist or other services, there is a waiting list. Special needs seems to be placed on the back burner at times, although more and more children/adults are in need of the services and/or resources. I have had to call and inquire from school administration and DPI (Department of Public Instruction). My best resources are from other parents that have children with similar needs.

Black parents also reported significantly higher reliance on print materials (books, pamphlets, and magazines) for information about the local community, including helping their children find autistic peers, and finding sports, recreational, and other community-sponsored activities for individuals with autism (sponsored by ASD-centered organizations and those sponsored by other community organizations).

Education and Online Information Networks

Respondents in higher education brackets were heavier users of online information. There was some evidence of a relationship between education level and the type of information source parents selected but with very limited differences after the bachelor's degree (see table 6). Parents who indicated high school as their highest level of education were less likely than those with bachelor's and master's degrees to seek certain kinds of information from a range of sources. For example, they were significantly less likely to find information about gross- and fine-motor development from local organizations or to find information about autism-friendly local activities, sports, and recreation on local online forums or email listservs.

Respondents who indicated an associate degree as their highest level of education were significantly more likely than those with high school degrees to use forums and email listservs to seek information about sup-

Table 6. Significant differences by education for "Where do you look for information about the following topics related to your child?"

		Education Level				
Source	Topic	HS	Assoc.	BS	MS+	% Diff
National organization websites	Physical growth and development	21.30%	**44.20%**			–22.90%
		21.30%		**44.20%**		–22.90%
National online forums or listservs	Administrative information about your child's school, such as IEP planning, classroom placement, or testing		5.20%		14.10%	–8.90%
	Techniques and exercises to support child's schoolwork	1.60%	**9.80%**			–8.20%
		1.60%		**6.30%**		–4.70%
Local level online forums or listservs	Sports/Recreational ASD-focused activities	6.60%	**20.20%**			–13.60%
		6.60%			**21.80%**	–15.20%
	Community-sponsored ASD-focused activities	4.90%	**22.00%**			–17.10%
		4.90%		**20.60%**		–15.70%
		4.90%			**21.20%**	–16.30%
	Recreational ASD-focused activities	6.60%	**22.00%**			–15.40%
		6.60%		**17.50%**		–10.90%
		6.60%			**21.20%**	–14.60%
	Techniques and exercises to support child's schoolwork	**15.00%**	5.40%			9.60%
Local Organizations	Gross- and- fine motor skills	3.00%		**15.00%**		–12%
Books/Pamphlets/ Magazines	Behavior management		20.00%	**32.00%**		–12.00%

*Significance was set at .05.

Boldface percentages represent higher preference rates of an information source per topic area.

porting their children's learning and schoolwork, school systems, and the education process (i.e., administrative information such as classroom placement and testing), and local recreational, sports, and autism-friendly activities in the local community.

Respondents who indicated a bachelor's degree were significantly more likely to use local online forums or email listservs to help support their child in school than parents with an associate degree. There were no significant differences observable between people who had master's degrees and those who had bachelor's degrees.

Income

The sections below highlight statistically significant differences found among groups by income and present related qualitative responses. All respondent groups, except those in the middle-income group, reported

Table 7. Significant differences by income for “Where do you look for information about the following topics related to your child?”

		Annual Household Income				
Source	Topic	Less than $24,999	$25,000–$49,999	$50,000–$74,999	$100,000 and more	%Diff
National organization websites	Puberty		**33.86%**		17.68%	16.18%
National online forums or listservs	Administrative information about your child’s school, such as IEP planning, classroom placement, or testing		5.51%		**15.47%**	–9.96%
Friends and family	Behavior management	15.07%			**30.39%**	–15.32%
Social workers	Independent living	1.37%		**7.73%**		–6.36%
Local organizations	Sensory-friendly activities		**30.71%**		16.02%	14.69%

*Significance was set at .05.

Bolded percentages represent higher preference rates of an information source per topic area.

doctors and therapists as their most frequently used information source, and social workers and local libraries as the least frequently used source.

There were a few detailed trends that did not conform to the broad trends. Parents who reported an annual household income at or below the federal poverty level (National Center for Children in Poverty at Columbia University 2018) were significantly less likely to consult friends or family for information on behavior management (helping their children manage social/behavioral differences) than those making $100,000 or more annually. They were also less likely overall to seek information from others than from social workers, but significantly more likely to look to social workers for information on helping their young adult children live more independently (see table 7).

Some parents in this group described high levels of frustration seeking information— especially from local government organizations. One wrote, “With regard to services, one sometimes needs to know the secret password in order to find out what is available. This is mostly true when dealing with government agencies. Very frustrating.” The theme of distrust in government agencies and organizations extended to schools, and the perception of mistreatment and lack of training among staff. One mother wrote about her decision to homeschool her child,

> I have researched autism for around 6 years now and I’ve read everything I could find and talked to anyone I could with any knowledge on the subject but the more I’ve researched the more I realize most people have no idea about autism and the ones who do don’t have

> much useful information especially for older kids with autism, the school systems treatment of the autistic kids is barbaric, most parents I speak with home school because of this reason.

For white parents making less than $25,000 per year, the tension between attempting to build strong personal information networks and relying on community services sometimes became frustrating. One parent wrote about their difficulty maintaining knowledgeable personal contacts,

> There seems to be an unusually high percentage of disabled people (all types) in my county, who fill the slots for any kind of targeted activity/living situation quickly. Also, it seems the agencies all seem to work independently and don't know what the others are doing, or don't share with parent other possibilities. I've had to search on my own, wait on waiting lists, not get followed up on waiting lists, get booted off waiting lists w/o being told, gone in circles trying to find any and all services that could help my son throughout his development over the last 15 years. A few individuals have been helpful, but the turnover is high for the various agencies, so I lose my knowledgeable contacts and have to start the process over.

Black parents in this income group overwhelmingly wrote that there are few to no information sources or services available for their children. One parent cited school systems as a source of information, and another cited statewide advocacy groups (the Arc of North Carolina and the Autism Society of North Carolina) as sources of information and services.

Respondents who reported incomes between $25,000 and $49,999 were significantly more likely to find information on sensory-friendly activities from local organizations than respondents with higher incomes. They were also more likely to find information about puberty and sexual development from national organization websites.

Many white parents in this income group discussed a strong reliance on their child's school for information. When schools did a good job of connecting parents to information about local services and educational support for their children, parents were happy. When schools were not supportive or as forthcoming with information, parents expressed pessimism and frustration. One parent wrote, "The IEP process[2] has been very hard to navigate through and fined [*sic*] accurate and helpful incormation [*sic*] about what the process and entails. Our experience with the school system in our area has been awful because he is high functioning and able to get okay grades, they refuse to even accept his diagnosis in the educational rhealm [*sic*]."Another parent described her satisfaction with what she saw as positive outcomes for her child,

> Overall, my child is high-functioning, so right now he is more like a "typical" child with a few quirks. I was much more concerned about his autism and development when he was younger (he was nonverbal

> well into his third year and didn't toilet train until well past his fourth birthday). But early intervention and the help of the local public school district has really seemed to help him get to a place where he interacts with his peers well, keeps up with schoolwork, and is a joy to have in the family.

The little qualitative feedback offered by black parents in this group ($25,000–$49,999) focused on gaps in school systems and the need for additional advocacy in support of their children. One parent wrote, "Some schools need to have more information about asd and where parents can get help."

Location

Parents in metropolitan areas reported significantly higher usage of a range of information sources across *topics* than parents in nonmetropolitan areas, but there are more limited differences in *information sources* between parents in metropolitan and nonmetropolitan areas. The sections below highlight statistically significant differences found among groups by location and present related qualitative responses (see table 8).

People in metropolitan areas reported a significantly higher reliance on local online and national forums and local email listservs than parents in nonmetropolitan areas on a broad range of topics, including helping their child find peers with a similar diagnosis and relate to neurotypical peers, sexuality and dating, independent living for adults with autism, sports and/or recreational activities designed for individuals with autism, and postsecondary school life (higher education, job training, and employment). They also reported significantly higher use of social media for administrative information about their child's education (such as IEP planning, classroom placement, or testing).

Respondents in metropolitan areas also reported significantly higher reliance on local organizations (non-internet interactions, such as meetings, conferences, and presentations) for information on physical growth and development, behavior management, puberty, helping a child find friends (autistic and nonautistic), sexuality and dating, recreational activities, and administrative information about education.

They also reported significantly higher reliance on local libraries, social workers, and printed materials for a range of topics related to locally relevant information needs (e.g., helping a child find peers with similar diagnosis, helping a child relate to neurotypical peers, and finding local sports, recreational, and community activities).

Parents in nonmetropolitan areas reported significantly lower use of most sources, across most topics, with a few exceptions. These parents reported higher reliance on national organization websites for information about how to support their child's school work, and higher reliance on friends and family than parents in metropolitan areas for information

Table 8. Significant differences by location for "Where do you look for information about the following topics related to your child?"

Source	Topic	Metropolitan	Not Metropolitan	% Diff
Local level online forums and email listservs	Administrative information about your child's school, such as IEP planning, classroom placement, or testing	**14.80%**	7.20%	7.60%
	Community-sponsored recreational activities designed for individuals with autism	**20.70%**	10.10%	10.60%
	Helping your child find peers with a similar diagnosis	**13.50%**	1.40%	12.10%
	Helping your child relate to neurotypical peers (peers without ASD)	**10.27%**	0.00%	10.27%
	Higher education, job training, and employment	**7.39%**	1.45%	5.94%
	Independent living	**7.75%**	0.00%	7.75%
	Recreational activities designed by organizations focused on individuals with autism	**20.00%**	8.70%	11.30%
	Sensory-friendly activities	**16.60%**	4.30%	12.30%
	Sexuality and/or dating	**3.78%**	0.00%	3.78%
	Sports and/or recreational activities designed for individuals with autism	**18.70%**	8.70%	10.00%
Local organizations	Helping your child find peers with a similar diagnosis	**31.40%**	8.70%	22.70%
	Puberty	**11.90%**	2.90%	9.00%
	Behavior management	**25.00%**	8.70%	16.30%
	Physical growth and development	**15.90%**	7.20%	8.70%
	Recreational activities designed by organizations focused on individuals with autism	**37.50%**	20.30%	17.20%
	Sensory-friendly activities	**24.14%**	14.49%	9.65%
	Helping your child relate to neurotypical peers (peers without ASD)	**12.10%**	5.80%	6.30%
	Administrative information about your child's school, such as IEP planning, classroom placement, or testing	**30.63%**	18.84%	11.79%
	Sexuality and/or dating	8.80%	0.00%	8.80%
National level online forums and email listservs	Helping your child find peers with a similar diagnosis	**3.40%**	0.00%	3.40%
	Higher education, job training, and employment	**6.50%**	1.40%	5.10%
	Recreational activities designed by organizations focused on individuals with autism	**4.50%**	0.00%	4.50%
	Independent living	**5.95%**	1.45%	4.50%
	Community-sponsored recreational activities designed for individuals with autism	**3.80%**	0.00%	3.80%
	Helping your child relate to neurotypical peers (peers without ASD)	**5.40%**	1.40%	4.00%
	Sexuality and/or dating	**2.50%**	0.00%	2.50%
My local library	Puberty	**3.60%**	0.00%	3.60%
	Recreational activities designed by organizations focused on individuals with autism	**1.40%**	0.00%	1.40%
	Techniques or exercises to support your child's schoolwork	**4.00%**	0.00%	4.00%
	Independent living	**2.00%**	0.00%	2.00%
	Sports and/or recreational activities designed for individuals with autism	**3.40%**	0.00%	3.40%
	Community-sponsored recreational activities designed for individuals with autism	**2.70%**	0.00%	2.70%

continued

Table 8. *continued*

Source	Topic	Metropolitan	Not Metropolitan	% Diff
Social worker	Community-sponsored recreational activities designed for individuals with autism	**5.23%**	0.00%	5.23%
	Helping your child find peers with a similar diagnosis	**4.90%**	0.00%	4.90%
	Recreational activities designed by organizations focused on individuals with autism	**4.70%**	0.00%	4.70%
	Sensory-friendly activities	**4.86%**	1.45%	3.42%
	Sports and/or recreational activities designed for individuals with autism	**4.90%**	0.00%	4.90%
	Helping your child relate to neurotypical peers (peers without ASD)	**5.00%**	1.40%	3.60%
Books, pamphlets,and magazine	Administrative information about your child's school, such as IEP planning, classroom placement, or testing	**10.99%**	4.35%	6.64%
	Helping your child find peers with a similar diagnosis	**5.60%**	1.40%	4.20%
	Sports and/or recreational activities designed for individuals with autism	**9.70%**	2.90%	6.80%
	Community-sponsored recreational activities designed for individuals with autism	**9.01%**	0.00%	9.01%
	Recreational activities designed by organizations focused on individuals with autism	**8.60%**	1.40%	7.20%
Doctors	Helping your child find peers with a similar diagnosis	**12.10%**	5.80%	6.30%
	Puberty	**48.50%**	33.30%	15.20%
Other parents with my child's special needs or disability	Behavior management	**42.00%**	26.10%	15.90%
	Recreational activities designed by organizations focused on individuals with autism	**25.00%**	13.00%	12.00%
Friends and family	Higher education, job training, and employment	11.40%	**23.20%**	–11.80%
National organization websites	Techniques or exercises to support your child's schoolwork	19.10%	**30.40%**	–11.30%
My local library	Administrative information about your child's school, such as IEP planning, classroom placement, or testing	**2.70%**	0.00%	2.70%
Other parents with my child's special need or disability	Administrative information about your child's school, such as IEP planning, classroom placement, or testing	**29.37%**	14.49%	14.88%
National level online forums and email listservs	Helping your child relate to neurotypical peers (peers without ASD)	**5.41%**	1.45%	3.96%
Other websites	Speech and/or language development	**15.90%**	5.80%	10.10%
Social media	Administrative information about your child's school, such as IEP planning, classroom placement, or testing	**10.60%**	4.53%	6.07%

*Significance was set at .05.

Boldface percentages represent higher preference rates of an information source per topic area.

about postschool life (higher education, job training, employment). One parent wrote, "We live in a Rual [*sic*] area 40 mins from a major city. Resources to connect with other with ASD or developmental disabilities are non exsistant [*sic*]."

Discussion

Parents of People with Disabilities have Additional Information Needs

Fundamental to this study is the recognition that parents of people with ASD have information needs related to their children, their own well-being, and seeking information and services in their local communities that differ from those of other parents (Tehee, Honan, and Hevey 2009). The data showed that these parents had difficulty accessing information within their own communities and, overwhelmingly, did not consider the local public library a useful source for addressing their information needs or a place to develop information-seeking skills. There was no mention of libraries in the open-ended responses. This suggests that, despite ongoing efforts to make libraries more accessible spaces, parents were not making meaningful use of the library to fulfill stated information needs.

This suggests that public library systems must do more to build stronger institutional knowledge, policies, and practices if they are to effectively address the diverse information needs of families of people with ASD within their communities. This involves developing strong collaborative partnerships with local support agencies, healthcare facilities, schools, and both parent- and self-advocacy ASD groups to ensure well-informed library staff, boundary-spanning services, inclusive and targeted programming, and collections that are accessible and relevant to all members of the community.

Universal is Not Enough—Intersectional Burdens and Information Access

While the reported data does not demonstrate causality, it does suggest relationships between information-seeking behavior, disability, racial identity, and other demographic characteristics and casts doubt on the effectiveness of one-size-fits-all (or "universal") programming, services, advertising, and collection development for people with disabilities and their families. In addition to the identified variations in information needs by age and life stage, as cited in Gibson, Kaplan, and Vardell (2017), this secondary analysis suggests that parents' information needs and the spaces in which they seek information may be uniquely influenced by intersecting variables, including race, income level, and education level. These intersections of identity were situated within a larger geographical context that determined, broadly, the level of perceived access and barriers to local information and resources (including libraries).

Libraries that seek to meet these families' needs cannot do so by providing "ability blind," "colorblind," or even "need blind" services that do not acknowledge or understand the differing impacts of race, gender, income level, and other markers of identity on family experiences and needs (both in and outside the library). Explicitly evaluating the impacts of library policies—specifically collection-development policies, behavioral policies, borrowing policies, and program participation policies—on different segments of the community can prevent libraries from excluding community members who fall outside of norms established by "universal" or "identity-blind" approaches to librarianship. Those community members whose needs are not served (especially those who are socially or economically vulnerable, such as undocumented community members, or people who work full-time and have incomes at or below poverty level) often avoid the time and/or risk involved in making official complaints; instead, they leave and do not return to the library. Without intentional, structured, and consistent mechanisms for assessing these needs, libraries exclude whole segments of local communities from libraries and are none the wiser.

Services to People with ASD and Their Families: Beyond Access

The data supports recent calls for expansion of library services (and research) for and with people with disabilities to encompass more than basic access and accessibility (Kumbier and Starkey 2016). Most respondents did not consider their local libraries to be useful sources for seeking information related to their children. Despite rhetoric and research about libraries as third places and community anchors (Elmborg 2011), and close partnerships between county libraries and local school systems (e.g., tutoring programs and shared public/school library programming), parents did not perceive libraries as useful places to find information about local community services and activities or as helpful in developing strategies to better support their children with school work.

Local Knowledge and Building Inclusive Places

Autistic people and their families often experience stigma and social exclusion in their local communities (Kinnear et al. 2016). The data suggests the importance of local information literacy—knowledge about what local community, services, and information sources exist in and outside of the library, and knowledge of *how* to find that information in the local community. Several respondents discussed an inability to find a local community and the lack of any sort of local information clearinghouse—a space where they could go to find locally relevant information. While it might not be reasonable to expect public librarians to maintain this knowledge or these spaces alone, they can serve as community anchors by referring community members in need to local organizations and, with permission, knowledgeable individuals (Moxley and Abbas 2016).

Limitations

The primary limitation of this study is that it presents secondary analysis of a nonrandomized data sample. The panel sample is composed of parents of people with ASD who access medical or other services through the University of North Carolina (or its remote area health-education centers) and who have agreed to participate in research studies. As there are other major healthcare providers in the state, this is far from a census of the population. Although this severely limits the generalizability of the data, the sample size suggests that it does provide a suitable sample for studying the effects in question. Because this is a secondary analysis, there was an insufficiently representative sample with which to study racial groups other than black and white. Future research should include oversamples of respondents in other racial and ethnic categories, so that data analysis may be expanded.

Conclusion

Autistic people are not a monolith, and they and their families have a variety of needs. Understanding how race, income, education, and location can impact parents' access to information and source preferences can help libraries and library staff to plan services and develop collections that serve this population effectively. Libraries, as local community institutions that purport to be anchors or third places (Elmborg 2011), can impact the way individuals and groups experience their communities and their ability to seek access to various kinds of information. American libraries provide valuable services to vulnerable populations, offering access to the internet, clean and safe study and meeting spaces, information, written and other materials, education, and connection to community support resources and services.

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Notes

1. See also the *Chicago Manual of Style Online*, 17th ed., § 5.260, "Avoiding other biased language," accessed August 15, 2018, https://www.chicagomanualofstyle.org.
2. Individualized education plans or programs (in U.S. public schools) are intended to document disabilities and establish annual academic needs of a child with a disability. They should include any modifications to the general curriculum and pedagogy, alternate assessments, and assistive technology needs, and should comply with federal and state law. IEPs should be written by a team that includes the child (if over thirteen years old), the

child's parents, teachers, school-based therapists, and special education administrators (Individuals with Disabilities Education Act 2004. 20 U.S.C. § 1400).

References

Al-Daihani, Sultan M. and Huda I Al-Ateeqi. 2015. "Parents of Children with Disabilities in Kuwait: A Study of Their Information Seeking Behaviour." *Health Information & Libraries Journal* 32 (2): 131–42.

ALA (American Library Association). 2006a. "Core Values of Librarianship." http://www.ala.org/advocacy/intfreedom/corevalues.

———. 2006b. "Library Services for People with Disabilities Policy." Association of Specialized and Cooperative Library Agencies (ASCLA) (website). December 4, 2006. http://www.ala.org/asgcla/resources/libraryservices.

———. 2008. *ALA Code of Ethics.* Chicago: American Library Association. http://www.ala.org/united/sites/ala.org.united/files/content/trustees/orgtools/policies/ALA-code-of-ethics.pdf.

———. 2013. *Libraries Change Lives: Declaration for the Right to Libraries.* Chicago: American Library Association Public Programs Office.

Barker, Denise. 2011. "On the Outside Looking In: Public Libraries Serving Young People with Disabilities." *APLIS* 24 (1): 9–16.

Burke, Susan K. 2009. "Perceptions of Public Library Accessibility for People with Disabilities." *Reference Librarian* 50 (1): 43–54.

Carbone, Paul S., Diane D. Behl, Virgina Azor, and Nancy A. Murphy. 2010. "The Medical Home for Children with Autism Spectrum Disorders: Parent and Pediatrician Perspectives." *Journal of Autism and Developmental Disorders* 40 (3): 317–24.

Carter, Erik W. 2013. "Supporting Inclusion and Flourishing in the Religious and Spiritual Lives of People with Intellectual and Developmental Disabilities." *Inclusion* 1 (1): 64–75.

Carter, Erik W., Thomas L. Boehm, Elizabeth E. Biggs, Naomi H. Annandale, Courtney E. Taylor, Aimee K. Loock, and Rosemary Y. Liu. 2015. "Known for My Strengths: Positive Traits of Transition-Age Youth with Intellectual Disability and/or Autism." *Research and Practice for Persons with Severe Disabilities* 40 (2): 101–19.

CDC (Centers for Disease Control and Prevention). 2014. "Prevalence of Autism Spectrum Disorder among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010." *Morbidity and Mortality Weekly Report. Surveillance Summaries* 63 (2): 1–21.

Charman, Tony, Andrew Pickles, Emily Simonoff, Susie Chandler, Tom Loucas, and Gillian Baird. 2011. "IQ in Children with Autism Spectrum Disorders: Data from the Special Needs and Autism Project (SNAP)." *Psychological Medicine* 41 (3): 619–27.

Chatman, Elfreda A. 1996. "The Impoverished Life-World of Outsiders." *Journal of the American Society for Information Science (1986–1998)* 47 (3): 193–206.

Christensen, Clayton M. 1997. *The Innovator's Dilemma : When New Technologies Cause Great Firms to Fail.* Boston: Harvard Business School Press.

Crenshaw, Kimberlé. 2016. "Kimberlé Crenshaw on Intersectionality." WOW 2016 Keynote. YouTube video. 30:46. Available on Southbank Centre blog. https://www.southbankcentre.co.uk/blog/kimberl%C3%A9-crenshaw-wow-2016-keynote.

Cummings, Janet R., Frances L. Lynch, Kristal C. Rust, Karen J. Coleman, Jeanne M. Madden, Ashli A. Owen-Smith, Vincent M. Yau, Yinge Qian, Kathryn A. Pearson, and Phillip M. Crawford. 2016. "Health Services Utilization among Children with and without Autism Spectrum Disorders." *Journal of Autism and Developmental Disorders* 46 (3): 910–20.

Cylke, Frank K., Michael M. Moodie, and Robert E. Fistick. 2007. "Serving the Blind and Physically Handicapped in the United States of America." *Library Trends* 55 (4): 796–808.

Dawson, Michelle, Isabelle Soulières, Morton Ann Gernsbacher, and Laurent Mottron. 2007. "The Level and Nature of Autistic Intelligence." *Psychological Science* 18 (8): 657–62.

Dunn, Dana S., and Erin E. Andrews. 2015. "Person-First and Identity-First Language: Developing Psychologists' Cultural Competence Using Disability Language." *American Psychologist* 70 (3): 255–64.

Elmborg, James K. 2011. "Libraries as the Spaces between Us: Recognizing and Valuing the Third Space." *Reference & User Services Quarterly* 50 (4): 338–50.

Gibson, Amelia N. 2014. "A Better Place? Factors in Community Assessment for Parents of

Children with Down Syndrome." *Proceedings of the Association for Information Science and Technology* 51 (1): 1–10.

Gibson, Amelia N., Samantha Kaplan, and Emily Vardell. 2017. "A Survey of Information Source Preferences of Parents of Individuals with Autism Spectrum Disorder." *Journal of Autism and Developmental Disorders* 47 (7): 2189–204. https://doi.org/10.1007/s10803-017-3127-z.

Harris, Roma, Judy Stickney, Carolyn Grasley, Gail Hutchinson, Lorraine Greaves, and Terry Boyd. 2001. "Searching for Help and Information: Abused Women Speak Out." *Library & Information Science Research* 23 (2): 123–41.

Heilker, Paul. 2012. "Autism, Rhetoric, and Whiteness." *Disability Studies Quarterly* 32 (4). http://dsq-sds.org/article/view/1756/3181.

Holmes, Jennifer L. 2008. "Patrons with Developmental Disabilities: A Needs Assessment Survey." *New Library World* 109 (11/12): 533–45.

Jackson, Rachel, Wendy Baird, Loretta Davis-Reynolds, Christine Smith, Stephen Blackburn, and Janet Allsebrook. 2008. "Qualitative Analysis of Parents' Information Needs and Psychosocial Experiences when Supporting Children with Health Care Needs." *Health Information & Libraries Journal* 25 (1): 31–37.

Jacobson, John W., and James A. Mulick. 2000. "System and Cost Research Issues in Treatments for People with Autistic Disorders." *Journal of Autism and Developmental Disorders* 30 (6): 585–93.

Jaeger, Paul T. 2018. "Designing for Diversity and Designing for Disability: New Opportunities for Libraries to Expand Their Support and Advocacy for People with Disabilities." *International Journal of Information, Diversity, and Inclusion* 2 (1–2): 52–66.

Kenny, Lorcan, Caroline Hattersley, Bonnie Molins, Carole Buckley, Carol Povey, and Elizabeth Pellicano. 2016. "Which Terms Should Be Used to Describe Autism? Perspectives from the UK Autism Community." *Autism* 20 (4): 442–62.

Kinnear, Sydney H., Bruce G. Link, Michelle S. Ballan, and Ruth L. Fischbach. 2016. "Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives." *Journal of Autism and Developmental Disorders* 46 (3): 942–53.

Knott, Cheryl. 2016. *Not Free, Not for All: Public Libraries in the Age of Jim Crow.* Amherst: University of Massachusetts Press.

Kumasi, Kafi D. 2012. "Roses in the Concrete: A Critical Race Perspective on Urban Youth and School Libraries. *Knowledge Quest* 40 (5): 32–37.

Kumbier, Alana, and Julia Starkey. 2016. "Access Is Not Problem Solving: Disability Justice and Libraries." *Library Trends* 64 (3): 468–91.

Mackintosh, Virginia H., Barbara J. Myers, and Robin P. Goin-Kochel. 2005. "Sources of Information and Support Used by Parents of Children with Autism Spectrum Disorders." *Journal on Developmental Disabilities* 12 (1): 41–51.

Mann, Horace. 1957. "Twelfth Annual Report to the Massachusetts Board of Education." In *The Republic and the School: Horace Mann and the Education of Free Men,* edited by Lawrence A. Cremin, 79–112. New York: Teachers College Press.

Miller, Lucy J., Darci M. Nielsen, Sarah A. Schoen, and Barbara A. Brett-Green. 2009. "Perspectives on Sensory Processing Disorder: A Call for Translational Research." *Frontiers in Integrative Neuroscience* 3:1–12.

Montgomery, Janine M., Vicki L. Schwean, Jo-Anne G. Burt, Danielle I. Dyke, Keoma J. Thorne, Yvonne L. Hindes, Adam W. McCrimmon, and Candace S. Kohut. 2008. "Emotional Intelligence and Resiliency in Young Adults with Asperger's Disorder: Challenges and Opportunities." *Canadian Journal of School Psychology* 23 (1): 70–93. https://doi.org/10.1177/0829573508316594.

Moxley, David P., and June M. Abbas. 2016. "Envisioning Libraries as Collaborative Community Anchors for Social Service Provision to Vulnerable Populations." *Practice* 28 (5): 311–30.

Naisbitt, John. 1984. *Megatrends: Ten New Directions Transforming Our Lives.* New York: Warner Books.

National Center for Children in Poverty at Columbia University. 2018. "North Carolina Demographics of Poor Children." Accessed August 20, 2018. http://www.nccp.org/profiles/NC_profile_7.html.

Özyazıcıoğlu, Nurcan, and Gonca Buran. 2014. "Social Support and Anxiety Levels of Parents with Disabled Children." *Rehabilitation Nursing* 39 (5): 225–31.

Pionke, JJ. 2017. "Toward Holistic Accessibility: Narratives from Functionally Diverse Patrons." *Reference & User Services Quarterly* 57 (1): 48–56.

Prendergast, Tess. 2016. "Seeking Early Literacy for All: An Investigation of Children's Librarians and Parents of Young Children with Disabilities' Experiences at the Public Library." *Library Trends* 65 (1): 65–91.

Putnam, Michelle. 2005. "Conceptualizing Disability: Developing a Framework for Political Disability Identity." *Journal of Disability Policy Studies* 16 (3): 188–98.

Riosa, Priscilla Burnham, Victoria Chan, Andrea Maughan, Victoria Stables, Carly Albaum, and Jonathan A. Weiss. 2017. "Remediating Deficits or Increasing Strengths in Autism Spectrum Disorder Research: A Content Analysis." *Advances in Neurodevelopmental Disorders* 1 (3): 113–21.

Rose, Stephen. 2016. *The Growing Size and Incomes of the Upper Middle Class.* Research report. Urban Institute, Income and Benefits Policy Center. June 2016. https://www.urban.org/sites/default/files/publication/81581/2000819-The-Growing-Size-and-Incomes-of-the-Upper-Middle-Class.pdf.

Savolainen, Reijo. 1995. "Everyday Life Information Seeking: Approaching Information Seeking in the Context of 'Way of Life.'" *Library & Information Science Research* 17 (3): 259–94.

Scheuffgen, Kristina, Francesca Happeè, Mike Anderson, and Uta Frith. 2000. "High 'Intelligence,' Low 'IQ'? Speed of Processing and Measured IQ in Children with Autism." *Development and Psychopathology* 12 (1): 83–90.

Schomberg, Jessica. 2018. "Disability at Work: Libraries, Built to Exclude." In *The Politics of Theory and the Practice of Critical Librarianship,* edited by Karen P. Nicholson and Maura Seale, 111–23. Sacramento: Library Juice Press.

Scotch, Richard K. 2000. "Models of Disability and the Americans with Disabilities Act." *Berkeley Journal of Employment & Labor Law* 21:213–22.

Shildrick, M. 2012. "Critical Disability Studies: Rethinking the Conventions for the Age of Postmodernity." In *Routledge Handbook of Disability Studies*, edited by Nick Watson, 44–55. London: Routledge.

Sin, Sei-Ching Joanna, and Kyung-Sun Kim. 2008. "Use and Non-use of Public Libraries in the Information Age: A Logistic Regression Analysis of Household Characteristics and Library Services Variables." *Library & Information Science Research* 30 (3): 207–15.

Stripling, Barbara K. 2013. "President's Message: Libraries Change Lives." *American Libraries* 44 (7/8): 6–7.

Tehee, Erin, Rita Honan, and David Hevey. 2009. "Factors Contributing to Stress in Parents of Individuals with Autistic Spectrum Disorders." *Journal of Applied Research in Intellectual Disabilities* 22 (1): 34–42.

Teti, Michelle, Nancy Cheak-Zamora, Bridget Lolli, and Anna Maurer-Batjer. 2016. "Reframing Autism: Young Adults with Autism Share Their Strengths through Photo-Stories." *Journal of Pediatric Nursing: Nursing Care of Children and Families* 31 (6): 619–29.

Thomas, James, and Angela Harden. 2008. "Methods for the Thematic Synthesis of Qualitative Research in Systematic Reviews." *BMC Medical Research Methodology* 8 (1): 45.

Wehmeyer, Michael L, and Karrie A Shogren. 2014. "Disability and Positive Psychology." In *Perspectives on the Intersection of Multiculturalism and Positive Psychology*, edited by Jennifer Teramoto Pedrotti and Lisa M. Edwards, 175–88. Dordrecht, Netherlands: Springer.

Weiss, Jonathan A., Barry Isaacs, Heidi Diepstra, Andrew S. Wilton, Hilary K. Brown, Caitlin McGarry, and Yona Lunsky. 2018. "Health Concerns and Health Service Utilization in a Population Cohort of Young Adults with Autism Spectrum Disorder." *Journal of Autism and Developmental Disorders* 48 (1): 36–44.

Williams, P. 2002. "The Competent Boundary Spanner." *Public Administration* 80 (1): 103–24.

Wilson, Thomas D. 2000. "Human Information Behavior." *Informing Science* 3 (2): 49–56.

Xu, Guifeng, Lane Strathearn, Buyun Liu, and Wei Bao. 2018. "Prevalence of Autism Spectrum Disorder among US Children and Adolescents, 2014–2016." *JAMA* 319 (1): 81–82. https://doi.org/10.1001/jama.2017.17812.

Young, Roxanne K. (2007) 2009. "Disabilities." In *AMA Manual of Style: A Guide for Authors and Editors*." 10th ed., edited by Cheryl Iverson et al. New York: Oxford University Press, 2007; online ed., 2009. http://www.amamanualofstyle.com/view/10.1093/jama/9780195176339.001.0001/med-9780195176339-div2-353.

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