
Benefits and Challenges for Social Media Users on the Autism Spectrum

Tao Wang

University of California, Irvine
Irvine, CA 92617 USA
taow4@uci.edu

Monica J. Garfield

Bentley University
Waltham, MA 02452 USA
mgarfield@bentley.edu

Pamela Wisniewski

University of Central Florida
Orlando, FL 32816 USA
pamwis@ucf.edu

Xinru Page

Brigham Young University
Provo, UT 84602 USA
xinru@cs.byu.edu

ABSTRACT

Individuals with Autism Spectrum Disorder (ASD) often face difficulties creating and maintaining social connections with others, which has been shown to negatively affect their well-being. Some researchers have investigated whether social media use can lead to social benefits, but with mixed results. To better understand how social media use can be beneficial and what challenges it poses, we conducted an interview study with eight adults on the Autism Spectrum. We report on the perceived benefits and real challenges participants faced when trying to engage with others through social media. Often the benefits users hope for are overshadowed by negative ramifications and safety risks that accompany their social media use. We conclude with recommendations for designing social media for neurodiverse users.

KEYWORDS

Social Media; Users with Autism Spectrum Disorder; Interviews

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the Owner/Author.

CSCW '20 Companion, October 17–21, 2020, Virtual Event, USA

© 2020 Copyright is held by the owner/author(s).

ACM ISBN 978-1-4503-8059-1/20/10.

<https://doi.org/10.1145/3406865.3418322>

INTRODUCTION

Social media usage has been linked to increased bonding and bridging social capital, as well as the ability to maintain social connections [8]. This effect is particularly pronounced for those starting with lower life satisfaction or self-esteem [8]. While prior work studied general social media users, we explore whether social media presents a unique opportunity for helping people with Autism Spectrum Disorder (ASD) overcome some of the challenges they face when developing social relationships with others. Since social media's text and photo-based communication channels de-emphasize the need for interpreting nonverbal cues and provides more structured communication, conceivably, it could be a medium that puts neurotypical individuals and those on the spectrum on a more uniform playing field for social interaction. To gain a deeper understanding of the benefits and challenges of social media usage by individuals with ASD, we interviewed eight adults on the Autism Spectrum to understand their perceptions and experiences. Our findings contribute to a more nuanced understanding of the experience of users drawn from a different population than the typical college attending and mobile individuals in autism technology studies.

BACKGROUND

It is estimated that between 1-2% of the world's population is on the Autism Spectrum [7]. A defining characteristic of ASD is that these individuals develop social skills differently than neurotypical individuals; therefore, they may have difficulties understanding neurotypical behaviors and social norms [19]. Compared to the general population, people with ASD report higher levels of loneliness [11,15] and more restricted networks of friends, which results in lower satisfaction with their social networks [2]. Specifically, they are interested in forming more social connections [3,4,11]. Studies also revealed that informal social support, such as readiness of help [17], is also associated with quality of life for adults with ASD [13].

Meanwhile, research on social media and users with ASD has painted a complex but incomplete picture. Having a supportive social network has been shown to be a significant factor in improving the quality of life for people with ASD [12]. Yet, this research was not specific to the use of online social networks. For adolescents with ASD, social media use was associated with increased friendship quality but moderated by anxiety levels; this research shows that social media may help facilitate social engagement but at the cost of displacing offline social interactions [14]. Meanwhile, Ward et al. [18] found that adults with ASD who used Facebook reported being happier than those who were not on Facebook, but this effect diminished with high levels of use. The researchers did not find a similar effect with Twitter. Even when users with high-functioning ASD have found social media useful, there are barriers to maintaining those relationships due to issues of trust, privacy, inflexible thinking, and perspective taking [6]. These prior works and others [1,5,9,10] start to unpack some of the nuance of social media use for individuals with ASD, but the findings were primarily based on survey studies, on specific ASD populations, or evaluating task-driven use cases. In contrast, we conducted an in-depth interview study with formally diagnosed adults with different abilities. Our goal was to capture the broader spectrum of experiences, both good and bad, related to social media by adults with ASD.

Table 1: Interview Participants

| <i>ID</i> | <i>Site*</i> | <i>Social Media Used</i> | |
|-----------|--------------|--------------------------|--|
| P1 | M | A | Facebook |
| P2 | F | A | Facebook, Instagram |
| P3 | F | A | Facebook, former user of Instagram |
| P4 | M | ** | Facebook |
| P5 | F | B | Facebook, Instagram, Snapchat |
| P6 | M | B | Snapchat, former user of Facebook, former user of MeetMe |
| P7 | M | B | Twitter, Facebook, Reddit, Instagram, Snapchat |
| P8 | M | B | Facebook, Instagram, Twitter, Snapchat |

* Site A serves adults with intellectual or developmental disabilities, whereas Site B serves mainly individuals with developmental disabilities; IQ was part of the criteria for being eligible for the different services of the two organizations.

** P4 was recruited via Site B but does not attend either organization.

EXEMPLAR QUOTES

Maintaining Existing Relationships

“I can contact family members [on Facebook] that live far from me. Family that I don’t usually see. They live far. Too far for me to even go visit.” –P3

Reducing boredom

“Oh, God. No! I wouldn’t deal. I would give up the \$1000 [a hypothetical compensation that she jokingly proposed] for the social media. I’d be bored. I think that’s what it is. I think I’d just be really bored.” –P5

METHODS

To recruit participants, we partnered with two community organizations serving adults with ASD in a metropolitan area in the Northeastern United States. We interviewed eight adults on the spectrum (aged 23-41). Table 1 summarizes interviewee characteristics. We consulted with the service providers regarding the proper consent process: we obtained written consent prior to the interviews from interviewees who are their own legal guardians or written consent from their legal guardians and assent from interviewees. A staff member or caretaker was present for each interview to provide support if necessary. At the beginning of the interview, we explained the protocol again and obtained positive confirmations from all participants before proceeding. The interviews followed the same protocol and focused on understanding why participants used social media, and the benefits and challenges they faced. The first and second authors coded for benefits and challenges following an open coding process [16] and came to consensus on the final codes.

FINDINGS

Benefits and Motivations for Using Social Media

Participants expressed that social media was beneficial for maintaining existing relationships and reducing boredom. Some also expressed their desire to gain new social contacts via social media.

The ability to maintain existing relationships. Many interviewees were still living in their hometowns, often with their parents, while high school friends and siblings had gone off to college or moved away for work. Therefore, maintaining relationships with existing contacts was a common motivation for using social media. Others also mentioned it was particularly important for keeping in touch with geographically distant family members. However, social media was also critical for local contacts. None of our participants drove, so it was difficult to arrange in-person visits with friends. Interacting on social media removed the need to travel to engage with others.

Reducing boredom and pursuing special interests. Social media was the top destination for participants when they were looking to fill their time and pursue their special interests. Typical activities on social media include “[posting] something that I really liked” (P6), “looking at posts” (P5), “just to have something to do” (P2). P5 and P7 expressed having strong interests in movies and sports respectively. They were able to use social media to pursue their passions by joining many fan groups on Facebook. When asked about how they would feel if they had no access to social media for a month, most pushed back strongly. They explained that they did not have jobs, or enough work hours, or other things to do to occupy their time. Few participants explained they would find other ways to kill time, such as watching YouTube videos or reading comic books.

Seeking new relationships. Participants described attempts to make friends on social media or seek romantic relationships, but the outcomes were often discouraging. P6 frankly stated that dating was a main motivation for him to use social media, but the experience often ended up in frustration. P1 also tried to befriend many people on Facebook, but often was rejected. P3, in contrast, was on the receiving end. She received many friend requests from strangers who would block her upon learning she had a boyfriend. While making new friends was often a perceived benefit of social media, many were left confused and often disappointed when it was not realized.

EXEMPLAR QUOTES (Continued)

Seeking New Relationships

“There's gotta be a million people that are on Facebook and what have you, but the other thing is that they don't wanna become your friends.” – P1

Anxiety

“I've done it [deactivate his Facebook account] a few times to take a break from it and it's because of the stress. If I get all the drama. If I feel like I'm getting too anxiety. I'll take it down for a day or two. Or maybe a while and then put it back up.” - P7

Harassment and Drama

“I don't like it when people give negative comments or post something inappropriate. Something like really immature, something that is more like, insensitive or can consider be like a harassment in a way.” -P4

Privacy Concerns

“I didn't really go overboard with posting everything about my life because I didn't really think that my life was ... or certain aspects of it were people's business.” -P6

Challenges and Drawbacks of Social Media Use

Participants identified anxiety, harassment/drama, and privacy as key social media challenges.

Anxiety. Participants expressed how anxiety was a major issue in using social media. Often interviewees would feel this anxiety when a message or friend request was not answered right away and had to come up with ways to cope with it. P1 shared one time after being rejected, “I actually went out for a walk and it calmed me down right away.” P7 regularly took a “break” from social media by deactivating his Facebook account: “I've done it a few times to take a break from it and it's because of the stress.” Other interviewees left social media completely. P6 explained how the drawbacks of leaving Facebook was worth it: “I don't really keep in touch with [my Facebook contacts] anymore, but at the end of the day, my mental health is more important.”

Harassment, and drama. Participants were disturbed by harassment and bullying that they witnessed or experienced on social media. These incidents happened both in public posts and private group chats. P2 complained about “people talking about other people behind their backs. People like to talk about people and call them names over Facebook... This person likes this person, this person likes this person when it's not even true.” P5 tried to overlook negative content and “scroll right past by them.” Participants tried not to engage in negative interactions, but when the harassment became too much, some resorted to blocking the perpetrator or negative poster.

Privacy concerns. Participants often drew a line between private and public information for safety reasons. P2 explained, “I don't want people finding where I live.” Most also stated that they did not connect with strangers online. P8 said, “I would need to get to know them a little bit more before [connecting].” However, in their own visual inspection of their friend lists, most participants acknowledged they had been interacting with strangers.

DISCUSSION AND CONCLUSION

Overall, social media was beneficial for helping our participants maintain existing relationships and occupying their time. While these benefits are not unique to individuals on the spectrum, they were magnified due to immobility (e.g., inability to drive, being left behind as friends and siblings move away) and abundance of free time (e.g., difficulty getting a job or not enough hours). However, the unrealized potential benefits related to bridging social capital (i.e., making new friends), as well as the negative consequences to one's mental health and privacy often outweighed the benefits of engaging with people beyond their existing trusted connections. Participants often struggled with the “social” aspects of social media to the point that it negatively impacted their mental health. Hence, a key implication of this work is that we identify the development of bridging social capital as a deficit in the design of social media platforms. Therefore, future research should consider how we might design social media that promotes neurodiversity and scaffolds new relationship formation in a way that is healthy and beneficial for adults with ASD. Furthermore, users' abilities influenced their objectives, expectations, and pain points on social media. More in-depth exploration should focus on understanding these underlying connections, as well as effective mediation tactics. Finally, we learned that developing relationships, especially romantic ones, was a strong motivation for many to use social media. Considering the challenges and risks in building relationships online, future research should examine this topic more carefully.

REFERENCES

- [1] Susan Abel, Tanya Machin, and Charlotte Brownlow. 2019. Support, socialise and advocate: An exploration of the stated purposes of Facebook autism groups. *Res. Autism Spectr. Disord.* 61, (May 2019), 10–21. DOI:<https://doi.org/10.1016/j.rasd.2019.01.009>
- [2] A. E. van Asselt-Goverts, P. J. C. M. Embregts, A. H. C. Hendriks, K. M. Wegman, and J. P. Teunisse. 2015. Do Social Networks Differ? Comparison of the Social Networks of People with Intellectual Disabilities, People with Autism Spectrum Disorders and Other People Living in the Community. *J. Autism Dev. Disord.* 45, 5 (May 2015), 1191–1203. DOI:<https://doi.org/10.1007/s10803-014-2279-3>
- [3] Nirit Bauminger and Connie Kasari. 2000. Loneliness and Friendship in High-Functioning Children with Autism. *Child Dev.* 71, 2 (2000), 447–456. DOI:<https://doi.org/10.1111/1467-8624.00156>
- [4] Nirit Bauminger, Cory Shulman, and Galit Agam. 2003. Peer Interaction and Loneliness in High-Functioning Children with Autism. *J. Autism Dev. Disord.* 33, 5 (October 2003), 489–507. DOI:<https://doi.org/10.1023/A:1025827427901>
- [5] Adham Beykikhoshk, Ognjen Arandjelović, Dinh Phung, Svetha Venkatesh, and Terry Caelli. 2015. Using Twitter to learn about the autism community. *Soc. Netw. Anal. Min.* 5, 1 (June 2015), 22. DOI:<https://doi.org/10.1007/s13278-015-0261-5>
- [6] Moira Burke, Robert Kraut, and Diane Williams. 2010. Social use of computer-mediated communication by adults on the autism spectrum. In *Proceedings of the 2010 ACM conference on Computer supported cooperative work (CSCW '10)*, Association for Computing Machinery, Savannah, Georgia, USA, 425–434. DOI:<https://doi.org/10.1145/1718918.1718991>
- [7] CDC. 2020. Data and Statistics on Autism Spectrum Disorder | CDC. *Centers for Disease Control and Prevention*. Retrieved June 20, 2020 from <https://www.cdc.gov/ncbddd/autism/data.html>
- [8] Nicole B. Ellison, Charles Steinfield, and Cliff Lampe. 2007. The Benefits of Facebook “Friends”: Social Capital and College Students’ Use of Online Social Network Sites. *J. Comput.-Mediat. Commun.* 12, 4 (July 2007), 1143–1168. DOI:<https://doi.org/10.1111/j.1083-6101.2007.00367.x>
- [9] Hwajung Hong, Jennifer G. Kim, Gregory D. Abowd, and Rosa I. Arriaga. 2012. Designing a Social Network to Support the Independence of Young Adults with Autism. In *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work (CSCW '12)*, ACM, New York, NY, USA, 627–636. DOI:<https://doi.org/10.1145/2145204.2145300>
- [10] Hwajung Hong, Svetlana Yarosh, Jennifer G. Kim, Gregory D. Abowd, and Rosa I. Arriaga. 2013. Investigating the Use of Circles in Social Networks to Support Independence of Individuals with Autism. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13)*, ACM, New York, NY, USA, 3207–3216. DOI:<https://doi.org/10.1145/2470654.2466439>
- [11] Jill Locke, Eric H. Ishijima, Connie Kasari, and Nancy London. 2010. Loneliness, friendship quality and the social networks of adolescents with high-functioning autism in an inclusive school setting. *J. Res. Spec. Educ. Needs* 10, 2 (2010), 74–81. DOI:<https://doi.org/10.1111/j.1471-3802.2010.01148.x>
- [12] Micah O. Mazurek. 2013. Social media use among adults with autism spectrum disorders. *Comput. Hum. Behav.* 29, 4 (July 2013), 1709–1714. DOI:<https://doi.org/10.1016/j.chb.2013.02.004>
- [13] J O Renty and Herbert Roeyers. 2006. Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism* 10, 5 (September 2006), 511–524. DOI:<https://doi.org/10.1177/1362361306066604>
- [14] Gerrit I. van Schalkwyk, Carla E. Marin, Mayra Ortiz, Max Rolison, Zheala Qayyum, James C. McPartland, Eli R. Lebowitz, Fred R. Volkmar, and Wendy K. Silverman. 2017. Social Media Use, Friendship Quality, and the Moderating Role of Anxiety in Adolescents with Autism Spectrum Disorder. *J. Autism Dev. Disord.* 47, 9 (September 2017), 2805–2813. DOI:<https://doi.org/10.1007/s10803-017-3201-6>
- [15] Paul T. Shattuck, Gael I. Orsmond, Mary Wagner, and Benjamin P. Cooper. 2011. Participation in Social Activities among Adolescents with an Autism Spectrum Disorder. *PLoS ONE* 6, 11 (November 2011). DOI:<https://doi.org/10.1371/journal.pone.0027176>
- [16] Anselm L. Strauss. 1987. *Qualitative Analysis for Social Scientists*. Cambridge University Press.

- [17] Megan C. Tobin, Kathryn D. R. Drager, and Laura F. Richardson. 2014. A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life. *Res. Autism Spectr. Disord.* 8, 3 (March 2014), 214–229. DOI:<https://doi.org/10.1016/j.rasd.2013.12.002>
- [18] Deborah M. Ward, Karen E. Dill-Shackleford, and Micah O. Mazurek. 2018. Social Media Use and Happiness in Adults with Autism Spectrum Disorder. *Cyberpsychology Behav. Soc. Netw.* 21, 3 (February 2018), 205–209. DOI:<https://doi.org/10.1089/cyber.2017.0331>
- [19] 2013. *Diagnostic and statistical manual of mental disorders: DSM-5™, 5th ed.* American Psychiatric Publishing, Inc., Arlington, VA, US. DOI:<https://doi.org/10.1176/appi.books.9780890425596>