

Social Use of Computer-Mediated Communication by Adults on the Autism Spectrum

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ABSTRACT

The defining characteristics of autism, including difficulty with nonverbal cues and need for structure, and the defining characteristics of computer-mediated communication (CMC), including reduction of extraneous cues and structured exchange, suggest the two would be an ideal match. Interviews and observations of 16 adults on the high-functioning end of the autism spectrum reveal that many seek greater social connectedness and take advantage of interest-based online communities to foster successful, supportive relationships. However, CMC intensifies problems of trust, disclosure, inflexible thinking, and perspective-taking, making it difficult for some to maintain relationships. Interventions in the form of information visualization and CMC-specific social skills training are presented. Intervention considerations and participatory design opportunities are discussed.

Author Keywords

Computer-mediated communication, online communities, autism spectrum disorders, social support

ACM Classification Keywords

H.5.3 [Information Interfaces]: Group and Organization Interfaces - Collaborative computing, Web-based interaction, Computer-supported cooperative work.

General Terms

Design, Human Factors

INTRODUCTION

The interpersonal challenges of autism

The defining characteristics of autism and the inherent properties of computer-mediated communication (CMC) suggest that the two would be an ideal match. Many individuals with autism spectrum disorders (ASD) have difficulty making eye contact, interpreting nonverbal cues such as facial expressions, processing non-literal language, thinking flexibly, and understanding others' perspectives [45]. Therefore, turn-taking, small talk, and overall social connection can be challenging. Furthermore, some individuals with ASD are hypersensitive to environmental stimuli, such as bright lights, loud sounds, or strong smells. Combined, these factors make

face-to-face interaction difficult, and for teens and adults with ASD who seek friendships, this can result in increased feelings of loneliness and depression [23]. Though the causes and cognitive mechanisms are unclear, diagnoses of autism have dramatically increased, from 1/2500 children in 1966 to approximately 1/150 in 2002 [8,26].

Autism spans a spectrum of behaviors and abilities, from nonverbal children needing intensive therapy for basic life skills to highly intelligent adults who live independently but have trouble with social communication [1]. The field of human-computer interaction (HCI) has made great advances in pattern-finding and training technology [e.g., 16,47] to aid parents, teachers, and counselors working with more profoundly disabled individuals. However, for those on the high-functioning end of the spectrum, including those with Asperger Syndrome, autism may be nearly invisible to others, simply appearing as social awkwardness, and little HCI research exists addressing their needs. Studies of the social challenges of adults with Asperger's reveal intense isolation, problems initiating interactions, communication difficulties, and a desire for intimacy and call for facilitated social interactions, opportunities to observe or model socially appropriate behavior, and alternative modes of communication [4,17,30]. For these adults, ASD is interpersonal, a problem primarily evident in communication. Therefore, alternative forms of communication, such as CMC, and alternative platforms, such as online communities, may be helpful both for practical and social reasons.

Properties of computer-mediated communication

The social affordances of CMC have been heavily examined [e.g., 19,48] and the reduced bandwidth makes it potentially ideal for adults with ASD¹. Text-messaging, email, and Facebook wall posts all provide a highly structured environment without extraneous stimuli, and their asynchronicity allows users additional processing time. Without prosody and intonation, CMC provides a level playing ground for interpretation (or misinterpretation [22]). In a series of email interviews of adults with ASD, Benford found that "the visual anonymity, flexible timing, and permanent nature of the Internet serve to diminish the social, emotional and time

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¹ From this point on, "ASD" will refer to the high-functioning end of the autism spectrum, unless otherwise specified.

pressures of interpersonal communication and also the cognitive complexity of the processes involved. The drive for greater control over social communication was a major motivation for use of the Internet." [4].

In fact, many adults with ASD already write extensively online. Studies of the blogs and forum posts by adults with ASD reveal no discernable differences between their writing and that of other posters [12,32]. Jones et al. found that bloggers with Asperger's used the Internet as a way to role-play neurotypical² behavior [18]. Clinical psychologist Tony Attwood encourages adults with Asperger's to use the Internet as a way to communicate with "greater eloquence" [1].

Beyond simple communication mechanics, the Internet also affords social benefits. Web users find conversation and information regardless of location or time of day. Online communities provide a forum for people with similar interests, such as anime or genealogy, or for advice and self-advocacy with others with similar life stories or diagnoses. Readers can observe others interacting without directly participating themselves and still receive informational and social benefits [36]; in a popular autism issue forum with 25,000 members, one typical thread describing an "Aspie car" had 71 replies but 998 views, implying that the majority of participants were lurkers [12].

Numerous findings from the HCI and autism research communities imply Internet use impacts quality of life. Internet use has been associated with increased perceived social support and psychological well-being [e.g., 21], particularly among individuals with lower self-esteem and life satisfaction [10]. Perceived formal and informal support is highly correlated with quality of life for adults with ASD, while disability characteristics (such as their degree of autistic behavior) and actual received support are not [40]. Jennes-Coussens et al. end their study of men with Asperger's by stating "intervention goals must shift from survival-oriented behaviours to more sophisticated abilities so that individuals are better able to share feelings and ideas with social partners leading to more satisfying, supportive and intimate relationships" [17]. Online communities afford this sharing of feelings and reading others' disclosures, potentially increasing users' quality of life.

However, CMC has drawbacks, as well, that may interact with aspects of autism. Chat rooms quickly switch speakers and topics, making it difficult to follow a conversation thread [46]. Window management introduces opportunities for error in instant messaging, such as when a teen intends to gossip about one friend to another, but instead sends the gossip to the person being gossiped about [14]. Spelling and grammar conventions are violated or re-normed, which may be difficult for adults

² "Neurotypical" or "NT" is commonly used to refer to those not on the autism spectrum.

with ASD who have less flexible writing standards. Finally, general cognitive abilities may override any benefits of the medium. For example, in a study of partners giving map directions over the phone and via text chat, some participants with ASD showed no difference across media because overarching planning difficulties led them to use an inefficient turn-by-turn strategy rather than a global landmarks strategy, wiping out potential speed gains from either medium [39].

Goals of the present study

The present study examines the successes and challenges adults on the high-functioning end of the autism spectrum experience when using computer-mediated communication and online communities for social support. Through interviews and observation, we evaluate existing systems including text messaging, email, instant messenger, and social networking sites at both a communication-mechanics and social-psychological level. Three research questions drive this work: (1) What are the current social communication needs of adults with ASD, (2) How well does existing CMC technology address those needs, and (3) What opportunities exist for improving CMC experiences, including tools or training?

We first describe the context of adults with ASD, and highlight the few studies investigating CMC use by adults with autism. We then present results of interviews with 16 adults with ASD, identifying their needs and areas in which technology and training can address those needs.

HIGH-FUNCTIONING ADULTS WITH AUTISM

Autism research often focuses on children, when interventions may have the greatest impact on skill attainment [44]. The popular press and support organizations also frequently portray autism as a children's disease [12]. However, adults have unique needs that are often unmet. First, in the United States, state services typically expire at age 21, leaving adults with few supports [e.g., 2]. Communication and social behavior may improve with age, though the underlying cognitive mechanisms may not [45]. Adults may be naïve [1], but still living independently and thus susceptible to financial deception. Many adults with ASD who have college degrees find themselves underemployed [17]. Finally, many individuals with milder impairments are not diagnosed until they are adults. Because autism is genetic and high-functioning forms like Asperger's have only been widely diagnosed recently, adults often find an explanation for their own experiences when their children or other younger relatives are diagnosed. Personal narratives of adults diagnosed later in life describe decades of feeling "different" and not knowing why [42].

As a result of these issues, there is a growing movement among adults with ASD for self-advocacy, raising awareness, participatory research, and support for major life transitions, such as from high school to college [43]. Much of this movement is coordinated online and is part of a culture focusing on positive differences instead of medical deficits

[12]. Peer advice-giving on dating, job interviews, and making friends fill the forums at sites like WrongPlanet.net, a community for people both on and off the spectrum.

With a lack of formal support and the growing use of the Internet for informal support, it makes sense to study how adults with ASD use these naturally occurring social systems online. However, few studies exist. Notable exceptions include early work using the virtual world Second Life for teaching and simulated job interviews [5,6]. In a content analysis of blogs written by adults with Asperger's and a random sample of all blogs on the Internet, Newton et al. found no significant differences between the two groups, except that bloggers with autism had greater variance in their use of social words, which may reflect the variability of sociality among adults with ASD [32]. In email interviews adults with ASD reported feeling outside the mainstream, and appreciated features of CMC for control, clarity, liberation, and empowerment [4]. Overall, these studies indicate the great potential of the Internet for adults with autism; the current study contributes to this work by evaluating the success adults with ASD have with current technology and identifying ways the technology could be improved to better support social outcomes.

METHOD

Participants

Sixteen adults (13 men and 3 women) on the high-functioning end of the autism spectrum were recruited for interviews. The gender balance reflects the typical distribution of autism diagnoses of 4:1 [3]. Participants ranged in age from 17 – 37 (mean age 25.6), and all had formal diagnoses of autism and normal IQs (70 or higher). Diagnoses included Asperger Syndrome, High-Functioning Autism, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). No distinction is drawn between these for the purpose of this study because they share the relevant characteristics.

To obtain participants with a variety of Internet use (and non-use), we recruited via college disability counselors and local support group leaders. Counselors were apprised of the research goals and asked to invite anyone with whom they worked to participate, regardless of their level of Internet activity. Individuals interested in participating contacted the researchers via email or phone, who then provided additional information and scheduled an interview. Two participants were recruited directly from an autism discussion forum because they were heavy posters and lived in the area.

A few days before the interview, participants identified which websites they used at least once a month³. Sites such as Wikipedia, where the majority of users read but do not interact were included to establish baseline, non-social web usage.

³ From list: Facebook, MySpace, online dating, World of Warcraft, Second Life, Wikipedia, YouTube, Craigslist, discussion or news forums, Twitter, own personal website or blog, none of the above

Interview protocol

Interviews took place in the participant's home, school, or for the one user without a home computer, his typical Internet access point, the public library. Interviews were one-on-one and lasted approximately one hour. Participants received \$15.

The semi-structured interview focused on interactions with people, both face-to-face and online. Interviewees introduced themselves, described their hobbies, and then walked through their activities the previous day (or another typical day). The interviewer probed mentions of other people, or other potentially social times such as lunch. After a rapport was established, the interviewer asked about the interviewee's diagnosis and perceptions of interactions with other people.

After the initial portion of the interview, the participant logged in to his or her computer and walked through email, instant messenger, and up to five social websites. For each site, interviewees stepped through the activities they performed the last time they logged in and explained why they first joined and what they liked and disliked. They showed content they had produced, such as blog or forum posts, YouTube comments, or short stories, and described their relationship to others on the site. Participants also discussed phone and SMS use.

Audio was recorded with permission and transcribed. We also read any public content online, such as blog posts, fan fiction, or public profiles. The interviewer wrote field notes immediately after the interviews with additional information about participants' communication style, computer setup, and any usability issues observed.

Ethical considerations

To ensure sensitivity to participants' needs and establish trust, we worked closely with college counselors and support group leaders. Meeting in participants' homes not only aided with contextual validity, but also meant that the participants had greater control over environmental stimuli. All participants read the consent form several days in advance. All had normal IQs and were capable of understanding the consent process.

Identifying themes and claims

To identify themes related to social interaction online and off, we used a grounded theory approach [11]. Transcripts were coded at two levels. First, all mentions of communication channels and social interactions were tagged with qualitative analysis software. Interviews were then re-sorted by tags to identify initial patterns. Emergent patterns were then incorporated into later interviews. For example, we did not initially ask about online dating, but so many mentioned it that we added it to the list of sites and began asking about dating, online and off, and emailed earlier participants about it. In addition to this low-level coding, we used an open-coding scheme [9]. At the half-way point in data collection, transcripts were chunked at the incident level, labeled with short, active words related to communication, social interaction, desires, and concerns, and roughly organized into initial themes. We linked the themes with claims about their relationships, looked for

evidence to disprove the claims and finally retained those claims supported by data from at least half of the interviewees. The interviewer confirmed the claims with an expert, the co-director of a local autism research center with years of clinical experience, including experience with many of the participants.

RESULTS

Overall, CMC was beneficial for initiating social interactions, particularly through interest-based groups and pre-defined icebreaker activities, defined below. However, beyond initial interactions, many participants were dissatisfied with their experiences online.

We first report descriptive statistics and basic pros and cons of CMC at the communication-mechanics level. Then we present five major themes and linking claims. The first theme is *initiating contact*, and the mechanisms that were successful. Next, we discuss *problems maintaining contact*. We claim those problems are caused for three reasons, described as the final three themes: *knowing whom to trust*, *knowing how much to disclose*, and *understanding CMC-specific social norms*. These problems are related to characteristics of their cognitive processes and past experiences, including naiveté, inflexible perceptions of others' intentions, and difficulty understanding how others perceive their actions. Many lend themselves to the design of interventions, discussed at the end.

Participants used a variety of social technology. More than half (10 people) had profiles at Facebook or MySpace, nine post to discussion forums, and six used online dating sites. All but one had a cell phone, and the remaining participant had landlines at home and work. However, only six (38%) regularly use their phone for calls; the other ten only use it for emergencies or checking in with a parent. Most had tried text messaging (12) though only half currently used it; the others generally said it cost too much. None were current users of 3D environments like Second Life or World of Warcraft, though many were active video gamers offline. Table 1 presents basic demographics, and Table 2 shows their CMC use.

Communication mechanics: Pros and cons of CMC

As expected, participants liked functional aspects of CMC: it provides additional time to think of a response, removes pressure for eye contact, and reduces self-consciousness about paralinguistic cues.

"You're not looking at them and they can't see your facial expressions on an email. Talking face-to-face is harder because you have to keep eye contact and give them your attention . . . and talk yourself when there's a proper break." (Ryan, age 23)⁴

"And, one guy, I was talking to him online. He was like, 'This is not John. John stutters and talks fast. John's a retard. This is not John.' I talked so intelligently, articulately online that he couldn't believe it was me." (John, age 24)

⁴ Names are pseudonyms, and portions of quotes have been omitted for brevity or to remove identifying information, but otherwise quotes are in participants' own words.

Sex	81% Male	<u>Living situation</u>
Age	17-37, M=25.6	By self 2
Age of diagnosis	3-30, M=15.7	With roommates 3
Driving	10 have license	With family 11
<u>Employment</u>		
Full-time student	5	<u>Education level</u>
Grocery bagging	2	High school 2
Data entry	2	Some college/AS degree 10
Info technology	3	Bachelor's degree 3
Unemployed	4	Master's degree 1

Table 1. Participant demographics (N=16)

	This Sample	U.S. Average
Cell phone	94%	71%
Text messaging (SMS)	50%	40%
Email	81%	94%
Instant messaging	31%	59%
Social networking	63%	67%
Online dating	38%	6%
Discussion forums	56%	40%

Table 2. Communication technology use. U.S. Average for adults 18-29 [33], except cell and SMS for all adults [34].

Several also mentioned liking the semi-synchronicity of instant messenger:

"It's often easier to communicate with people using instant messenger. Get more instant responses. Gives me an opportunity to think about what I want to say." (Charles, age 30)

But as in many technology studies, usability issues caused frustration. Most issues were not specific to this group: difficulty entering text on cell phone number pads, forgetting website passwords, poor Internet connections, and frozen machines. Two-thirds (11 of 16) of the interviewees had good computer skills, including typing speed, window management, and browser navigation.

Some problematic aspects of CMC were specific to this group. A few mentioned having trouble with spelling or writing, and others missed the feedback available face-to-face. For individuals with slower reaction times, the phone was particularly difficult for both giving and receiving feedback:

"On the phone, we usually hang up too fast. If I have trouble thinking of something to say, usually that ends it. But in person, I have longer to think of things." (Alex, age 32)

Another avoids shopping online because he misses the feedback from spending cash in stores. And another explained why deadlines in online classes lacked necessary feedback:

"Well, if you have a teacher in front of you who is yelling about the Chem 101 report, and every day that week, and it's the final one, you're going to get it done because he says it. But online, they'll say, 'Submit this draft by this date,' and you will have none of the draft, or none of the reading assignment done, and all of a sudden half way through they're like 'Oh, by the way, Chapter XYZ is due tomorrow.' And to me it's like 'Oh, crap!'" (Andrew, age 21)

Difficulty with task prioritization is characteristic of autism, and so for these students the lack of feedback about task

progress may be more problematic than for another student. Online classes may provide individuals with autism an explicit structure and less dynamic communication. However, these affordances may be overridden by the lack of feedback. Because of their poor reciprocal communication skills, individuals with autism frequently depend on their communication partner (or instructor) to carry a greater share of the interaction, an aspect that may not be clear to the partner when using CMC.

Somewhat surprisingly given their reported difficulty interpreting facial expressions, many participants said they missed intonation and emotion in text-based communication.

“Well, it’s generally the tone, sometimes it’s more reserved. If I’m talking to my dad over email or through my IM client then I don’t have the opportunity to really kind of cut loose and make jokes, because a lot of that online is lost. There’s no chance for facial expressions.” (Mary, age 23)

“A keystroke is not the same as an intonation, in any language. So that’s what I’ve realized. If you’re making fun of someone, like jokes get misinterpreted online or in an email because it’s just a word; but if it’s an intonation, you can tell if someone is laughing.” (Andrew, age 21)

Initiating social contact

Contrary to the literal “inward-looking” definition of autism, many of these adults were looking outward. Half (56%) were looking for new friends or romantic partners, but had difficulty initiating contact, appearing “normal” when meeting potential friends, or maintaining the connection beyond its initiation.

“They had a lunchroom for the workers. A lot of times I might sit with somebody, but I would be freaking. I’m just a little socially awkward. I don’t know exactly how to start a conversation, what to talk about. I don’t think I’m good at small talk, but that seems to be the only thing I know how to do when I meet someone new.” (Grace, age 29)

“Because I talk fast, the speed of which I talk turns people off and makes people think I’m different and they don’t pay attention to the content of what I’m saying, just the speed of which I talk.” (John, age 24)

“I can’t meet women face-to-face. That’s the thing. I can’t approach a woman in person at all without freaking or either (a) creeping them out or (b) the conversation goes nowhere and I have nothing in common with them.” (Michael, age 25)

Two features of online communities were helpful in overcoming hurdles to initiating contact: interest-based groups and pre-packaged social interactions. First, many interviewees used fan pages and profile data to connect with people and ground their interaction in shared interests.

“After Pirates of the Caribbean came out, I was just looking for stuff and found a LiveJournal community for it. And from there . . . I moved to the social networking aspect of it, this time talking to people about the Johnny Depp movies. Now I’m talking to them about how the plum tree in their front yard just came down or their son didn’t make it into the high school play. This is the sort of thing that you would be talking about over white picket

fences, but unfortunately they live in southern California. . . . So it’s a very large picket fence.” (Mary, age 23)

“I find the best way to initiate a conversation with someone is if I find I have a commonality with them, either a common interest or belief. [I find out their interests] by reading their conversations on discussion threads or looking at their profiles or something like that.” (Michael, age 25)

Their relationships began as identity-based, in which they conversed about shared favorite movies, music, or games, and then progressed to more dyadic bond-based relationships, disclosing personal news and calling on each other for support. Identity and bond are two heavily studied attachment mechanisms for groups [37], and for these adults, relationships grounded in shared identity appeared to have the strongest roots, at least initially. And in some cases, the relationships formed online moved offline successfully:

“It helps that a lot of people I knew through LiveJournal lived in the Bay Area. So sometimes they would say, ‘I’m going out for sushi tonight. Does anyone want to meet me?’ And I’d be able to go and meet with them for sushi.” (Mary, age 23)

Even without moving offline, the relationships had practical benefit, as one man with a history of depression explains:

“She’s someone I met from WrongPlanet. I really like her a lot because one time when I was really struggling she would text me to remind me to take my medication, so she’s been real good support for me. [She continued to do it] for a month.” (Michael, age 25)

In addition to establishing friendships through shared interests, well-defined, pre-packaged social interactions also appealed to a few participants:

“I think they call them ‘smiles’ that you could just really quickly send anyone after reading their profile. I thought that was a nice icebreaker to get something going without having to think about what to put in an email.” (Nathan, age 31)

Several appreciated the birthday reminders in social networks, and would send birthday greetings without having to think of something to say. Another used Facebook’s “like” button, to leave an “I like this” comment.

Problems maintaining the connection

Despite using the Internet to ease into initial contact with potential friends, most interviewees reported trouble maintaining those connections. The very properties that aided connections—non-copresence and a large pool of semi-interchangeable people with similar interests to talk to—may have contributed to the failure of the fledgling relationships. Several reported people “disappearing” over time:

“Nobody’s ever really online. The people that I met on the Internet just never—I think it’s because they’re getting on with their lives or becoming a lot busier. They have more active social lives. And that really sucks for me because when I go on instant messenger, they’re never there.” (John, age 24)

And without co-presence or mutual friends, the potential friends are able to end communication without strings:

"I find that pretty much every time I've been on when she's on, she has set her status to 'away.'" (Alan, age 20)

"I don't see what I did wrong or what I could have possibly done wrong. She just completely cut me off and told me she wants nothing more to do with me, and I don't know why. . . . She ended the communication with me." (John, age 24)

As a consequence of having few close friends face-to-face and ephemeral relationships online, many said they had no one to talk to online. When describing the contents of their email inboxes, few had personal messages from individuals outside of their immediate family. Many subscribed to distribution lists for local or national autism groups, humorous news, or coupons. And while two individuals particularly liked connecting with other adults with Asperger's in a local face-to-face group, the few who used online communities organized around autism were not satisfied with the relationships they formed there, for the same reason of "disappearing" friends. Another remarked that because other psychiatric problems often co-occur with autism, his experience in autism-specific communities online was full of drama:

"At first community was supportive. But then people started to become real clique-ish. They started forming on other IRC channels. And some people were excluded and banned. It got kind of messy. I have to admit, I'm not totally innocent in participation of the drama. I did a few things I shouldn't have done. And this isn't an excuse for my actions or anything but I also have comorbid bipolar disorder and at the time it was out of control. I was saying things and doing things to hurt other people that I normally wouldn't do." (Michael, age 25)

Furthermore, for one man, connecting with geographically distant individuals with Asperger's wasn't enough:

"I wasn't satisfied with the level of conversation I was having with people there because it was still too dispersed. There are people from all over and right now what I want more than anything else is to deal with people in my age bracket with my level of functionality here in reality in this city. And I understand that's a tall order, but that's what I need now and I'm not going to find that online." (David, age 22)

For those seeking connections, the problem appeared to lie between initiation and continued contact. The following three themes explain contributing factors.

Knowing whom to trust

Many of the participants reported troubling histories of bullying and being taken advantage of, rooted in their willingness to believe others' words. Several men said that they were teased in high school after being made to believe they were the object of affection of popular girls. The revelation that they were being deceived was extremely painful. And this credulity continued beyond school, with one participant the victim of credit card fraud, and another being mugged:

"When I first moved into my first apartment, I saw a whole bunch of people standing around drinking, you know, 40-ounce beer bottles out of paper bags. And I thought those guys were people I could be friends with. Most people would know to stay away from those guys. I went up and tried talking to them. Next

thing I know, they're in my apartment stealing my stuff and the one guy punched me in the jaw. And they chased after me. So I've been victimized my entire life because of this disorder." (John, age 24)

For many, repeated incidents of victimization resulted in wariness of new "friends" online. They wanted to form relationships but were concerned about being deceived:

"A lot of people that go on the Internet now . . . what they say about themselves may not be who they really are because they enjoy faking—give you a false face on the Internet." (Ryan, age 23)

"You never know who you're going to find online [dating]. It's just scary in the Internet sometimes. You need to be careful." (Grace, age 29)

Some participants explained that they simply would not connect with anyone unknown online because of their past experiences and stories they had heard about predators. Another characteristic of autism is cognitive inflexibility, making an evaluation and then being unable to see nuance or exception. This was evident in some of the participants, who had solidified their beliefs into firm rules that kept them from using social spaces online at all:

"I don't go in the chat rooms or anything. I never use it to chat with other people that I don't know because you don't know what they're soliciting. . . . I've been learning that since '93, like don't talk to strangers in kindergarten. . . . As far as I'm concerned, I'm off the grid from Facebook." (Barry, age 21)

"I don't do any of that stuff Facebook or MySpace. I keep thinking of what happened to me several years ago [identity theft]. I don't want to give too much personal information out there" (William, age 37)

Knowing how much to disclose

Beyond general worries about strangers online, several participants were concerned about how much information they should share with potential friends.

"That's probably the problem with my blog, I don't know where to draw the line of privacy because I don't want to give too much about myself, I don't want to give too little, I don't want people harassing me about certain things." (Andrew, age 21)

And one told a story of cyberbullying, after trying to share:

"There's some guy that I met in the chat room, and I thought it was a girl. And I was so stupid back then. But I sent this really unflattering, really embarrassing picture of me with my shirt off, my boxers sticking out. I said, 'Is this a girl?'" And then he thought I was some kind of freak. So they posted that picture on the web site. From then on, they continued to do all kinds of horribly embarrassing things [in Photoshop] with that picture. And hundreds of people started spamming me . . . sending me instant messages, making fun of me" (John, age 24)

In particular, deciding whether to disclose anything about autism was a difficult decision for many participants. Most simply did not reveal anything about it, face-to-face or online.

"I make it a point to do that without disseminating my personal information [about ASD] because I feel that cheapens it for me

because then they just kind of give you the benefit of the doubt and they don't treat you like a real person. They just walk you along and hold your hand and tell you everything's going to be all right. And that's good for some people but that's not good for me. I want to get by socially on my own credentials." (David, age 22)

"I have a feeling that if I were to tell somebody, like my employer when I was working, that they might think, 'Why is that? Is there something wrong with you? Because I feel like I'm . . . because in society people like that aren't perceived very well." (Grace, age 29)

Several pointed out that others simply don't understand what it means to be on the autism spectrum:

"Generally speaking though, I would almost never tell the general public about this. . . . This is something that is not as easily understood as something like cancer." (Alan, age 20)

"I met a girl [on a dating site]. And I talked to her on the phone and she made fun of my voice because I have a slow, monotone voice. I met her at a local restaurant. I tried to explain to her that I have a disorder but she didn't understand. And, like, a day later, she gave me a blocked sender." (Alex, age 32)

Understanding CMC-specific social norms

The final theme explaining the difficulty participants have maintaining relationships they initiate online relates to understanding social norms specific to CMC. Cognitive mechanisms often lead individuals with ASD to focus on details, rather than the general picture, and so many have trouble learning from example [1,13]. Instead, many need assistance devising explicit rules to guide behavior, and then they do not necessarily translate those rules to other contexts.

Many participants described learning social rules for interacting with people face-to-face:

"When you're bringing up a topic make sure it's appropriate for the context. Don't approach people unless you really have a reason, like studying the same thing or looking at the same book." (Michael, age 25)

"I was taught not to talk too much about myself by showing interest in other people." (Ryan, age 23)

However, some were unsure how the social rules they had learned face-to-face translated to CMC, or had not figured out rules unique to the new media. Communication volume and timing caused problems for one participant, who met a woman at a dating site, went out with her once, and then sent a "few hundred" text messages to her over two days. He was used to communicating heavily by SMS with another friend, and expected this woman to want to text just as frequently:

"Well, we were just talking and stuff, and suddenly, she said, 'I'm canceling Thursday. Please don't call ever. Don't text me either.' I said, 'Why? What did I do? I'm deeply hurt. Please just tell me what the problem is. If you don't explain to me what I did wrong, I will never know. I'm going to keep texting you until you give me a reasonable explanation.'" (John, age 24)

Another man wanted to connect with childhood classmates, and would use a combination of Facebook, Google, and college

directories to find their contact information. He typed in personal details he remembered, such as their parents' names or where they moved after elementary school. Then, when he emailed or called, he would describe his process:

"In my email I included a very detailed description of how I knew her, and it included a number of precise dates. And she said she was surprised I would remember all of that. . . . She said that she was a little freaked out that I, like the method in which I used to track her down." (Alan, age 20)

Though he had good intentions, he did not recognize that the amount of detail he revealed might be unsettling from her perspective. Another participant reflected on his own experience intuiting social norms:

"The only thing I can throw out there is it's okay to be awkward. I'm never going to stop being awkward socially. There's a difference between being awkward and being creepy and that takes a little bit of work. . . . It's just a matter of personal reflection of being self-aware of the things you are doing. . . . I always imagine what I'm going to do in the third person and how I perceive that. And you go, 'Well, that doesn't look right.'" (David, age 22)

Some participants had successfully created guidelines specific to CMC:

"Sometimes, you have to set limits of like how many times to call the person." (Barry, age 21)

"Originally when I was Facebooked I used the law of averages which is, okay, 'How many friends do I have and how many times do they update their status' because apparently this is a big deal. And then you could update it that much but a lot of people do too much and a lot of people are just like 'whatever.' And I know if you just go with the mathematical average you can't go wrong because then you're just right there in the middle of everyone else and you stand out just right as much as you should." (David, age 22)

DISCUSSION

In summary, the adults on the high-functioning end of the autism spectrum interviewed for this study found many benefits of computer-mediated communication, including reduced stress from nonverbal signals, the ability to find people with similar interests, and pre-defined interaction mechanisms, like birthday greetings. However, beyond establishing initial contact with potential friends, many had difficulty maintaining those relationships, in part because they had trouble deciding whom to trust, how much personal detail to disclose, and what social rules to apply.

Previous research suggests that people use social technology to communicate with people they already know face-to-face [14,24]. Therefore, we might expect individuals who already have few friends to not benefit as much from CMC. The participants who had no one to talk to online confirmed this. The "disappearance" of fledgling relationships impacted them more than it would for others with wider social circles. However, research examining the Internet use of individuals with greater loneliness or lower self-esteem shows that they are

more likely to benefit from talking to people online [10,29]. This was true for those who found friends in interest groups.

Yet these adults were not always able to cash in on shared interests and form longer-term relationships or find romantic partners. Difficulties arose from their legitimate concerns about trusting others, and their ability to act according to socio-technical norms. This then undercut the power of that technology for fostering social relationships.

And so we revisit our three research questions. First, what are the current social communication needs of adults with ASD? All participants felt pressure when communicating face-to-face: managing eye contact, interpreting others' expressions, and responding at the right tempo. Many said they needed support initiating contact. Also, half who were out of school were either un- or underemployed. Though job and interview training were outside the scope of this study, in theory with extended social connections they would have potential access to other jobs and better navigate the social aspects of the workplace.

Next, how well does existing CMC technology address their needs? Online discussion groups, fan sites, and social networking sites supported their relationship formation by introducing them to others with shared interests, and some sites contained well-defined, pre-packaged interaction mechanisms. However, we do not know how their partners felt; pre-packaged interactions have the potential to be interpreted as less valuable because they take less effort, or may be ambiguous depending on the context of the relationship (e.g., Facebook's "poke" button). The outcomes of these kinds of icebreakers should be studied in more depth. Other downsides of CMC included the lack of intonation and synchronicity. Several participants said they preferred communicating voice-to-voice or liked people's company, even if it required effort, and didn't feel as connected when waiting for an email response. Furthermore, they missed feedback necessary to gauge others' reactions and track their own actions.

Finally, what opportunities exist for improving CMC experiences? The findings suggest three potential interventions.

Opportunities for interventions

Three breakdowns in the current study could be addressed with training or tools, including CMC-specific social skills training, information visualization of own behavior, and reputation systems for potential friends.

CMC-specific social skills training

Current approaches to social skills training focus on making the implicit explicit, giving feedback, and providing opportunities for practice. Virtual scenarios and virtual peers have been used for face-to-face social skills, including handling inappropriate requests from strangers, such as for money or a home address, [38], making decisions, such as where to sit in a crowded café or bus [28], or how to use gestures and turn-taking contingent on others' responses [47]. Similar scenarios, whether in the

form of text-based computer games, group role-play, or programmable virtual agents, could focus on phishing or predatory requests, or what personal information to reveal to a potential date.

Information visualization of own behavior

With millions of people communicating remotely and only a narrow window into some people's actions, it can be difficult for any social web user to determine how his or her own behavior fits into the norm. However, it is possible to reveal behavioral patterns in aggregate and use information visualization techniques to plot an individual's activities against a descriptive norm. Just as David uses a "law of averages" for updating his Facebook status, other adults on and off the autism spectrum could better see how their frequency of sending text messages, their number of forum posts, or their percentage of negative emotion words in email compares to others' in similar contexts. Furthermore, two interviewees referred to problems they had staying online all night, primarily on instant messenger, and as a consequence being late or tired the following day. Simple displays such as plotting the times of day one is online, or presenting a colored icon showing hours online could be used to set personal goals, such as ending communication by a particular hour, and then obtain visual feedback when breaking those goals. This intervention could help anyone, but may have particular benefits for individuals with autism by making their behaviors explicit.

Reputation and trust metrics for potential friends

Finally, many participants had trouble judging the trustworthiness of potential friends. While social networking sites have implicit reputation systems embedded in a social graph of mutual acquaintance and responsibility, the participants in this study generally would not benefit from those structural reputation mechanisms, because they have few close friends in their networks to start.

This problem of reputation persists throughout the web, and generally has been addressed by making behavioral attributes more salient. In eBay, for example, numeric scores and text reviews from past buyers form a robust reputation system that benefits sellers and buyers alike [41]. One participant in the current study mentioned generally worrying about others' intentions online, but successfully using eBay feedback to guide her purchase decisions. Similar mechanisms have been proposed in Wikipedia, making page revision and conflict history—and thus an article's potential trustworthiness—salient [20], and modeling editing and communication behavior of candidates for promotion to administrator [7]. Models that display attributes of potential friends—such as whether they list a legitimate email address, whether they tend to socialize with others in their age group, and whether they continue communicating with the same partners for long periods of time—could aid decision-making. Similar factors are already studied in the context of phishing and spam detection [49]. This approach would require study to protect privacy and ensure that

it does not simply reveal weaknesses of these participants' own interactions, but could have great impact.

Ethical considerations of interventions

It should be noted that only half of the adults in this study were actively seeking to build relationships. Many were content with their social lives, and as designers we should be cautious to apply interventions only where appropriate. As two adults with ASD write, "*There exists a value judgment within the NT world that emotional relatedness is a prerequisite to achieving happiness and success. The authors ask you to consider that this judgment may be preventing some ASD children from becoming happy, functioning adults*" [13]. At the same time, half of the adults in this study were attempting social overtures but having difficulty communicating their desires. These two outlooks reflect a spectrum of personalities independent of their shared cognitive impairment, and researchers ought to be sensitive to each individual's situation. A common saying is "once you've met one person with autism, you've met one person with autism."

Opportunities exist for participatory design, as well, through organizations such as the Academic Autistic Spectrum Partnership in Research and Education⁵. The disability rights community reminds researchers that individuals affected by the research should be involved at all stages [27]. Involving those affected by the research matches the fundamental inclusionary principles of HCI. Through participatory design, we shift the emphasis from medical "lacks" toward understanding the way adults with ASD see the world, and positively supporting them.

There is also no reason to believe that the interventions proposed here would not generalize to self-diagnosed individuals, as well as anyone who has difficulty with face-to-face communication, intuiting social norms, or evaluating trustworthiness. By focusing on the needs of adults with ASD, we may develop tools that impact all social CMC users.

Limitations and future work

The adults interviewed in this study tended to be relatively young and may have had greater access to support services than others, since they were recruited through counselors. Older adults may have even less exposure to social communication technology, been incorrectly or never formally diagnosed, or have even less formal support. Additionally, with so few women in the sample, it is difficult to determine whether their needs are similar to those of their male peers. Asperger's affects roughly four times as many men as women [3], so this sample is representative of the natural skew, but many factors may lead women to have different relationship communication needs or interpret nonverbal cues differently [15]. Furthermore, these participants agreed to a face-to-face interview, which

may indicate they are more comfortable talking or more outgoing than others. In that case, we would expect them to have better outcomes, making this work fairly conservative.

Additionally, there is no formal control group. However, there are many studies on the psychosocial benefits of CMC for typical users [e.g. 10,21]. Though some of the present findings related to cyberbullying and trust are common, many findings, such as the problem of having no one to talk to, sending too many messages, or not figuring out norms are novel, and are consistent with cognitive aspects of autism.

To address the limitations of a relatively small sample size and lack of a control group, we intend to follow with a much larger survey of adults, recruiting through counselors and support groups across the United States, linking social CMC use to outcomes like perceived social support, quality of life, loneliness, or empathy. With a larger sample, we can better explore the relationship between particular activities, like identity-based group membership and social satisfaction.

Furthermore, this study does not specifically examine the relationship between temporal and social pressure: CMC may alleviate stress from nonverbal social cues, but for adults with ASD who need additional processing time, synchronous or semi-synchronous forms may still impose overwhelming pressure to respond quickly. Controlled lab experiments comparing social conversations over media varying in channel bandwidth and synchronicity (e.g. face-to-face vs. instant messenger, and chunked video dispatches vs. email) are needed to disentangle the impacts of these factors. In general, however, we see many opportunities for HCI research to understand and meet the social communication needs of adults with autism.

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REFERENCES

1. Attwood, T. *The complete guide to Asperger's syndrome*. Jessica Kingsley Publishers, 2006.
2. Autism Task Force. *Needs of Adults (Ages 21 and older)*. Department of Public Welfare, Commonwealth of Pennsylvania, 2007.
3. Baron-Cohen, S., Knickmeyer, R.C., and Belmonte, M.K. *Sex differences in the brain: implications for explaining autism*. American Association for the Advancement of Science, 2005.
4. Benford, P. The use of internet-based communication by people with autism. Ph.D. Dissertation, University of Nottingham. 2008.
5. Bignell, S. Autism, Aspergers and Second Life. 2008. <http://www.miltonbroome.com/2008/06/autism-aspergers-and-second-life.html>.
6. Brady, J. How 'Second Life' therapy helps Asperger's patients. 2008. http://www.wfaa.com/sharedcontent/dws/wfaa/localnews/news8/stories/wfaa080111_lj_brady.11fb5bac.html.

⁵ <http://www.aaspireproject.org>

7. Burke, M. and Kraut, R. Mopping up: modeling wikipedia promotion decisions. *Proc. of the ACM 2008 conference on Computer supported cooperative work*, ACM (2008), 27-36.
8. Centers for Disease Control and Prevention. *Prevalence of Autism Spectrum Disorders--Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002*.
9. Charmaz, K. Grounded theory. *Qualitative psychology: A practical guide to research methods*, (2003), 81-110.
10. Ellison, N.B., Steinfield, C., and Lampe, C. The benefits of Facebook" friends:" Social capital and college students' use of online social network sites. *Journal of Computer-Mediated Communication*, 4 (2007), 1143.
11. Glaser, B.G. and Strauss, A.L. *The discovery of grounded theory: Strategies for qualitative research*. Aldine, 1977.
12. Goodman, J. Think Different: Autistic Culture And I.E.P's: Exploring Online Forums From Autistic Community Websites. McGill University, Montreal, Quebec, Canada.
13. Grandin, T. and Barron, S. *Unwritten Rules of Social Relationships: Decoding Social Mysteries Through the Unique Perspectives of Autism*. Future Horizons. 2005.
14. Grinter, R.E. and Palen, L. Instant messaging in teen life. *Proc. CSCW*, ACM (2002), 21-30.
15. Hall, J.A. Gender Effects in Decoding Nonverbal Cues. *Psychological Bulletin*, (1978).
16. Hayes, G.R., Gardere, L.M., Abowd, G.D., and Truong, K.N. CareLog: a selective archiving tool for behavior management in schools. *Proceeding of the twenty-sixth annual SIGCHI conference on Human factors in computing systems*, ACM (2008), 685-694.
17. Jennes-Coussens, M., Magill-Evans, J., and Koning, C. The quality of life of young men with Asperger syndrome: A brief report. *Autism* 10, 4 (2006), 403.
18. Jones, R.S.P. and Meldal, T.O. Social relationships and Asperger's syndrome: a qualitative analysis of first-hand accounts. *Journal of Intellectual Disabilities* 5, 1 (2001), 35.
19. Kiesler, S., Siegel, J., and McGuire, T.W. Social psychological aspects of computer-mediated communication. *Computer-supported cooperative work: A book of readings*, (1988), 657-682.
20. Kittur, A., Suh, B., and Chi, E.H. Can you ever trust a wiki?: impacting perceived trustworthiness in wikipedia. *Proc. CSCW*, ACM (2008), 477-480.
21. Kraut, R., Kiesler, S., Boneva, B., Cummings, J., Helgeson, V., and Crawford, A. Internet paradox revisited. *The Wired Homestead: An MIT Press Sourcebook on the Internet and the Family* 58, (2003), 347.
22. Kruger, J., Epley, N., Parker, J., and Ng, Z. Egocentrism over e-mail: can we communicate as well as we think? *Journal of Personality and Social Psychology* 89, 6 (2005), 925.
23. Lainhart, J.E. and Folstein, S.E. Affective disorders in people with autism: a review of published cases. *Journal of Autism and Developmental Disorders* 24, 5 (1994), 587-601.
24. Lampe, C., Ellison, N., and Steinfield, C. A Face (book) in the crowd: Social searching vs. social browsing. *Proc. of the 2006 20th anniversary conference on Computer supported cooperative work*, ACM New York, NY, USA (2006), 167-170.
25. Lindsay H. Shaw and Larry M. Gant. In Defense of the Internet: The Relationship between Internet Communication and Depression, Loneliness, Self-Esteem, and Perceived Social Support. 2004.
26. Lotter, V. Epidemiology of autistic conditions in young children. *Social Psychiatry and Psychiatric Epidemiology* 1, 3 (1966), 124-135.
27. Meyer, L.H., Park, H.S., Grenot-Scheyer, M., Schwartz, I., and Harry, B. Participatory research: New approaches to the research to practice dilemma. *The Journal of The Association for Persons with Severe Handicaps* 23, 3 (1998), 165-177.
28. Mitchell, P., Parsons, S., and Leonard, A. Using virtual environments for teaching social understanding to 6 adolescents with autistic spectrum disorders. *Journal of Autism and Developmental Disorders* 37, 3 (2007), 589-600.
29. Morahan-Martin, J. and Schumacher, P. Loneliness and social uses of the Internet. *Computers in Human Behavior* 19, 6 (2003), 659-671.
30. Muller, E., Schuler, A., and Yates, G.B. Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism* 12, 2 (2008), 173.
31. Murray, D. *Coming out Asperger: diagnosis, disclosure and self-confidence*. Jessica Kingsley Publishers, 2006.
32. Newton, A.T., Kramer, A.D., and McIntosh, D.N. Autism online: a comparison of word usage in bloggers with and without autism spectrum disorders. *Proc. CHI*, ACM (2009), 463-466.
33. Pew Internet and American Life Project. *Usage Over Time*. 2009.
34. Pew Internet and American Life Project. *Post-Election Tracking Survey*. 2008.
35. Postmes, T., Spears, R., Lee, A.T., and Novak, R.J. Individuality and social influence in groups: Inductive and deductive routes to group identity. *Journal of Personality and Social Psychology* 89,5(2005),747.
36. Preece, J., Nonnecke, B., and Andrews, D. The top five reasons for lurking: improving community experiences for everyone. *Computers in Human Behavior* 20, 2 (2004), 201-223.
37. Prentice, D.A., Miller, D.T., and Lightdale, J.R. Asymmetries in Attachments to Groups and to their Members: Distinguishing between Common-Identity and Common-Bond Groups. *Personality and Social Psychology Bulletin* 20, 5 (1994), 484.
38. Rajendran, G., Mitchell, P., and Rickards, H. How do individuals with Asperger syndrome respond to nonliteral language and inappropriate requests in computer-mediated communication? *Journal of autism and developmental disorders* 35, 4 (2005), 429-443.
39. Rajendran, G. and Mitchell, P. Text Chat as a Tool for Referential Questioning in Asperger Syndrome. *J Speech Lang Hear Res* 49, 1 (2006), 102-112.
40. Renty, J.O. and Roeyers, H. Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism* 10, 5 (2006), 511-524.
41. Resnick, P., Zeckhauser, R., Swanson, J., and Lockwood, K. The value of reputation on eBay: A controlled experiment. *Experimental Economics* 9, 2 (2006), 79-101.
42. Robertson, S. Life with Asperger's: One Man Tells His Story. *The Bergen Record*, 2006. <http://www.autisticadvocacy.org/modules/smartsection/print.php?itemid=6>.
43. Robertson, S. and Ne'eman, A. Autistic Acceptance, the College Campus, and Technology: Growth of Neurodiversity in Society and Academia. *Disability Studies Quarterly*, 28(4).
44. Rogers, S.J. Interventions That Facilitate Socialization in Children with Autism. *Journal of Autism and Developmental Disorders* 30, 5 (2000), 399-409.
45. Seltzer, M.M., Krauss, M.W., Shattuck, P.T., Orsmond, G., Swe, A., and Lord, C. The Symptoms of Autism Spectrum Disorders in Adolescence and Adulthood. *Journal of Autism and Developmental Disorders* 33, 6 (2003), 565-581.
46. Smith, M., Cadiz, J.J., and Burkhalter, B. Conversation trees and threaded chats. *Proc. CSCW*, ACM New York, NY, USA (2000), 97-105.
47. Tartaro, A. Authorable virtual peers for children with autism. *CHI '07 extended abstracts on Human factors in computing systems*, ACM (2007), 1677-1680.
48. Walther, J.B. Computer-mediated communication: Impersonal, interpersonal, and hyperpersonal interaction. *Communication research* 23, 1 (1996), 3.
49. Zinman, A. and Donath, J. Is Britney Spears spam? *Proc. of Conference on Email and Anti-Spam*, 2007.