

A Survey of Information Source Preferences of Parents of Individuals with Autism Spectrum Disorder

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Abstract For parents of children with an Autism spectrum disorder (ASD), high quality, easily accessible information and a strong peer network can be the key to raising a happy, healthy child, and maintaining family well-being and emotional resilience. This article reports the findings of an anonymous survey examining the information source preferences for 935 parents of individuals with ASDs in North Carolina. Data indicates that parents show similar information seeking patterns across the age spectrum, that availability of information (as indicated by overall information source selection) decrease as children age. It also shows that parents rely heavily on local sources of information, preferring them to nonlocal sources (such as the internet) for many types of information.

Keywords Autistic disorder · Family · Information seeking behavior parents · Social support · TEACCH

Introduction

For parents of children with an Autism spectrum disorder (ASD), high quality, easily accessible information and a strong peer network can be the key to raising a happy, healthy child, and maintaining family well-being and emotional resilience (King et al. 2006). Parents search, browse, organize, store, use and share sometimes highly specialized information related to their children's particular diagnoses

and needs (e.g., information related to health, development, education, and independent living) (Rodrigue et al. 1992). Those who actively seek information have increased levels of information literacy related to a range of everyday life information topics (Walker 2009). Besides serving to inform parents, information seeking (individually and socially) can serve as a coping mechanism to manage stresses (Pifalo et al. 1997), and help parents make connections with other parents and engage with local and nonlocal communities of support (Gibson 2014; Özyazıcıoğlu and Buran 2014).

Although parent information seeking is important to child welfare, few survey studies examine information seeking behaviors and source preferences. The lack of quantitative information seeking data limits understanding of information seeking behavior of parents across age (and other demographic) groupings, and limits comparisons between and among information source types. This type of data would be useful in highlighting gaps between information needs and information source availability and accessibility. Ideally, research on information seeking drives evolving information technology and systems design, and research on information needs drive policy and service planning. This research should take into account the expanding needs of people with ASD and their families, who often seek information on their behalf (Gibson 2014). As services and interventions improve and people with ASD face new possibilities and challenges, their parents and caretakers experience new medical, educational, and social information needs. Understanding these changing needs benefits families and individuals with ASD as they inform organizational and governmental policy on health, education, social communication and information provision.

This article examines information source preferences of parents of individuals with ASD from the perspective of

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the information seeker. Of particular interest are contrasts between use of local and non-local sources, parent use of internet based sources, and differences in information seeking as children age. The study explores the following research questions:

- 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 needs?
- What is the role of local information sources in meeting parent information needs?

Literature Review

Information Seeking and Autism

Few survey studies have examined the information seeking behaviors of parents of individuals with ASD. Mackintosh, et al. (2005) surveyed parents of 498 children, and examined sources of information and sources of support. The researchers found that written materials (e.g., books, web pages, email listservs, and newsletters) were the most popular sources of information about ASD, and that other parents of children with ASD were, by far, the most popular face-to-face source of information (as opposed to physicians, teachers, or other professionals). Rhoades et al. (2007) examined provision of information to parents of children with ASD at the point of diagnosis. The researchers surveyed 146 parents about the amount of information they received from their providers at the time of diagnosis, the autism-related services they used, and their evaluations of those services. They found that most providers gave parents information about ASD at the time of diagnosis, that most children with ASD are diagnosed at age 3 or later, and that parents and caregivers used “the media, conferences, and other parents to learn more about ASD” (Rhoades et al. 2007, p. 8). Both studies found that financial resources, and personal and family social networks had a strong influence on parent information sources and emotional well-being.

Qualitative studies have explored various facets of information in the lives of people with ASD. Researchers have found that information seeking and social support play an important role in coping and parent resilience (e.g., Rivers and Stoneman 2003; Twoy et al. 2007). Others have focused outside of the family on institutional perspectives, such as programming for individuals with ASD in libraries (Akin and MacKinney 2004; Flaherty 2013; Halvorson 2006; Winson and Adams 2010); technical interventions, such as telehealth (Nazneen et al. (2015), and assistive technology (McEwen 2014).

Few studies have addressed the information behavior and needs of individuals with ASD or their caregivers from the perspective of the information seeker. Twombly et al. (2011) did examine the information behavior of ASD caregivers—but only their internet usage for caregiving information. Grant et al. (2016) found “parents’ preferred style of information and content changed throughout their journey” (p. 131) and also reported some information behaviors—such as using ASD workshops or services to make treatment decisions, but the Australian parents participating in their interviews and small focus groups were demographically rather homogeneous.

Age at ASD diagnosis can vary widely and some studies have found significant demographic variation. Examining Canadian children diagnosed between 1997 and 2005, Ouellette-Kuntz et al. (2009) found statistically significant geographic region variation. Delayed diagnosis has been found repeatedly among African American and black children in the United States (Mandell et al. 2002, 2009). Despite this, little attention has been given to demographic variation in information behavior.

This study fills a gap current knowledge about information source selection, the availability of information sources, and information seeking behavior among parents of individuals with ASD.

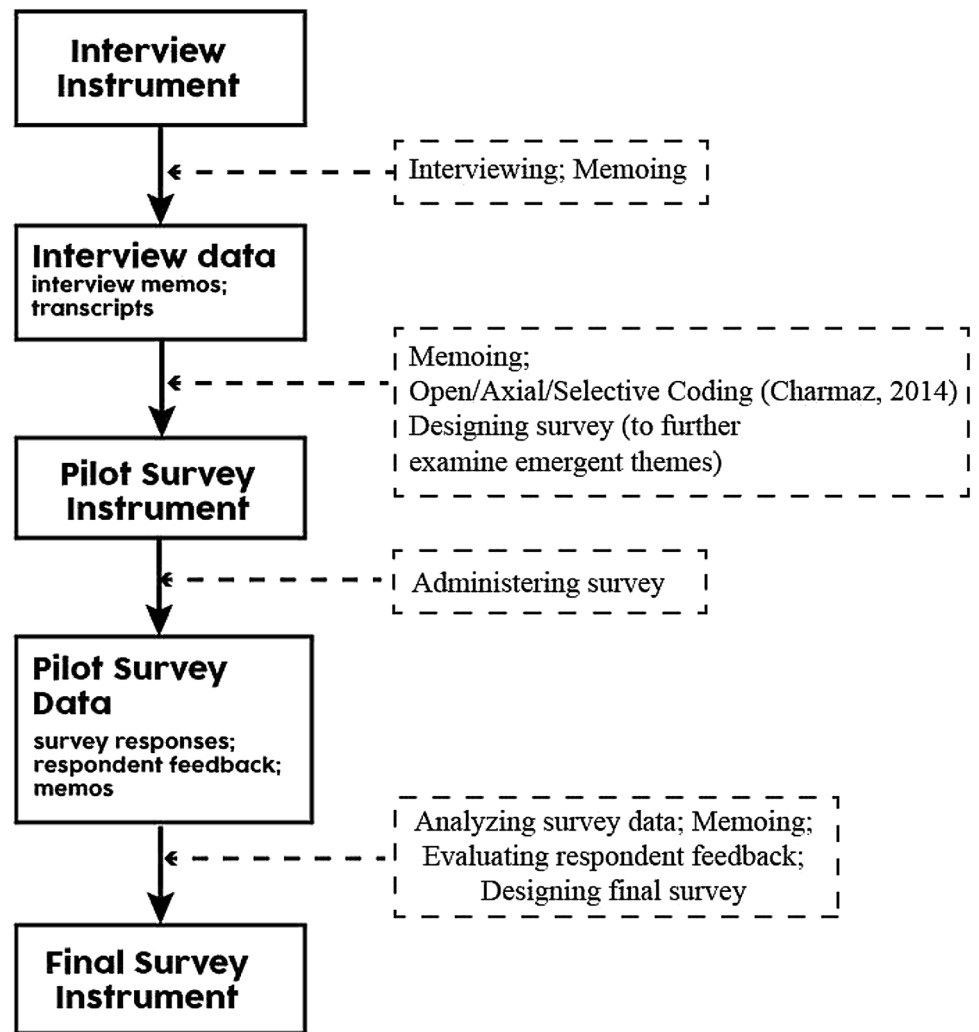
Methods

This study engaged a two-phased, mixed-method research design that included semi-structured interviews and a parent survey. Figure 1 illustrates the survey development process from development of the interview instrument through development of the final survey. Findings from interviews and a review of the literature on information seeking among parents of individuals with ASD were used to develop a pilot survey, which was administered face-to-face in December of 2014. Findings and memos from the pilot survey were used to develop an expanded, final web survey instrument. The final web survey was launched during June of 2015, and was open for 1 month. This article reports findings of questions 7–11 of the survey, which asked parents where, in the last 12 months, they had sought information about 16 specific topics.

Sample and Recruiting

Interview Sample

The initial sample of six interview participants (all mothers of individuals with ASD ages 3–18 years of age) was taken from a larger sample of parents (N=41) of individuals with various disabilities collected between 2011 and

Fig. 1 Survey development process

2015. The larger sample was drawn for a grounded theory study on parent information needs, information access, and information behavior in community, and included parents in five U.S. states (Texas, California, North Carolina, Florida and Georgia). Interview participants were primary caretakers for a child with a diagnosed developmental disability (Down syndrome or ASD), living in the United States. Theoretical sampling was used for interviews (Charmaz 2014), and interviews were halted when theoretical saturation for the entire sample was reached. The survey instrument was developed to examine whether interview findings related specifically to ASD were applicable to a larger sample (and wider age range) of participants who were parents of individuals with ASD.

Web Survey Sample

Survey findings are based on a non-random sample of parents of individuals with ASD who had sought support or services through the University of North Carolina

at Chapel Hill or one of its affiliate organizations, and had agreed to participate in autism-related research as part of the Research Participant Registries Core (N=4200). No exclusions were made for comorbidities or dual diagnoses. Survey recruiting was done in partnership with the Carolina Institute for Developmental Disabilities (CIDD) Research Participant Registries Core and local community leaders. Potential participants were emailed an introduction to the study and a direct link to the survey by the CIDD.

Because there is no complete census of individuals with ASD, there is no way to establish a complete sampling frame. An approximation of the required sample size was determined using the North Carolina Autism and Developmental Disabilities Monitoring Network ASD prevalence of one in every 58 children in the state of North Carolina in 2014 (CDC 2014). In 2014, the population of North Carolina was estimated at 9,943,964, making the approximated ASD population 171,448. Although this was a web survey with a nonprobability sample, a minimum sample size was calculated using a confidence

Table 1 Participant demographics (Final survey data)

Reported sex (n=629)	
Female	87.4% (n=550)
Male	12.2% (n=77)
Other	0.3% (n=2)
Reported parent income (n=615)	
Less than \$10,000	3% (n=16)
\$10,000–\$24,999	9% (n=57)
\$25,000–\$49,999	21% (n=127)
\$50,000–\$74,999	19% (n=116)
\$75,000–\$99,999	19% (n=118)
\$100,000 or more	29% (n=181)
Reported race (n=632)	
White	84% (n=531)
Black/African American	11.4% (n=72)
Asian/Asian American	1.6% (n=10)
Native Hawaiian/Pacific Islander	0.2% (n=1)
Native American	0.3% (n=2)
Two or more races	1.7% (n=11)
Other race	3.3% (n=21)
Reported ethnicity (n=629)	
Hispanic	4.1% (n=26)
Not Hispanic	94.3% (n=593)
Child age of diagnosis (n=636)	
0–12 months of age	0.6% (n=4)
13 months to 3 years of age	37.1% (n=236)
37 months to 5 years and 11 months of age	28.9% (n=184)
6–12 years of age	27.2% (n=173)
13 years of age or older	6% (n=38)
Child's current age (n=635)	
0–12 months of age	0.5% (n=3)
13 months to 3 years of age	1.9% (n=12)
37 months to 5 years and 11 months of age	6.2% (n=40)
6–12 years of age	39.4% (n=250)
13–17 years of age	29.1% (n=185)
18 years of age or older	22.8% (n=145)

level of 95%, and a confidence interval of 3.5, making a minimum target sample size of 780 respondents. Out of N=4200 invitations, there were n=935 responses (22% response rate). See Table 1 for a summary of demographic participant data, which are rounded to the nearest whole percent. It should be noted that participants were not required by the survey form to answer demographic questions, so the total number of responses for each question are indicated. This variation has implications for analysis of age data, in that the sample size for this data was smaller than the complete sample.

Instrument Design

Because this article focuses on survey findings, description of the interview data collection and findings are presented here as part of the discussion of survey instrument design.

Interview Design and Qualitative Analysis

The initial interview protocol was adapted from the information horizons interview protocol (Sonnenwald et al. 2001), which prompts participants to describe a wide range of information seeking experiences and preferences.

The qualitative analysis process was guided by Charmaz's (2014) constructivist grounded theory framework. Data collection and analysis occurred iteratively and concurrently, with summative and analytical memos (Charmaz 2014) done by the interviewer and one other researcher. Iterative coding of interview data began with a list of general coding categories based on previous research of parents of individuals with disabilities (Gibson 2014). These included information needs, information seeking, and information sources related to the following broad (parent-identified) categories:

- Medicine and health
- Therapy
- School and education
- Employment and higher education
- Social and recreational activities
- Government agencies/Financial assistance

Researchers also used open and axial coding to identify newly emergent themes related to parent information needs and source preferences (coding category A), information access and poverty in local communities (coding category B), and patterns of information behavior post-diagnosis (further explored in Gibson 2016). Design for the survey was based on Information Needs and Source Preferences codes. Initial simple (percentage) intercoder agreement was scored at 80%. Periodic debriefing ensured continued intercoder agreement on coding. Expansion and refinement of the previously listed categories resulted in a new set of emergent coding categories.

Within the Information Needs and Source Preferences category, three themes emerged. This article examines themes 1 and 2 (theme 3 will be examined in a separate article as it requires more expansive analysis than can be provided here):

1. Importance of child age and life stage for determining parent information needs. Parent information needs varied with the ages of their children, and parents of children in the same age group shared similar informa-

Table 2 Information needs by reported child age (Interview data)

Age	Information needs
13 months–3 years	Information about day care/school options; school entrance; milestones/development; therapy/early intervention; diagnosis
37 months–5 years	Therapy; growth and development; school placement; school transportation issues; diagnosis; medical care
6–12 years	Behavior management; school placement/education/student's rights/IEP; therapy; social interaction & recreational activities; medical care
13–17 years	Behavior management; social interaction & recreational activities; school/education; school transitions; higher education and employment, sexuality and relationships; independent living/self-care

Table 3 Emergent source categories (Interview data)

Online/internet sources
National organization websites
Social media
Local email listservs
National online forums/email listservs
Other websites
Non-internet sources
Local organizations
Therapists
Social workers
Other parents of people with ASD
Doctors
Friends and family
Local library

tion needs. Table 2 outlines parent information needs reported by interview participants according to child age.

- Importance (and sometimes scarcity) of local, transactional and procedural information and information sources. As an example, one mother describes how difficulty finding information about the process of preschool enrollment in her local community discouraged her from enrolling her daughter in preschool (*edited for brevity and clarity*):

I was like “I wish there was just a map that said, this school has this program, this school has...just so I kind of understood how it all worked and the process of it, because it's very overwhelming.” And I feel like I'm asking very basic questions to people and they can't even give me an answer sometimes... for a long time I wasn't sure if I was going to send her to even the pre-K she's at now.

Table 3 outlines information sources described in interviews and pilot survey findings (not just those focused on transactional information).

- Differences in information seeking behavior and source preferences among parents of different racial and ethnic backgrounds.

Findings were used to create survey questions, possible responses, and to determine age categories for data analysis. Categories and codes generated from interview data were drafted into a pilot (paper form) survey that was conducted at a family fair for parents of children with disabilities in December of 2014 ($n=22$). Verbal and written feedback from the pilot survey forms, and findings from a literature review on parent information needs were incorporated into development of the web survey instrument.

Pilot Survey

A short version of Table 3 data was used to design an initial eight-question paper pilot survey ($N=22$ participants) that did not separate information needs into topic areas. Table 4 lists pilot survey questions. Overwhelming feedback from participants (outside of survey responses) indicated that a more needs-specific, segmented approach was necessary. Survey question #5, which asked about information needs broadly, was expanded to questions 7–11, which asked about information seeking and source choices related to 16 specific topics.

Translation to Survey Design

Figure 2 illustrates one of four resulting survey question matrices as presented to respondents via the online survey administered in Qualtrix. The 4 question sets covered a total of 16 information-seeking topics (y-axis in matrix) and 13 information sources (x axis in matrix). An open response question asked “Is there any other information you'd like to share about your experiences seeking information related to your child with ASD?” Trends are discussed in findings.

Table 4 Pilot survey questions
(Pilot survey data)

Where do you look for information about things that you consider related to your child or loved one's special need or disability? (PLEASE CIRCLE ALL THAT APPLY)

The Internet

Websites (Ex: WebMD)	Local level online forums / email listservs
National organization websites	National level online forums / email listservs
Social media (Ex: Facebook, Twitter, Pinterest)	Other: _____

Non-Internet

Local organizations (such as ASNC or Piedmont Down Syndrome Network – please name)	Other parents of children with my child's special need or disability
Therapists	Doctors
Social Worker	Friends/Family members
Books/pamphlets/magazines	My local library
Other (please describe): _____	

Think about the last time you had difficulty finding information about a matter related to your loved one's special need. Please describe the information you needed, and please list the steps you took to find the information.

Where do you think you *should* have been able to find this information?

Where, in the last 12 months, have you looked for information about the following topics related to your child?															
	Internet						Non-Internet								
	National organization websites	Social media	Local level online forums / email listservs	National level online forums / email listservs	Other websites	None of these	Local organizations	Therapists	Social Workers	Books/ pamphlets/ magazines	Other parents with my child's special need or disability	Doctors	Friends and family	My local library	None of these
Helping your child find peers with a similar diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helping your child relate to neurotypical peers (peers without ASD)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexuality and/or dating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Independent living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Fig. 2 Information seeking question matrix

Quantitative Data Analysis

Quantitative data were analyzed in three steps. First researchers tallied the total number of parents who selected each source for the given topic, and calculated the percentage of parent use of each of 13 given information sources (“source selected”) for each of 16 information seeking topics. This data was used to create percentage of information source selection tables for all age groups, and disaggregated by age (see Table 5). This data was used as the basis for discussion of information source selection regarding specific topics, and for calculation of Parent Information

Sources Accessed by Category tables and charts presented in the Findings.

Parent Information Sources Accessed by Category

These scores were used to describe the relative popularity of each information source without regard to the specific topic. To assign this score, researchers calculated the percentage of parents in each age group who used each of 13 given information sources across all given topics. This score of Parent Information Sources Accessed by Category was calculated as follows:

Table 5 Example of percentage of information source selection by age and topic (Final survey data)

13 months to 3 years of age					
#	Question	Local orgs (%)	Therapists (%)	Soc. workers (%)	Books/ written (%)
1	Physical growth/development	16.67	58.33	16.67	33.33
2	Behavior management	33.33	75.00	25.00	25.00
3	Speech and/or language development	25.00	83.33	16.67	25.00
4	Gross and/or fine motor skills	27.27	72.73	18.18	27.27
5	Puberty	9.09	9.09	0.00	18.18
6	Helping your child find peers with a similar diagnosis	54.55	45.45	18.18	0.00
7	Helping your child relate to neurotypical peers	36.36	36.36	18.18	0.00
8	Sexuality and/or dating	0.00	0.00	0.00	0.00
9	Independent living	0.00	10.00	0.00	10.00

$$\frac{\sum \text{source counts for age category}}{(\# \text{participants in age group} \times \# \text{sources selected})}$$

These scores are represented in Fig. 3, and are used to support discussion about parent information seeking within age groups, by category. Finally, the means of these scores were calculated across all categories for a comparative score of parent information seeking by age group (see Fig. 4). Because the study was based on a nonrandom sample, results are presented and discussed in terms of trends for future study.

Results

Each subsection of the results presents findings on three levels of analysis. The first compare the popularity of each information source (e.g., National organization websites, social media, or local organizations) across all 16 topics (a list of topics can be found in Table 6) for all age groups. The second compare a subset (4 out of 16 total topics) of more granular data describing percentages of parents who selected specific information sources by age group. Finally, these two datasets are complimented by qualitative data from the open-ended question on parent information source selection.

Patterns in Parent Information Seeking by Reported Child Age

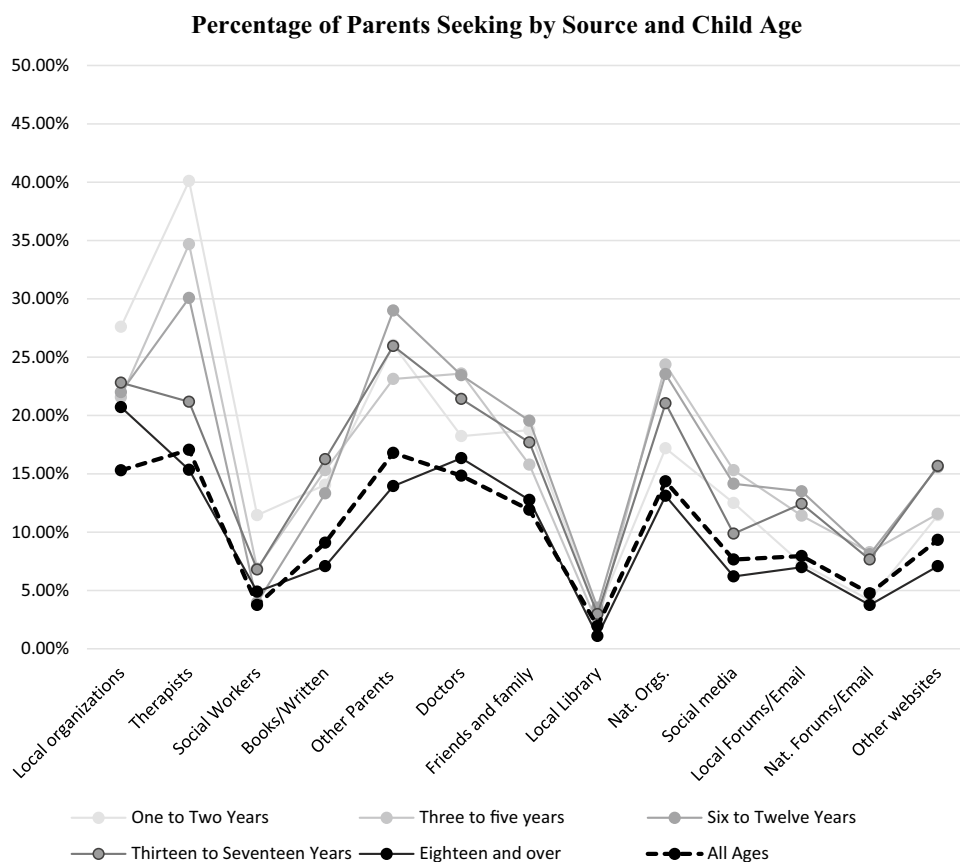
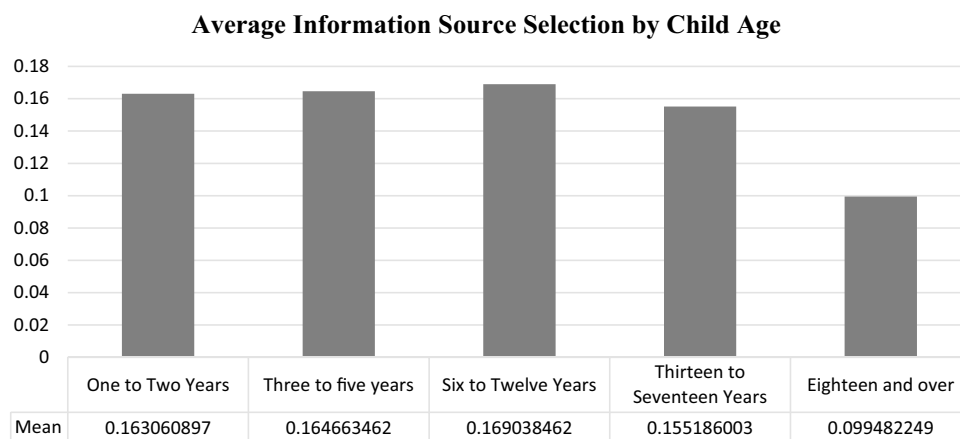
Survey data showed that parent selection of information sources followed similar patterns over the range of child ages, with an overall reduction in total information source selection as children aged into adulthood. Figure 3 describes aggregated responses to questions about

information sources used during the previous year, sorted by the reported age of the participant's child with ASD. The dotted line (All ages) indicates responses for all respondents, including those who did not indicate their child's age ($n = 935$).

Parents of children in different age groups showed similar relative patterns of information source preferences. For parents of children ages 1–12, therapists were the most frequently consulted information source, followed by other parents of individuals with ASD. For most parents, social workers, and the local library were not used as a sources of information. Parents of adult children consulted fewer information sources on average than parents in other groups (see Fig. 4). The following provides a brief summary of information seeking related to development, school, social interaction, puberty and sexual development, higher education, and employment. For each age group, the most and least frequently used sources are described.

One to Two Years Old

These parents also reported high levels of information seeking via national organization websites for health topics like speech and/or language development (62.5%), via doctors for information on physical growth and development (66.67%) and via local organizations for community sponsored recreational activities designed for individuals with autism (63.4%). Therapists were reported as the most popular source of techniques and strategies to support school work for children in this age group (72.3%). Information seeking about puberty (local average = 12.5%, internet average = 3.3%), higher education, (local average = 4.17%, internet average = 1.67%) sexuality and dating (local average = 1.04%, internet average = 0%) were among the lowest reported for this age group.

Fig. 3 Percentage of parent seeking by source and child age**Fig. 4** Average information source use by child age

Three to Five

Respondents in this group reported highest levels of local information seeking about speech and language development from therapists (85.71%), and physical growth and development from doctors (82.35%). Parents in this age group sought information for supporting child's schoolwork most frequently from therapists (55.8%) and national organization websites (40%). Information seeking about sexuality and dating (local average=2.81%,

internet average=0%), and independent living, (local average=5%, internet average=0.94%) were among the lowest reported for this age group. The few open-ended responses for this age group belied apprehension about lack of information, therapies, and resources. One parent wrote, "Information should be readily available in pediatric [*sic*] offices of any type. My child is only 3 and it would be nice to have more information on schools, therapists, etc, to help prepare him for new mile stones in his life." Another wrote,

Table 6 Comparison of usage of national and local online forums/email listservs by information need (Final survey data)

Information need/topic	National (%)	Local (%)
Helping your child find peers with a similar diagnosis	4.14	15.98
Relating to neurotypical peers	6.79	12.55
Sexuality and/or dating	3.09	4.54
Independent living	7.55	9.18
Sensory friendly activities	7.73	18.05
Recreational activities designed for individuals with autism	5.20	22.54
Community sponsored recreational activities designed for individuals with autism	4.29	25.15
Recreational activities designed by organizations focused on individuals with autism	5.26	23.98
Techniques or exercises to support your child's schoolwork	11.22	12.38
Administrative information about your child's school, such as IEP planning, classroom placement, or testing	11.55	17.73
Higher education, job training and employment	7.68	8.46
Physical growth/development	11.78	10.62
Behavior management	18.66	17.72
Speech and/or language development	11.94	12.55
Gross and/or fine motor skills	11.06	10.65
Puberty	11.90	10.89

NC Medicaid is way behind on what they help with as far as therapies and medically needed equipment for children with Medicaid! They need to really do research on Autism instead of sitting behind a desk thinking they do know about the patients.

Six to Twelve

Parents of children in this age group reported highest levels of information seeking related to physical growth and development from doctors (76.21%). They also reported high levels of information seeking from therapists related to behavior management (61.4%), speech and language (64.16%), and motor skills (62.84%). Parents sought information to support their children's schoolwork most frequently from therapists (53.88%). One parent wrote, "In a perfect world, doctors, BCBA's, physical therapists, speech therapists, and occupational therapists would be housed under one roof to help children with autism. They need to be able to collaborate in order to best help children." Sexuality and dating (local average = 4.9%, internet average = 3.36%) and higher education (local average = 4.8%, internet average = 4.64%) were among the lowest reported for this age group. Parents in this group described "teachers" as a frequently used resource. Several suggested that "Teachers" and "School Resources" should be an option on future survey instruments. Parent opinions on school were highly variable. One parent described a helpful school system,

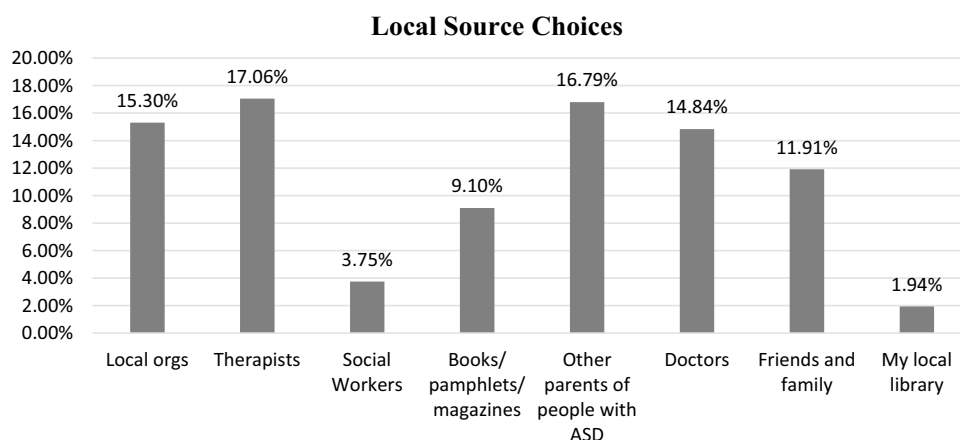
On many of these items, I speak at length to my son's teachers and administrators, as they are vastly knowledgeable about resources. School Resources would be my #1 answer for many of these items, were it an option.

Several other parents in this age group described problems with their local school systems, with one parent writing "the school systems treatment of the autistic kids is barbaric, most parents I speak with home school because of this reason."

Thirteen to Seventeen Years

Parents of children in this age group reported highest levels of information seeking related to physical growth and development (71.7%) and puberty (69.09%) from doctors. Information seeking about sensory friendly activities (local average = 5.72%, internet average = 12.13%), and sexuality and dating, (local average = 12.77%, internet average = 8.09%) were among the lowest reported for this age group. Parents of older children describe more difficulty finding resources for their children as they moved closer toward independence. One parent wrote "Finding employment resources for Teens with autism is impossible." There was some evidence that geography (rural vs. urban) played a role in parent access to information. One parent wrote, "There are very few places to get information in my area and so I basically gave up several years ago to get any help for my child near where I live." Another said, "Transition skills for post-secondary planning are non-existent in our

Fig. 5 Averaged percentages of local information source selections



area. This includes planning for educational, independent living, employment and understanding sexuality.” Insurance was mentioned more frequently among parents in this group. Several parents discussed difficulty understanding, qualifying for, or finding information about Medicaid and specific services covered by Medicaid (e.g., behavioral therapies).

Adults

Parents of individuals in this group reported the lowest overall levels of information source selection. They reported highest levels of information seeking for physical growth and development from doctors (56.78%), and higher education and job training from local organizations (48.48%). Sensory friendly activities (local average=4.67%, internet average=3.78%) and sexuality and dating (local average=9.62%, internet average=5.59%) were among the lowest reported for this age group. While there were a few parents (mostly of “high functioning” adults) who were very happy with the resources and information available, most parents of adults described frustration and fear about the lack of information and services available. One parent 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.” Others described apprehension about finding job training. One parent said, “Job training and placement resources are the most scarce and our greatest area of need as he gets older.” Another wrote,

My child is almost 21 and there isn’t really anything locally for adults and there hasn’t been any help with teenagers either so we have just been living with him being a loner and not making good judgement decisions. I don’t know how to help him anymore.

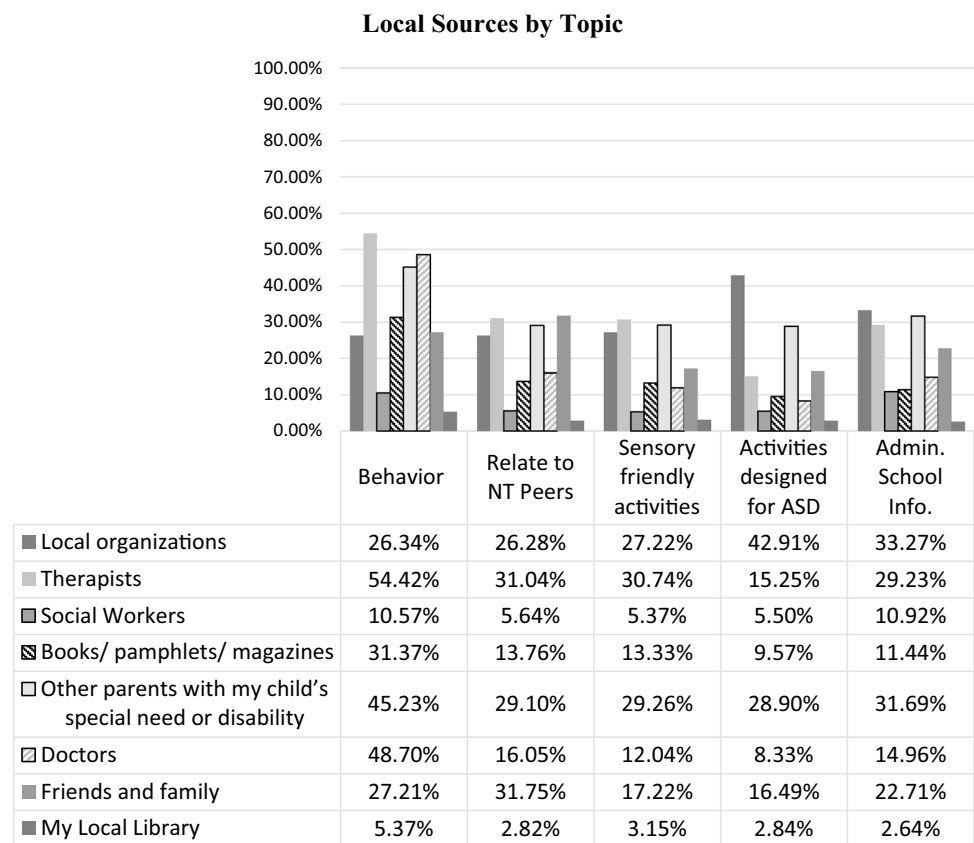
Local Information Sources

Therapists, and other parents of individuals with ASD were the most popular local sources of information, followed by local organizations (See Fig. 5) and doctors. Parent decisions about where to look for specific kinds of information varied according to the nature of the need. Figure 6 describes local information sources selected for 4 out of the 16 given specific information needs. While 45% of parents sought information about behavior management from other parents of a person with ASD, 26% sought this information from a local organization. When searching for activities designed for people with ASD, the percentages are reversed; 29% of parents sought this information from other parents, and 43% sought the information from organizations directly.

Although parents preferred using local sources when possible, many complained that there were insufficient local information sources to meet their everyday information needs, especially when those children did not fit easily into social and educational groups. One parent wrote about his or her teen, who was academically gifted but who needed training for the new social rules of the workplace,

My child is 16, going into 12th grade. It is hard to find local social activities. It has been a dead end trying to find a “job coach” so he could get a part-time job. Tried many resources and no one was able to help.

The local nature of information needs such as employment, social activities, and recreational programs meant that parents weren’t able to consult trusted national organizations for information. While parents did prefer local information sources, many described a need for convenient formats for dissemination and seeking of locally oriented information. Other parents praised local individuals and organizations that provided information and services

Fig. 6 Local parent information sources accessed by topic

specifically tailored to the local community and the needs of the family and child.

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... We got no help from the local school system at all. TEACCH¹ has been our greatest resource and one of the main reasons our boys are transitioning to young adulthood and adulthood, with a firm foundation and a bright future.

The Autism Society of North Carolina (ASNC) was also named as a helpful information source.

Not all local organizations were popular. In their survey responses, many parents described unhappiness with information available from local school systems. Libraries were the least frequently selected source of information (3.24%) for the needs listed. Local programs that helped parents develop health information literacy, provided information tailored to their specific needs, and allowed parents to

engage one another directly about specific topics were cited as particularly helpful. One parent expressed a desire for a community space where she could find information about local events and resources:

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.

That said, time was a scarce resource that many parents are unable to dedicate to extensive information searching, and to face-to-face support group activities. One participant wrote, "I feel isolated yet have little time for support groups."

Non-Local and Internet Sources

On the whole, parents were ambivalent about the internet, and wavered among appreciation, distrust, and overload when describing information seeking on the web. One parent wrote, "The Internet can be overwhelming with information and for a parent with a newly diagnosed child

¹ The University of North Carolina TEACCH Autism Program provides clinical services, parent training, counseling, and support to people with Autism and their parents in North Carolina through a system of community regional centers. (UNC School of Medicine 2016).

with ASD, this can be a bad place to start,” while another wrote, “Thankful I have a child who was diagnosed AFTER the advent of the internet and social media.” Lack of quality control, lack of trust, and reduced applicability of general information to specific circumstances were cited as reasons for parents to avoid the internet. Abundance of information and constant access were cited as reasons for internet use. For many parents, locally-oriented internet sources, such as Facebook groups for local organizations and local email listservs provided an acceptable compromise. Table 6 compares parents’ selection of local online forums and email listservs to national online forums and email listservs. One parent wrote,

In my opinion, the best place to find resources for your child is to join the local chapter of Autism Society in your area and get to know other parents who have been through and are going through the same journey. Searching the internet can be quite overwhelming as you don’t know which doctors, organizations that have your child’s best interest at heart.

Figure 7 presents non-local information sources without regard to specific topic. On average, national organization websites were the most frequently selected internet resource (14.35%). This was the third most frequently selected information source overall, behind therapists (17.06%) and other parents of people with ASD (16.79%) (see Fig. 5 for comparison with local sources). Forums and online listservs for national organizations were the least popular non-local source.

When considering source selection for specific topics (see Fig. 8), results are more complicated. Parents preferred national organization websites over social media, national level online forums/email listservs and other websites for locating information on behavior management (49.81%), helping their children relate to neurotypical (NT) peers (21.19%), finding sensory friendly activities (13.84%), and finding administrative information about their local school systems (27.09%). They preferred social media over national organization websites for helping their children find peers with a similar diagnosis (16.37%).

In the area of information related to information, parents reported social media as the most-used information source (i.e., 19.27% of parents reported using social media for sports/recreational activities, 20.08% for community-sponsored recreational activities, and 18.52% for recreational activities designed by organizations focused on individuals with autism). National level online forums/email listservs were the least preferred information source across all question domains.

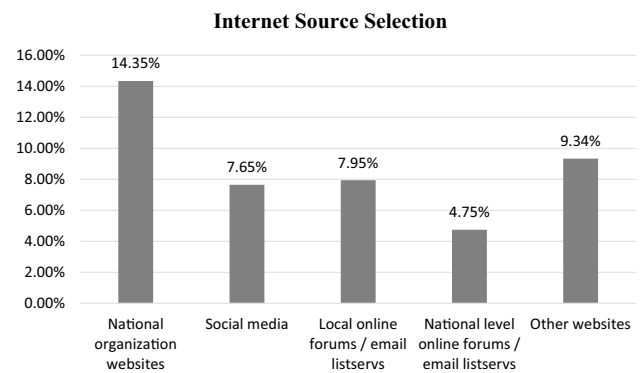


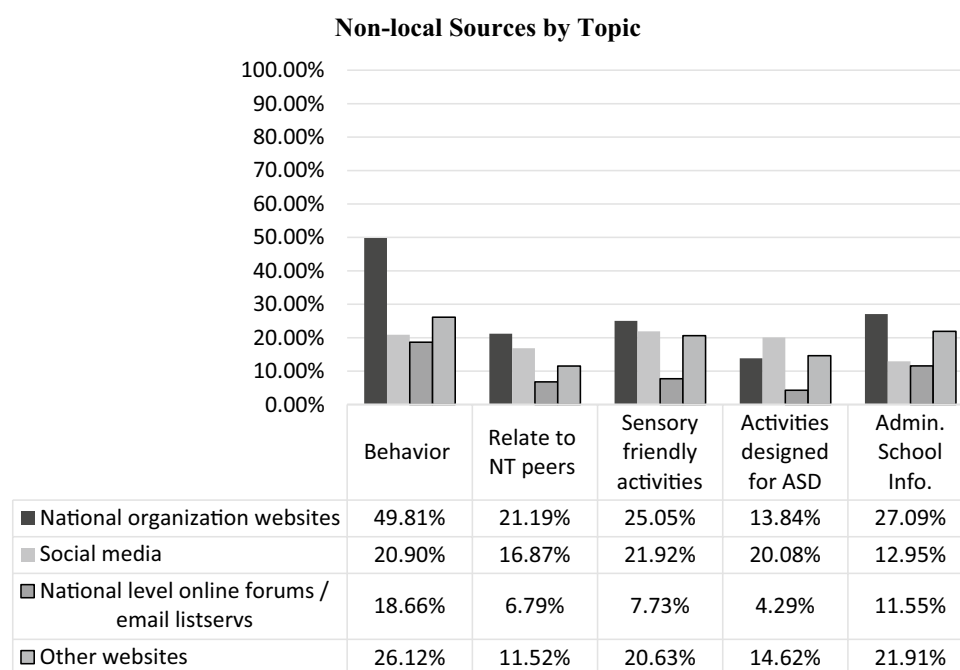
Fig. 7 Averaged percentages of non-local source selection

Discussion

Age and the Resource Gap

According to the data, parents demonstrated similar overall patterns of information source use, with interest in specific topics and use of specific information sources varying according to age. Overall information source selection was decreased for older teens and adults, producing an approximately 6% gap in resource selection for parents of adults (see Fig. 4) (that was reinforced by qualitative data). It is unclear whether this reduction in source selection was a result of an actual reduction in parents’ information needs (as parents shifted the responsibility of information seeking onto their children), a reduction in the amount of information available to parents of teens and adults, or a combination of the two. Some participants complained that there were insufficient resources and information for parents of adults who were not independent, and that they were unable to find information about topics for adults across the range of the spectrum, such as adult social interactions, managing violent behaviors, financial management, and planning. Several parents responded that their adult children were fairly independent, but that they had difficulty finding information on how to help them make adult transitions such as moving out of their parents’ homes, independent or group living, assuming management of their own medical care, and finding and keeping employment. Although symptoms of ASD may change as individuals age (Seltzer et al. 2003), family support, maternal positivity, and inclusion in community all continue to be important for individuals with ASD across their lifespans (Woodman et al. 2016). Ensuring that information is available for parents, even as their children age, helps improve outcomes for adult with ASD. As larger numbers of people with ASD and other disabilities move toward independent living in local communities, having well-designed and research-based information and service supports becomes more and more crucial. From a

Fig. 8 Non-local parent information sources accessed by topic



research perspective, a focus on increased information literacy, health communication, strong local information systems, and improved information retrieval and accessibility on the internet should explicitly include study with, and of, people with ASD and other disabilities that influence cognitive, social, and organizational aspects of information seeking.

Local versus Non-local Information Sources

Much of parent information seeking focused on meeting place- and community-specific information needs related to their children's daily lives. Parents sought this information from local organizations, other parents of individuals with ASD (through formal parent organizations or information social relationships), and trusted therapists. When parents looked for information on the Internet, it was most frequently through trusted national organization websites, other websites, local level online forums and email listservs.

Specificity of experience, and the ability to match expertise with the child's diagnosis, age, and specific needs, was a factor in information source selection. The geographically specific nature of some information needs, such as information about school policies (which might vary from county to county), social activities designed for individuals with autism (e.g., recreational and community sponsored—sponsored sports), and insurance coverage and policies (which vary with local economy) pushed parents to seek information from trusted local sources that could help parents sift

through data to figure out what information was specifically applicable to their children. The two sources named most frequently in the qualitative data as helpful (TEACCH and the Autism Society of North Carolina) represent research/professional and parent perspectives. Both were perceived as sources of trustworthy, good quality information, based on authority and credibility built on research, practice, and personal experience.

Several parents complained that there were few sources for local information in general, and social and recreational information in particular. They expressed desire for local spaces where they could find information about the local community, and ASD-friendly activities for their children. At the same time, local libraries, which often strive to be seen as community anchor institutions, learning spaces, and information hubs, consistently received the lowest scores for information source selection. This suggests that libraries and other community anchors either need to work harder to provide meaningful services and information to engage people with ASD and their families, or that they need to improve their outreach to community members who are unaware of what they offer. Meaningful service provision for populations of people with ASD and other disabilities requires more than a basic right to access community spaces (which is not always guaranteed, if an individual's behavior is considered “disruptive”). It requires development of deeper, more empirically-based understandings of the information needs and contexts of individuals in local communities, and a willingness to use local resources to ensure equity of service (Braveman and Gruskin 2003;

Leeder and Dominello 2005), rather than just serving all equally.

Access to information about local school, school services, parent and student rights, and the Individualized Education Planning (IEP) process was described, in interview and open-ended survey responses, as particularly problematic. It became clear, from open-ended responses, that future iterations of the survey should include “schools” as an information source option. Further examination of parent access to information related to education for children with ASD would be beneficial.

Limitations

Because there is no census of individuals with ASD in the State of North Carolina from which to build a complete sampling frame, this study uses a nonrandom sample. Although the panel provided by the Carolina Institute for Developmental Disabilities (CIDD) was large enough to build a statistically significant sample, it is populated by individuals who access disability related services through the University of North Carolina (UNC) system or an affiliate (the CIDD offers clinical services in all 100 counties in the state), and who agree annually to participate in research studies. It is possible that this sample excludes parents who are unhappy with information and services provided through this system, as it excludes parents who pay for private services outside of the UNC system, those whose children do not receive services, and those who have opted out of participation in CIDD studies.

In addition to nonrandom sampling, the small sample size for some age groups made ruled out useful testing of variances in means. Because of the average age of diagnosis for ASD, smaller samples of very young children are to be expected, but oversampling of these age groups for future studies, or larger study samples could help mitigate this problem. Finally, the geographically limited sample presents a possible limitation to the study. In the future, a larger (possibly) multi-state sample might yield a larger sample with exposure to a wider range of information systems and sources.

A Note on Terminology

Because the survey was designed to be as inclusive of (and to appeal to) as wide a range of parent groups (education and knowledge levels) as possible, terminology was, to some extent, based on participant interviews (and in participant voice). For example, the survey uses “doctors” instead of the more general “healthcare providers.” Future use of the survey instrument should involve an evaluation of survey language to ensure that the language is accessible by the target audience.

Conclusion

Information is vital for parents as they raise young children, and equip older children for independence. For parents of individuals with ASD and other disabilities, the information landscape is particularly complex, and parents who seek and manage information on behalf of their children sometimes face webs of disconnected, difficult to access information. For these parents, lack of access to quality information has meant reduced well-being and quality of life for their children, themselves, and their families.

The findings show that parents prefer information sources that can be tailored to the child’s and family’s specific needs, and that parents of adults with ASD perceive a dearth of information sources. Meeting these need is vital. As children age into adolescence and adulthood, successful integration into the local community relies on information about education, employment, health care, and social interactions provided through any number of local and national organizations and service providers. Although parents can mitigate information problems (to some degree) through collective information seeking and exchange (via parent support groups or formal parent organizations), a great deal of responsibility lies on organizations and researchers to improve design of information systems and services for this population. Intentional assessment of the impact of cognitive and social differences on information needs and behaviors would better inform design of information systems and services for people with ASD as they seek and manage their own personal and medical information in adulthood. Greater focus on customizable information systems and services that allow parents to access locally relevant information; and more emphasis, in local community organizations such as school and libraries, on understanding the information needs of people with ASD and their families, would help people with ASD and their families to find much-needed locally relevant information.

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Author Contributions AG conceived of, designed, and coordinated the study, performed the measurements and statistical analyses, interpreted the data, and drafted the manuscript. SK participated in the design and coordination of the study, acquisition and interpretation of the data, and helped revise the manuscript. EV participated in

the acquisition and interpretation of the data, and helped revise the manuscript. All authors read and approved the final manuscript.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Standards All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Appendix

Interview Instrument

Interview Schedule

1. How old is your child with Autism (follow parent's lead on terminology)?
2. What grade is s/he in/Tell me a little bit about him/her?

We are going to talk about some of the information/services you have search for on behalf of your child in the past year (especially related to Autism).

3. In the last year, what medical services or information have you searched for on behalf of your child (especially related to Autism)?

Follow up questions (as appropriate)

- a. *Why? [context question]*
 - b. *How did you find out about [that information/service]?*
 - c. *What did you do next? [info seeking process question]*
 - d. *Were you satisfied with the outcomes? How did you use the information?*
 - e. *Would you do it this way again (if you needed similar information at a later point in time)? If not, what would you do differently?*
4. In the last year, what education-related services or information have you searched for on behalf of your child (especially related to Autism)?
Follow up questions (same as Q3)

5. In the last year, what education-related services or information have you searched for on behalf of your child (especially related to Autism)?
Follow up questions (same as Q3)
6. Is there any other information or service you've looked for in the past year, that you'd like to tell me about?
7. Could you tell me about an experience you've had where you felt like you did not have sufficient information to make an informed decision on behalf of your child, or where you felt like you needed information and could not find it?
8. Please tell me about an experience you've had where you felt like you were given too much information to be able to make a decision on behalf of your child (prompt: when you have experienced information overload).
9. Please tell me about an experience you've had where you were pleased with the information you've received, and where you felt that information helped you make a more informed decision on behalf of your child. (prompt: *Where you had just the right amount of information*)
10. Would you say that your area of residence has a strong community of support for children with developmental disabilities and their families? Why or why not?
11. What advice would you have for the parents of a child who has just been diagnosed with having autism?

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