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More than Accessibility: Social and Critical Frameworks for Exploring Marginalization of People with Autism Spectrum Disorders

Introduction

Information science research focusing on people with disabilities has largely focused on assistive technology and the mechanics of access and accessibility (Hill, 2013). While this is an important, accessibility research in information science has largely been grounded in a medical (or individual) model of disability that considers social factors as *motivations* for accessibility, rather than analytically valuable concepts in and of themselves. As a concept, *disability* remains an under-theorized construct in the LIS literature (Jaeger, Bertot, & Franklin 2010; Mendel 1995; Casey, 1971).

The shift to the social paradigm for understanding disability (Shakespeare, 2006) has had broad implications for understanding the responsibilities of researchers, designers, and creators of information systems. Unfortunately, many remain unaware of the impact of their work on this large segment of the population, and are unequipped to examine how their work helps to encode the marginalization of people with disabilities into systems that serve the public.

Models for understanding disability

The traditional model of disability predominately centers on impairment, a condition to be corrected or alleviated through medical, therapeutic, or technological intervention (Oliver, 2013). This model provides a useful framework to address the design and implications of assistive devices, including personal, wearable and implanted technologies. In contrast, the social model of disability directs attention toward society, characterizing individual challenges as socially constructed, and marginalization as the natural outcome of institutional failure to properly ensure access.

The social model lays conceptual and theoretical groundwork for LIS frameworks that focus on systemic *barriers* to access (e.g., digital divide and accessibility frameworks). Critical models move beyond barrier-removal to intentional design and support for meaningful use (including the selection, organization, and delivery of *content* in ways that meet the needs of, and facilitate self-empowerment for people with disabilities). They shift focus from equality in design (providing the same amount of access to everyone without a focus on outcomes) to equity (providing whatever support is needed for equally successful outcomes), and are necessarily explicit in their examination of the ways that information systems create and replicate social and political power. Although critical frameworks in LIS are relatively few and far between, Chatman's (1996) work on Information Poverty, Jaeger and Burnett's (2010) theory of Information Worlds, and

Sonnenwald's (1999) Information Horizons theory all provide bases upon which to build critical frameworks for understanding disability and information.

The significance of meaningful access to information is underscored in the first declarative of the Developmental Disabilities Assistance Act and Bill of Rights. It states, "The goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information, skills, opportunities, and support to make informed choices and decisions about their lives" (Administration on Developmental Disabilities, 2000). Increasingly, self-advocates have become more aware, and more vocal about the social, economic, and political impacts of information, communication technology. Discussions around information, technology, and disability have progressed beyond basic accessibility and access issues (although these have not been resolved by any means), and have progressed into broader, more critical discourse on the social and structural implications of choices made by creators of systems intended to serve the diverse populations of people with disabilities (Roulstone, 2016).

Study description

This paper outlines the current state of an emerging theoretical framework underlying the authors' ongoing, 3-year study. The study focuses on developing a critical, intersectional praxis around community support for people with developmental disabilities. The first portion of the study will use interviews and focus groups with people with ASD and their family members to develop a model of information needs and information seeking and exchange strategies and tactics. The outcomes of this portion of the study will have broader theoretical implications for building praxis around marginalization, information access, and the design of local and online information systems.

Understanding ASD

Rates and Etiology. Autism spectrum disorder (ASD) is a developmental disability of unknown origin characterized by both communication and behavioral markers, ranging from mild to severe in impact. These markers may include delayed language development, difficulties with receptive and expressive communication, a rigid adherence to routines and structure, fixation on objects and special interest areas, sensory issues, repetitive self-stemming movement, and cognitive processing differences (U.S. Centers for Disease Control, 2017).

According to recent surveillance data, ASD affects 1 in 68 individuals in the United States, with higher prevalence reported in males (1 in 42) than females (1 in 189) (CDC, 2014). When looking at the data by ethnicity/race, the rates of diagnoses among African Americans (1 in 73) and Hispanic (1 in 99) are considerably lower than Whites (1 in 63). In North Carolina, the rates of diagnoses are higher than average, with approximately 1 in 58 children diagnosed in the state (U.S. Centers for Disease Control, 2015).

Race, Age, Gender and Income Matters. Oswald and Haworth (2016) propose several mitigating factors for the under-representation of ASD in individuals of color including socio-economic status, clinician bias, cultural and family dynamic, and stigma. Strong evidence suggests that early intervention of ASD may decrease the impact of ASD as individuals age

(Weitlauf et al., 2014). Unfortunately, children from low-SES communities are more likely to be diagnosed later, experience delays starting therapeutic treatment, and often receive less intensive treatment. Reason cited have included parental difficulty accessing services, out of pocket treatment costs, and an inequitable distribution of resources in low SES communities and schools (Gourdine et al, 2011; Fountain et al., 2011; Thomas et al, 2007; Palmer et al 2005).

Given the broad and varied nature of challenges experienced by individuals with ASD – both inherent and imposed by normative cultures - childhood and adolescence can be especially difficult for young people with ASD, academically and socially. Students with ASD are commonly educated in segregated classrooms with inadequate support, few positive peer role models, impractical educational goals, and limited transition planning (Wehman et al., 2014).

The challenges of living with ASD continue well beyond adolescence. Research on post-school outcomes of individuals with ASD report few opportunities for continued education, high unemployment rates, social isolation, chronic health conditions, mental health issues, vulnerability to abuse and victimization, limited self-direction and decision-making, and minimal support services (Roux et al., 2017; Wehman et al., 2014; Hendricks and Wehman, 2009). Shattuck et al. (2012) found that African Americans are 3 times less likely to receive support services after leaving high school than Whites and experience higher unemployment rates.

Parents. Parents raising children with ASD face significant challenges as well. Karst and Van Heck's (2012) review of the literature found that parents report higher degrees of stress, depression, anxiety, fatigue, and experience an overall decline in physical health. Ganz (2007) reported on financial impact of caring for a child with ASD, estimating that parents spend approximately \$3-5 million dollars more on average. Smith et al. (2010) observed that it is not uncommon in two parent households for one parent to leave the workforce, giving up the additional income to care for and coordinate supports for their child.

For African American families, the challenge of raising a child with ASD is often intensified by societal inequities and discrimination. Many parents of color are less trusting of practitioners and can be reluctant to seek outside support services (Gourdine et al., 2011). Despite challenges, Gourdine (2011) highlights several studies in which African American parents of children with disabilities reported fewer mental health issues and greater satisfaction in their parental caretaking roles due to a wide support network of family, friends, and churches.

Similarly, several other studies have shed light on positive aspects of raising a child with ASD. Parents have reported close child/parent bonds, feelings of admiration of child's strengths and personal qualities, and satisfaction watching their child grow, adapt, and overcome obstacles (Montes and Halterman, 2007; Bayat, 2007; Phelps et al., 2009; Little and Clark, 2006).

Autism and Information

Unlike earlier studies examining technology-based interventions and assistive technologies related to ASD (Grynszpan, et al., 2014), this article directs attention to the everyday life and health-related information needs, information seeking, information access and information retrieval for people with ASD and their families. A recent study by Gibson et al. (2017) found

that, despite limited confidence in their information literacy and ability to find information only, only 3% of their parent participants identified their library as a useful source for information related to their children. Participants reported feeling excluded from the library space, and viewed the library as more designed to meet the needs of “typical” families. Many also spoke of a need for local information “hubs” to gather and share information with families experiencing similar needs.

Information Seeking. The experiences and challenges of living with ASD, as well as those of raising and caring for a child with ASD point to innumerable areas of information need, particularly in support of individual and familial resilience and well-being. Information seeking as a mechanism for increased self-agency and coping is well recognized in the LIS literature (Harris et al., 2001; Wilson, 2000; Chatman, 1996; Savolainen, 1995) and though less prevalent, particularly observed in information behavior studies of parents who have children with significant health concerns and disabilities (Gibson, 2014; Al-Daihani & Al-Ateequi, 2015; Ozyazicioglu and Buran, 2014; Jackson et al., 2008; Mackintosh et al., 2005). Studies exploring information behaviors and needs from the perspective of individuals with developmental disabilities including ASD are less prominent in the LIS literature (Hanson-Baldauf, 2013; Holmes, 2008; Tarelton, 2004). Still, little suggests that their information needs and practices are largely different than individuals without ASD.

Information poverty. We define information poverty as a chronic lack of information access due to persistent social factors, and begin our study with a provisional acceptance of Chatman's (1996) six propositions. According to Chatman, people who are information poor perceive themselves to be devoid of information, are marked by some sort of class distinction, engage in self-protective behaviors, conduct risk-analyses when deciding whether to seek and share information, and selectively seek and trust information from new sources. Preliminary research has demonstrated that communities of people with developmental disabilities (and their families) often meet these criteria, despite the existence of strong local peer-to-peer networks. The reliance on peer-to-peer networks, which have great potential for information sharing, but can also amplify misinformation (Gibson, 2014; Gibson & Kaplan, 2015), and the relatively limited research on individual cognition in IR, HCI, and other systems design among people with ASD make this area especially important for research.

Information Worlds, Boundaries, and Power. This study uses Jaeger and Burnett's (2010) Information Worlds theory as a framework for describing the social and information structures of the study communities. We anticipate that the examination of boundary objects, conflicting information values, and power imbalances between actors in the information world will prove fruitful for developing explicitly critical frameworks for information poverty. Jaeger and Burnett's theory also provides structure within information science for application of many critical race and gender theories and concepts. As an example, Crenshaw's (1991) intersectionality concept, which theorizes the effect of social structures on intersecting identities (e.g., woman AND Black AND educated AND autistic) fits well with the idea that individuals can simultaneously occupy multiple overlapping information worlds, and need to negotiate multiple sets of information values all at once. It is our hope that these theoretical frameworks

will provide the structure and data needed to improve the field's ability to recognize, record, and mitigate the effects of marginalization as it relates to information.

Conclusion

The right to information is understood as a fundamental human right (United Nations, 1948), and affirmed as a guiding principle for the design of face-to-face and online information systems (American Library Association, 2017; World Wide Web Consortium, 2017). Unfortunately, this right has remained largely unrealized by individuals with developmental disabilities. LIS efforts to address and rectify inequities in access require tools for proactively understanding the complex social structures and information needs of the communities they serve and communities underserved. Critical theory plays an essential role in this process by ensuring diverse voices and values are recognized, validated, and incorporated into research, practice, and system design that serve to inform and support all.

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