

“I WANT IT THE WAY I NEED IT”: MODALITY, READABILITY, AND FORMAT CONTROL FOR AUTISTIC INFORMATION SEEKERS ONLINE

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Abstract

This qualitative analysis of 18 in-depth interviews with autistic individuals and parents explores themes related to information poverty and the influence of control and power in online environments toward knowledge growth, self-determination, and personal agency. The authors discuss the perspectives of participants on information seeking, including initiatives to access information through preferred platforms and the influence of control (or lack of control) in terms of the modality, format, and readability of information. Findings reveal highly motivated, self-directed, and critical information seekers in support of academic endeavors, skill development, personal interests, curiosities, entertainment, social connectedness, community access, and independent living. Participants indicated preferences toward video streaming and similar multimedia content to address information needs. For many, social media functioned as personal infrastructure for supportive place-based communities. The article concludes by posing critical questions and considerations for researchers, creators of online learning sites, and instructors who teach in these environments in support of neurodivergent learners.

KEY WORDS: disability, autism spectrum disorder, information seeking, information poverty, information access, user needs, user experience, online learning

1. INTRODUCTION

The central argument of user-centered system design is that information systems should be designed around the needs of users (Norman, 1988). Information systems should also

be inclusive and serve diverse users and contexts, including users representing the full range of ability and neurodiversity.† Achieving this standard requires complex and critical understandings of the social dimensions of disability and increased attention to the needs and perspectives of people with disabilities (Lewthwaite, 2014). Legal requirements for accessibility largely focus on basic access rather than equitable access and, as such, are insufficient for spurring development of online learning environments that meet the needs of people with disabilities. Truly inclusive design goes beyond simply following the letter of the law; it is an issue of ethics and justice.

Past research relating to information, technology, and autism has predominately employed a medical lens for investigation (Gibson and Hanson-Baldauf, 2017). From this perspective, impairment is the central focus and is positioned as a condition that is a deficit, abnormal, and undesirable. Within the research, the viewpoints and goals of professionals and parents are amplified as the most credible sources on matters relating to the lives of disabled individuals. Prioritized topics of study have focused on information systems and other technological mechanisms in the search for a cure (Le and Van, 2017; Pendergrass et al., 2014), for diagnostic screening (Gong et al., 2018; Petric and Kovacić, 2018), and to support normalization (Ploog et al., 2013; Parsons and Mitchell, 2002) and the reduction of challenging behaviors (Crutchfield et al., 2015; Sano et al., 2012). The underlying message in research of this vein is that there is something inherently wrong with autistic people.

A persistent tendency toward technological determinism has also been observed in much of the research. Technological determinism refers to the belief that our social structures, values, and way of life are highly influenced and shaped by technological innovation (Smith and Marx, 1994). Wajcman (2010), a feminist theorist, argues that “technology itself is crucially affected by the antagonistic class relations of production,” referring to the power imbalance between those who create the technology and those who have been excluded, intentionally or unintentionally, from its use. Much of Chatman's (1996) paper on information poverty describes and operationalizes these “antagonistic class relations” as information interactions between “insiders” and “outsiders.” More recently, research initiatives within disability studies, occupational studies, and public health have sought to address the technological marginalization and exclusion of disabled individuals by positioning the perspectives of autistic people‡ on the highest rung of the credibility hierarchy (Becker, 1966). This has meant the acceptance of the lived experiences of disability as evidence equal to the experiences of people who work with disabled people.

Chatman's (1996) theory of information poverty helps to unravel long held assumptions within the field of information science of historically marginalized groups of people as information poor by exploring the social mechanics of information access and information

poverty. According to Chatman, information poverty is the natural extension or embodiment of power imbalances between people who are information insiders and those on the outside. Chatman proposed that individuals who experience information poverty recognize a lack of what they perceive as sufficient information sources; are distinguishable by some form of class difference (i.e., income level, education level, etc.) from those who are information “rich”; commonly engage in assessments of risk and personal relevance before accepting information from sources outside their social group or information world; exhibit defensive information behaviors (such as secrecy or deception) if they feel that revealing an information need poses a potential threat to their well-being or sense of security; and, despite need, will often accept very limited amounts of information from outsiders.

Chatman's last two propositions, which address the risk involved in information seeking, also prompt us to ask more explicit questions about power relationships between organizations that provide information and the people who need it—especially for historically marginalized populations of individuals who continue to experience discrimination, patronization, and life-minimizing inequity. What does it mean to give autistic people the information *they* want, rather than the information others think they need? What would be necessary to give them control of their information processes/formats? Who suffers and who benefits when autistic people (or any group of people) have no control over the information process or information sources? Who determines what is “feasible,” what constitutes “undue burdens” in system design (Jones, 1995), and what are the ethical and justice implications of those decisions? What risks are acceptable in information seeking and who should face them? What would it mean to give people the information they want in the way that they want it, rather than the information we think they need?

2. RESEARCH QUESTION/PHENOMENON

This article discusses partial findings of a three-year qualitative study on information seeking and exchange among autistic people and their families in North Carolina—specifically, one large metropolitan area and a smaller metropolitan area. The study employed a grounded theory approach (Charmaz, 2014) to examine various facets of information seeking and exchange as they relate to expertise, placemaking (Schneekloth, 1995), identity development, self-determination, learning, and (for families) teaching and parenting. This article specifically examines themes related to knowledge growth, self-determination, and personal agency and the ways in which these themes are influenced by and embodied in opportunities for control over information and tools within the online environment. The research explores how one's power (or lack of power) to control aspects of modality (i.e., how information is delivered—for example: visually,

auditorily, tactilely, kinesthetically), format (i.e., how information is presented—for example: font type, color, background, bolding, graphics), and readability (i.e., language use and level) through fine control over settings, options, and tools creates a complex power relationship in information systems between information providers and users. This article addresses the broader question of how these power dynamics inform our understanding of information poverty and the influence of user control in online learning platforms.

3. METHODS

We conducted thematic analyses of 18 60–90 min interviews with autistic individuals and parents from one large metropolitan area and one small metropolitan area in North Carolina. Participants were asked to engage in the study as parent-child dyads; however, upon participant request, adjustments were made if joint interviews posed a burden on or compromised the confidentiality of a participant. One adult with autism spectrum disorder asked to be interviewed without her parent; one mother spoke without input from her nonverbal 5-year-old (not included in the study sample), and one couple (mother and father) asked to be interviewed as a couple (with their son's permission). The final study sample was comprised of nine parents (six mothers and three fathers) and nine autistic individuals. Study participants exemplified the diversity of the autism spectrum in terms of levels of independence and communication skills. It should be noted that all participants were capable of verbal communication.

The purposive snowball sample (Morgan, 2008) of participants began with participants recruited via a combination of emails sent from the Autism Society of North Carolina to their contact list and contacts of the investigators from previous studies. Participants were asked to share information about the study with personal contacts, as relevant to the study. Autistic participants over the age of 18 were asked to affirm that they had legal authority to sign a consent for participation. When necessary, parents were asked to sign consent documents. Participants who did not have legal authority to sign consent documents (those under 18 and those over whom another adult had legal guardianship) were asked to sign assent documents. Participants received incentives of \$20 each.

4. FINDINGS

Perhaps the most cohesive theme present in discussions about information and technology was that of social media and online environments as personal infrastructure for building supportive place-based communities (Gibson and Kaplan, 2017; Hampton, 2002). This was particularly true for adult participants, who engaged regularly in self-directed and interest-driven online learning tasks—for instance, seeking advice about a home maintenance concern through a neighborhood listserv. For some autistic participants, the

internet offered a manageable space where they had some degree of control over the mode of discovery and learning, clearly defined rules for interactions and safety indicators (within certain spaces and with certain applications), and some control over the ease with which they engaged with information.

4.1 A Manageable Information Environment

Whereas parents discussed the internet expansively, as an open, browsable space, (e.g., one parent said, “All I need is an internet connection and the world is mine, I can find anything I need”), participants on the spectrum described their engagement in online environments as more structured, manageable, and controllable in terms of addressing specific information needs. Most adult participants accessed the internet through applications (apps) installed or downloaded on their phones or tablet devices (as opposed to a search engine on a web browser). A few participants enrolled in academic programs reported that assigned use of online tools tended to present a bit of a challenge due to the complexity of systems and level of language used. For personal use, apps were explored, tested, and self-selected by participants for purposes of interest-driven learning, curiosities, entertainment, social connection, safety, community mobility, and independent learning. YouTube was frequently identified by participants as a helpful tool for learning and developing new skills. Transportation apps such as Uber, Lyft, and NextBus supported community mobility by enabling young adults to navigate and move independently within their communities. Participants used local community apps such as Nextdoor for safety and semipublic interactions with other community members. Facebook and Messenger were used for staying connected and communicating with friends and family. Twitter served as an important tool for in-the-moment, need-to-know information needs.

4.2 Safety, Community, and Control

Safety online and in place-based (as opposed to virtual) communities was a big concern for autistic participants and their parents alike. Parents expressed concerns about their children learning how to keep information and identities safe online, as well as how best to keep their children safe in their homes and communities. Systems that allowed parents to see their adult children's activities were popular among parents and tolerated by adult children. Young adult participants, on the other hand, had their own, more socially mediated means of managing personal safety in their communities, largely relying on known and trusted community members and authorities for support. For example, one male participant in his early 20s, who lived with a roommate in his own home, talked about his use of Nextdoor and another app that allowed him to use his phone to view individuals approaching his home via a small camera installed near his front door. He shared:

It's [Nextdoor is] basically Facebook and all these other social medias all in one. But really, it's just for your neighborhood... Even my dad is family – but if he wanted to join it, he couldn't because he has to prove you live in the neighborhood. Somebody came a couple months ago to the neighborhood to knock on doors... And I think it was a couple of doors down and I read their [a neighbor's] post before I opened the door...and next thing I know, the person is at my door and I just said, “Nope, I'm not going to answer that.” The [local news station] posts stuff on there. The [local police department] also posts on there.

While these apps afforded the young man a sense of independent connectedness and safety, his father presented a different perspective:

I grew up in a small community where everybody knew one another... Everybody was 99.9% Italian... Everybody knew everybody... Nobody locked their doors... I hate the whole idea of looking through a peephole, but I realize it's necessary... He found ___ [security service] on his own... I'm not that worried about his safety just because he's so worried about it I think he's got it covered.

In the online environment, a similar negotiation between independence and a reliance on administrative and cognitive authority was observed. One participant shared of a trial and error strategy and use of an app's safety mechanism, stating:

I try different apps and I only try on an android, now actually on Google they actually have more apps on there than need to be, and some are bad—you know, for different reasons and they actually tell you which ones—they have a checkmark or something underneath and actually they tested it and make sure it's safe and everything, so only the ones that are safe I use.

4.3 User Preference

4.3.1 Modality

For autistic participants, control over the mode in which information was received was often the difference between usable and unusable information, and sometimes the difference between tolerable and overwhelming sensory experiences. YouTube and other video platforms were popular for self-directed learning online. One participant describes his process for seeking and choosing technology:

I'm one of those people that will look at articles but really, they mean nothing to me... I watch a video much more times... Most people would read the article. I hate the article, but I'll go for the video, but a lot of times I have to remember that but I'm quick to send out the video [but] a lot of people don't want to see that.

4.3.2 Format

Among those participants who did enjoy reading, or who had to read regularly for school, there was a divide between those who enjoyed e-readers and those who preferred physical books. One participant in his early 20s said of his Nook, “I think you can carry—no matter how many books you have, not getting heavier—like weight.” Another autistic participant, an adult woman over 50, preferred the stability and unchanging constancy of physical books. She said, “Here we have electronics—always upgrading, always causing a problem, but you never have the problem when you have a book in your hand.” Despite struggling with reading, she had set a personal goal of reading 12 books over the next year. To make reading easier, she used color overlays and backgrounds to change the default presentation (black and white) of most of her reading materials. She spoke of the cost and effort required to change color on most online reading materials as one of the reasons she prefers offline print:

When I look at paper like that, that's not in color, it looks like ants crawling on the paper at a picnic table...That's what all this black and white looks like to me. So, I write in color a lot. I use color papers a lot. I print stuff on colored paper a lot because then my eyes will readjust, and I can read it...There is a pair of glasses that are used...but it costs too much, and I can't afford it, so I just use a piece of folder plastic in different colors.

4.3.3 Readability

Participants described themselves as active information seekers and consumers of information, exercising control over formats when possible and, in some cases, petitioning providers of information for sources in their preferred formats. One participant wrote about his search for more readable course material:

For a course that I'm in this semester some students use NC Live§ but some sources are a bit harder to understand than others so I try looking somewhere else, like somewhere outside of NC Live... Years ago, my parents helped me find sources for a psychology course I took once 'cause I wasn't able to do the research so they got me medical school articles. I mean even medical school stuff—I couldn't read those, so they got me the wrong sources, like they went to medical school...so they had to translate paragraphs for me in those sources.

4.4 Speed, Timeliness, and Authority

When discussing social media related to services, such as dining and transportation, and in support of personal interests, such as sports and arts, many participants showed a strong preference for clear authority structures and valued timeliness and accurate just-in-

time provision of information. They preferred information coming directly from original sources and relied heavily on the just-in-time delivery of information. Rather than accept information passively, they actively sought what they perceived as the “best” sources of information. This was most evident when information from the same source was provided via different platforms. One participant described his process for determining the best source for bus information:

But to find out about buses you can go to the ___ Transit website to find out bus stuff, but really I've learned that their Twitter page is better and I've learned that as an example, like the last snow storm we had, when I was trying to find out about the buses, their Facebook page and their Twitter page said different things because they don't update at the same time. So, Twitter was first, so I've learned that I always go to Twitter first.

Another young adult male participant spoke about his process for modifying the assigned readings for one of his classes. He had trouble understanding the readings, so he actively sought a combination of video and source material that was scaled to his understanding and reading level:

I found that I was visual, so usually it helps to see it, see the sources itself...some combination of both [video and writing], maybe something else sometimes, but especially pictures, pictures definitely help, I think. Like maps.

Another participant talked about the value of accuracy, especially for apps that were meant to provide just-in-time information:

Somebody asked them—they said—the app was wrong one time, and somebody on the bus said, “Your app was wrong” and they were like “It's not really our app, it's just a third party.” So, I said “Nah. Never mind.” There's one that I really like—if I were to take the bus every day I would use it... You know how some people don't pay attention to their stop? You actually tell it where you are going and where you are getting off and it gives you an alert of how many more stops before you need to get off.

Accuracy and timeliness became more than a preference for more vulnerable travelers—they were critical to personal safety and independence. Apps that were confusing, used stale data, were unreadable, or that were wrong could cause someone to become lost and, in some cases, result in injury or worse.

5. DISCUSSION

Participants provided a complex, self-driven, and highly motivated picture of their own information seeking and use. For the most part, they did not view themselves as passive recipients of information but as active seekers, self-reliant, and decisive in determining

best formats and sources of information to address their specific needs. Even with this proactive determination, several participants expressed frustration with and distrust in the quality of information available. This reflected Chatman's (1996) theory. Chatman proposed that people who experience information poverty negotiate information systems designed by people who occupy a relatively higher "social class" or who hold more power to control information flows. Engagement with those systems is done at risk to the person who experiences information poverty. Participants' awareness of this type of risk was clear when they discussed transportation and safety. For young adults who were still developing a sense of independence, the risk of getting lost on the bus, near a highway, during inclement weather, or on the way to work was very real. An app that mislabeled a bus stop location or a bus arrival time could make a significantly negative impact on the learner/user. Information sources that proved to be inaccurate or unreliable were quickly abandoned for better alternatives when available. When there were no better alternatives, the activity itself (taking the bus) might be abandoned. Participants had to bear the risk and costs of information system failures due to inaccuracy, lack of readability, or lack of usability (due to formatting issues) in the form of a potential threat to personal safety and loss of independence.

Increasing a user's ability to determine information delivery through their preferred modality and to control the presentation of information through format adjustments, as well as providing just-in-time options for accessing data and information, makes online learning environments more enjoyable for all learners. It also increases accessibility to a broader range of neurodivergent learners and empowers learners by enabling opportunities to be self-reliant in their online academic and personal pursuits.

6. CONCLUSION

This investigation's findings offer a nuanced perspective on information poverty and introduce questions for future research, pedagogy, and the design of online learning environments about trust, user control, and empowerment as keys to legitimate, meaningful access. For researchers, this means that an honest, rigorous exploration of the information needs and practices of autistic people requires critical examinations of the information practices of the individuals and organizations that create and design information systems. For library and information science faculty and practicing librarians who act as designers and facilitators of online and place-based learning environments, this means incorporating flexibility into as many spaces and resources as possible. It means finding ways to offer end users control over the formatting of learning materials (color, font, size) and, whenever possible, the modality (text, video, etc.). It means having hard conversations about what "whenever possible" means, and what it really means to choose not to meet the needs of autistic people in our communities.

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NOTES:

† Neurodiversity is a concept where neurological differences are to be recognized and respected as any other human variation. These differences can include those labeled with dyspraxia, dyslexia, attention deficit hyperactivity disorder, dyscalculia, autistic spectrum, Tourette syndrome, and others (National Symposium on Neurodiversity at Syracuse, 2011).

‡ For purposes of reporting, we alternate between identity-first language (i.e., autistic people) and people-first language (people with autism). This is intentional and reflects the rising trend in language preference among autistic adults, as noted by Dunn and Andrews (2015), and the observed use of language by participants and parents in this study.

§ Per the NC Live website NC Live offers free electronic access to digital information resources for residents of North Carolina through North Carolina public libraries. <https://www.nclive.org/>.