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“A Family Like Ours”: Demographic Variations in Information Seeking Behavior and Community Participation Among Parents of Individuals with Autism Spectrum Disorder (ASD)

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ABSTRACT

We surveyed 906 Autism/Autism Spectrum Disorder (ASD) about their information seeking experiences and preferred information sources. Our findings suggest that the most popular information sources are local doctors, therapists, national organization websites and local parent networks.

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Introduction

This poster describes a project focused on understanding the influence of demographic variables on information seeking behaviors and habits of parents of children with Autism/Autism Spectrum Disorder (ASD) within their local communities and on the Internet. The study examines this issue through an online survey administered between June 19 and August 7 of 2015.

Research has shown that parents of individuals with disabilities who seek information and support from their peers are more emotionally resilient (King, et al., 2006), engaged information seekers who actively participate in planning, treatment and care for their children. Because they have access to a larger pool of information than they might without connection to a network of parents, and consistent exposure to a richer information ecology, these parents have increased information literacy about health, education, social/recreational activities, therapy (including life skills), and utilization of government resources (Weston, 2001). Because parent support groups function as both information emotional support organizations, they present an opportunity for educating families, individuals with disabilities, and their local communities about health, quality of life, and other issues. These groups also serve as hubs for network-based legitimation (Haythornthwaite, 1996; Veinot, 2009) of information and information providers, allowing families to make informed choices about medical care, education options, and social activities.

Research questions

The study examines the following research questions:

1. What information sources/channels do parents of individuals with ASD use to seek information on behalf of their children?
2. What factors do parents consider when selecting information sources?
3. How do demographic variations impact information channel preferences?

Background literature

Community, Identity and Information Behavior

This study examines intersections between socio-economic, racial/cultural and community identity, and their influence on information seeking. The study uses a place-based definition of community derived from critical border studies and human geography literature, which view community and its borders as contested and constantly changing based on cultural and sociological factors influencing the resident population (Veinot, 2009; Stanton, Danoff, & Huggins 2002). In practice, this means that community members determine what is considered *local* through shared behavior and self-imposed community boundaries. Place-based communities exist within a specific geographic location, but also comprise the actors (people, groups, and institutions) that occupy that location, their experiences (behaviors and interactions), and social institutions, all of which create “sense of place” (Agnew, 1987, Tuan 1975). As such, examining varied facets of self- identity (racial/cultural, socio-economic, and geographic) can help us understand how these factors motivate individual to seek and exchange information along specific information channels, and how they motivate active participation within community-specific information networks. This study seeks to build on previous qualitative work exploring the role of local community in supporting the information needs of people with service-oriented medical needs in general, and families of individuals with disabilities in particular.

The Rapidly Changing Face of “Disability”

Research about parents of and families of individuals with disabilities has focused largely on emotional needs, resilience, and stress levels of parents (Atkinson, et al., 1995; Damrosch, 1989; Rodrigue, Morgan, & Geffken, 1992), rather than information needs of children and adults living in communities, or the needs of the family members who sometimes act as caretakers. This study builds on previous research that highlights the local focus of many disability-related services (e.g. medical/therapy, education, recreational) (Gibson, 2014). The local, place-based nature of these services makes advice from other parents within the local information network especially valuable, but may also be influenced by cultural issues that transcend local places.

As services and interventions improve, families face new medical, educational, and social situations, and experience new information needs. Understanding these changing needs benefits families and individuals with ASD, but also has implications for understanding the needs of other groups of individuals with information needs and networks connected to local places. ASD occurs in all ethnic, racial, and socioeconomic groups (Pálsdóttir, 2010). Other studies have explored the information seeking behaviors of individuals and families of individuals with developmental disabilities (Wilson, 1997; Wilson 2000; Case, Andrews, Johnson, & Allard, 2005; Wyatt, 2001), but this study focuses on the influence of place and demographics on information seeking.

Methodology

This study uses an online web survey to collect data about participant information needs, information seeking behaviors, and information source preferences. The survey explored the prevalence of information behaviors and information values identified in previously conducted interviews (Gibson, 2014).

Study Sample and Recruiting

A convenience sample of study participants was developed from biological, adoptive, or foster parents of individuals with ASD in the state of North Carolina. The initial sampling frame for the study was developed by the UNC Carolina Institute for Developmental Disabilities (CIDD), which maintains a registry of all individuals with an ASD diagnosis who access in-state disability related diagnosis or services through the University of North Carolina. This list comprises 4200 families who agree each year to participate in CIDD-sponsored research. Demographic composition of the CIDD email registry is found in Table 1.

Race	**Pop.**
Am Indian or Alaska Native	16

Asian	98
African American, Black	511
More than one race	38
Other or not reported	337
White, Not Hispanic	3020
White, Hispanic	180
Total	4200

Table 1: Demographic Composition of CIDD Email Panel

Study participants were recruited via email (sent from the CIDD) introducing the study and providing a URL for the online survey. Researchers also posted an invitation to participate to several ASD parent Facebook groups to boost participation from minority demographics. Table 2 describes respondents by race and ethnicity .

Race	**N=**
Am Indian or Alaska Native	3
Asian	10
African American, Black	69
More than one race	11
Other or race not reported	349
White	518
Ethnicity	
Hispanic	26
Not Hispanic	578
Ethnicity not reported	302
Total	906

Table 2: Respondents by race and ethnicity

Survey Questions

Survey questions covered a range of topics that cover previously identified information needs of parents of individuals with ASD, and asked participants to identify sources used to resolve specific information needs. See Table 3 for a brief overview of survey question topics. Findings reported in this poster highlight most frequent responses to Question Set 3: Information Sources Related to Specific Information Needs.

Limitations

This study demonstrates the limitation associated with self- reported survey data. Excluding families without Internet access potentially limits the study’s reach, as those families’ information seeking habits and preferences are likely to be distinct from the online sample. Future research examining this group would be useful in exploring these differences. The small number of responses for individuals who classify themselves as Asian/Pacific Islander and Two or More races is also a limitation to the study. Additionally, future data analysis will include more granular statistical analysis of survey data, examining relationships among race, income level, education level, zip code, information sources, and information behaviors. Qualitative data from open-ended survey questions will be used to support findings.

Question set	**Question topics**
Set 1: Diagnosis	Age of diagnosis; Info sources leading to diagnosis
Set 2: Medical Information	Factors in choosing doctors; Doctors/therapists consulted in the previous year
Set 3: Information Sources Related to Specific Information Needs	• Physical growth/development • Behavior management • Speech/language development • Gross/fine motor skills • Puberty • Finding/relating to peers • Sexuality/dating • Independent living • Sensory friendly activities • Sports/recreational activities • Help with schoolwork • Education rights and administrative Information (IEPs/Classroom placement/Testing) • Higher Education/Job training/Employment
Set 4: Participation in Parent Organizations	• Description of participation in parent organizations/support groups (Open-ended question)
Set 5: Demographic	• Child's age of diagnosis/current age; Other children/ages • Parent age; race; ethnicity; sex/gender; income; education; parenting arrangement • Zip code

Table 3: Survey Question Sets and Topics

Results

Physical Growth/Development, Behavior management and Speech/Language development were the three most popular information needs/sources reported. Among all participants, local doctors were the most popular source of information (n=389; 43%) about physical growth and development, and therapists (n=305; 34%) were the most popular information source for behavior management, and speech/language development (n=297, 33%). Tables 4 and 5 outline the two most frequently cited information needs and most popular sources by race for all participants, black or African American, and white participants. Reported numbers for participants who self-identified as Native American, Asian/Pacific Islander and two or more races are less than 3.25 confidence interval for study, so they are not included. Additionally, these tables do not necessarily demonstrate the most frequently cited sources within each race.

After doctors, the most frequent response for many of the source categories was "None of these." In open-ended responses, participants expressed frustration at a lack of resources about life after diagnosis through adulthood, and their own perceived lack of health-related information literacy.

	Doctors (local)	Natl. Org. Web.	Other parents (local)	Therapists (local)	Friends/ Family
All Participants	n=389 43%	n=252 28%	n=181 20%	n=175 19%	n= 127 14%
Black/African-American	n=37 53.6%	n=29 42%	n=14 20.3%	n=21 30.4%	n=10 14.5%
White	n=324 62.5%	n=199 38.4%	n=155 29.9%	n=143 27.6%	n=112 21.6%

Table 4: Most Frequently Cited Info. Source Preference - Physical Growth/Development

	Therapists (local)	Doctors (local)	Natl. Org. Web.	Other parents (local)	Books/ Pamph./ Mag.
All Participants	n=305 34%	n=273 30%	n=260 29%	n=255 28%	n=179 20%
Black/African-American	n=26 37.7%	n=30 43.5%	n=24 34.8%	n=18 26.1%	n=17 24.6%
White	n=256 49.4%	n=224 43.2%	n=215 41.5%	n=225 43.4%	n=149 28.8%

Table 5: Most Frequently Cited Information Source Preferences - Behavior Management

Being able to determine quality of information was important, and trusted Internet sources were most often nationally recognized support and advocacy groups. Participants in rural counties also complained that local information sources and information about local services were limited.

Significance & Discussion

The data demonstrates that the majority of information seeking among participants takes place face-to-face within local contexts. Studying information seeking and sharing between doctors, therapists, and patients; understanding parent relationships with and within nationally known (and trusted) support groups; and understanding local parent information networks and support groups are essential to filling gaps in health information communication. Creating information systems that support locally oriented information needs would help to empower parents and families in information seeking and decision-making. Continuing to identify variations in information seeking and sharing behavior related to cultural difference in the ASD community could identify opportunities for applied research targeted at underserved sections of this population. Information technology holds potential for solving some of the problems associated with social and geographic distance and this study will provide insight about how to reach parents who may not be participating in the ASD community because of those factors. Improving parents' access to information and childhood services improves outcomes for children and increases their ability to be independent adults. While the findings of this study relate specifically to families of individuals with ASD, they also have implications for understanding information worlds and behavior within other community-situated information networks.

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