Autism Online

The role of the Internet in the daily lives of people on the autism spectrum

A Report of Project Findings
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Introduction

In October 2008, we invited individuals to participate in an online survey about people’s experiences on the autism spectrum. We wanted to learn about the role of the Internet in the daily lives of people with autism. We were also curious to know if (and how) the Internet had facilitated the formation of online autistic communities.

With the help of various individuals, the invitation to participate was shared across the Internet by way of autism-focused forums, chat rooms, and blogs. When the survey was closed in May 2010, we had received 76 completed surveys: 44 from females, 28 from males, and four from participants who did not disclose their gender. ¹ This report provides a summary of what we learned from their very personal, detailed, and insightful responses.

There are many ways to address issues related to the autism spectrum (AS). We approach this research from a social science background. As social and cultural geographers, we are interested in connections between people and place. We value personal accounts based on first-hand experience from people who actually live on the spectrum. AS individuals teach us what it is like to move through

¹ Although 185 individuals started the survey, 109 did not finish it. Incomplete responses have not been included in the final analysis.
everyday spaces with autism, and how their social lives are influenced by both autism and the Internet. We do not have medical backgrounds, and we present this report as an alternative to clinical and scientific understandings of autism.

Before moving on to discuss the specifics of the survey and the main findings, we wish to acknowledge the 76 individuals who took the time to complete the questionnaire. Their responses are incredibly varied and show that we must be careful not to paint everybody on the autism spectrum with one brush. In many cases, participants provided very personal and, perhaps, emotionally difficult stories of what it is like to live with some form of autism.

We hope that our survey provided an outlet for our participants to reflect on their experiences and share important first-hand knowledge with autistic and non-autistic persons alike. We have included many direct quotes from participants, as they often say things better than we can. Please note that we have kept the original wording, including typographical errors, in these quotes, rather than trying to change or “fix” participants’ own words.

To the participants who may be reading this report, your contribution has been invaluable, and we invite all readers to contact us with feedback and further questions about the research. You will find our contact information on the back cover of this report.
Research Design

We designed our online questionnaire to be user-friendly and secure. There were 24 questions in the survey. Participants could skip a question, or write as much or as little as they liked. We encouraged participants to provide personalized and detailed responses. Each person was given the option to remain anonymous if they did not want their name attached to their responses.

Participants were encouraged to share their own definitions and names for autism that perhaps more accurately reflected their own experience. As many of our participants explained, there is an important difference between saying “autistic person” and “person with autism,” depending on whether autism is seen as something separable from, or a central part of, the person. Others preferred to call themselves by shortened names like “aspie” (short for Asperger’s Syndrome) or “HFA” (high-functioning autistic). We did not wish to create labels for our participants. We paid attention to the ways in which participants speak for and about themselves, as this is an important way to learn about how each person thinks about – and would like others to think about – autism.

Our survey was available in English only, and required reading, typing, and other computer skills that may have regrettably excluded some people on the spectrum. One participant pointed out: “remember that your survey will largely be taken up
by functionally verbal people, often with high IQ scores and university educations” (Female, 45, person with autism). Although many of our participants did not have a university education, this participant was right to point out how our survey might be directed at specific groups of people on the spectrum, those with the particular skills needed to take part. We must, therefore, emphasize that this report does not aim to generalize the experiences of every person on the spectrum. It is also important to point out that some of the participants may not agree with our interpretations of the data. This is understandable. Everybody’s experience on the spectrum is very different, as we found again and again while reading the responses to our questions. We hope to highlight some of these differences while also showing some of the many similarities that emerged.

We have learned considerably from our participants. Perhaps the most surprising finding is the way in which technology, which is often blamed for eroding social bonds and making people more insular, seems to allow many of those on the autism spectrum to feel more human and more connected to the world around them. But this, too, can have its dark side, as a number of our respondents went so far as to describe their Internet use in terms of an “addiction” that significantly interferes with their offline relationships.
Our goal is to use the findings of this study to promote awareness about autism and online communities. In this report, we have isolated some key findings that we think will be useful and interesting for our participants, the general public, and other researchers. The remainder of the report discusses these findings under the themes listed below, and points towards possibilities for future research on autism and online communication.

**Key Findings by Theme:**

1. Experiences of Life on the Spectrum
2. Online Communication
3. Perceptions of Safety
4. Mediated Isolation
5. Information, Activism, and Advocacy
6. Using Technology to Feel More Human

**KEY FINDINGS - 1: Experiences of Life on the Spectrum**

Recent research has found that the global prevalence of autism spectrum disorders (ASDs) is about nine to 12 people per 1,000 (Fombonne 2012); however, the prevalence of ASDs varies significantly by jurisdiction as well as by the type of autism spectrum condition. What seems consistent across jurisdictions is that the prevalence of ASDs is on the rise. Despite increased diagnoses and
discussion of autism, however, much of the general public’s understandings of what it means to be on the spectrum come from clinical definitions and representations in popular media that may not always reflect the experiences of the people who actually live with some form of autism. There is also considerable debate about what to call the autism spectrum. We opted to use the term “condition” because it seemed to be the most inclusive term at the time of our research, although we recognize that the boundaries within the spectrum are quite blurry. Some of our participants disliked the term “condition,” explaining that it does not accurately describe (and perhaps even trivializes) their own experiences. They feel the term “condition” makes autism a medical problem to be solved or cured. These varied responses show the complex and different experiences of autism, and encourage us to reflect further on the language we have chosen. There is no one term that suits everyone, and we think that when talking to someone with autism, or talking about that person’s experience, it is best to use the term that they themselves prefer. This is far better than making assumptions and using terms that might be considered inaccurate and misleading, or perhaps even offensive.

Social anxieties were the most commonly mentioned challenges for our participants. Inability to fit in with what is understood as “normal” social interaction causes anxiety for many people on the
spectrum. They feel excluded because they cannot follow expected codes of behaviour. Many participants feel these expectations are unfair. As one participant noted:

Many of us can do just fine, if only society would not place all of these expectations on us. We are different. Our brains are wired different. We think and perceive differently. Why does society require us to fit into their model?

(Male, 37, proud aspie)

Like this person, we think that there are good reasons to question widespread assumptions about what it means to be “normal.” As our participants stress, people on the spectrum should not be seen as somehow wrong or abnormal, or as “freaks.” Many consider themselves to be simply different, and think that this diversity should be embraced. Some participants call this “neurodiversity.”

Participants wrote about social challenges that include difficulty maintaining eye contact, short attention spans, and not understanding certain emotional cues or “small talk.” These difficulties have had very broad and sometimes devastating effects on their lives. Participants emphasized that their words and actions are not meant to be rude, but they are perceived as rude or anti-social by others because they do not fit typical social expectations. Unfortunately, participants often feel as if they suffer because of the broader public’s
misunderstandings of their behaviour. Maintaining close relationships with others, securing jobs, and carrying out everyday tasks like grocery shopping or using public transport can be very difficult and stressful because these activities typically require social interaction of some sort.

When some of our participants, such as those with Asperger’s Syndrome, engage in face-to-face interaction, they feel their communication style must be altered to suit the social expectations of others. For example, many “put on a face” or have pre-planned scripts to help them cope or come closer to “fitting in”:

I have a set of facades for in-person interaction because I freeze up and stutter when speaking about things related to my honest emotions or desires.

(Female, 25, on the autistic spectrum)

Over time, I have learned more “scripts” for professional interactions, phone calls, customer service, etc., but I still run into problems when I get flustered and “lose my lines,” or things start to deviate from the script, and other things.

(Female, 27, A sperger’s, or HFA)

Participants frequently reminded us that the various forms of autism have very diverse characteristics and effects that extend beyond social challenges.
Clinical descriptions of autism show that sensory issues are a very important part of recognizing and diagnosing autism. We found that our participants were able to describe sensory challenges in greater detail than some clinical accounts would suggest, particularly the effects of these issues on their everyday lives. As one woman explained:

I am extremely sensitive to noise and get severe anxiety attacks from doors closing unexpectedly or a car backfiring - I am usually completely knackered after a day at university and I need a lot of time on my own to “recover.” I find it hard to gather the strength necessary to get through the day and often I just “shut down” in the middle of the day and I have to go home...

(Female, 19, autistic person)

Another participant cleverly calls the shopping centre a “Maul,” which captures the overwhelming, even threatening, nature of large and often crowded public spaces. She described what having Asperger’s Syndrome means to her:

Walking the 3 miles to the Maul on a day you thought would be safe, except when you get there, you start to overload the moment you walk in the door, so you turn around, walk out and walk the 3 miles home.

(Female, 50, aspie, person on the spectrum, person with autism)
As we learned, the effects of these experiences go much deeper than what may be captured in clinical descriptions. Our participants described the complex emotions they have to deal with, including the embarrassment, guilt, sadness, or confusion they feel when they misinterpret social cues or are seen by others to be anti-social, rude, or annoying. As one woman with Asperger’s and ADHD (Attention Deficit Hyperactivity Disorder) stated:

The most negative aspects are the social insecurity – not only do I sometimes annoy people, but I often don’t know when I annoy people, and knowing this causes a lot of anxiety and low self-esteem because I am always worried that I’m missing something major in a social interaction.

(Female, 26, person on the autism spectrum)

From a more positive perspective, another female participant explained the satisfaction that came from recognizing her “ability to see things from a different perspective” and feeling “blessed” with creativity (Female, 43, aspie).

To us, these personal, often emotional, responses provide insight into what it is like to live with autism. In the following section, we discuss how online communication has allowed some people with autism to feel that they have more control over their own lives, and how this mostly leads to more positive experiences.
KEY FINDINGS - 2: Online Communication

All research participants reported that they generally prefer online communication to the kinds of face-to-face interaction that occur offline. However, their preferences tend to change depending on the particular situation or context. In this section, we explore the positive associations with Internet communication as well as what some of our participants describe as the negative aspects of spending more and more of their lives online.

Like many offline environments, Internet spaces are often social spaces, but they are social in different ways. Much of what is done online uses written text, which can be communicated without typical social cues that involve body language and tone of voice, and there is also less need for small talk, all of which tends to ease communication, according to our respondents. Participants also appreciate having more time to think about their online responses compared to in-person interaction. As one participant told us:

Online is WAY better. It’s concrete – words only - and you don’t have to worry about processing tone of voice and body language and all that. I understand people way better when I write to them, whether they're online or offline friends. Also, you have time to think about something before you say it, so you don't say stupid things nearly as often; and
you can communicate on your own time - feel overwhelmed, and you can log off and try again later. You can’t do that face to face.

(Gender unspecified, 25, autistic)

Another participant explained the importance of having time to process information:

The most positive aspect is that it is easier to communicate online. I have delayed hearing/processing and often can not keep up with real-time conversations. Email, forums, and social networking sites allow me to have as much time as I need to process something before responding to it.

(Female, 42, Asperger’s autism)

We found that the Internet serves as an important meeting place where participants can build meaningful relationships and share ideas with other people on their own terms. In other words, some people with autism value online communication because it gives them more control over their sensory environment. The Internet allows them to socialize without being required to have face-to-face, verbal interaction.

One participant explained that, through the Internet:

I communicate with people who are not on the spectrum in the same ways as I do with people who are on the spectrum.

(Female, 42, A sperger’s autism)
Many of our participants indicated that their online relationships are stronger than those they tend to have offline. Of course, this does not mean that all relationships formed online are necessarily positive or safe, a finding we take up in the next section.

Additionally, some respondents report recognizing (or having been told by family members) that they spend too much time online. One respondent describes his Internet usage as “total” (Male, 40, autistic) and several others go so far as to characterize their excessive Internet use in terms of an “addiction” that interferes significantly with offline relationships. Among those who recognize such overuse of the Internet, many report wanting to cut back:

Since I purchased my computer four years ago my Internet usage has been constant and high. I am hoping to stop using it quite so much as I would like to get more work done in studio.

(Female, 39, Asperger’s Syndrome, person with an ASD)

Five years from now, I would like to break my addiction to forums and get better at IRL communication.²

(Female, 25, on the autistic spectrum)

² IRL means “in real life.”
These responses, while troubling, are far from typical. Personal accounts of online experience are rarely so negative. However, some respondents do express ambivalence about the Internet’s impact on their lives:

I am somewhat less lonely yet probably more withdrawn from the 3 dimensional world.  
(Female, 62, woman with Asperger’s)

I spend less time outside, unfortunately [but] I haven’t become a recluse because I’m online.  
(Female, 29, Asperger’s Syndrome)

**KEY FINDINGS - 3: Perceptions of Safety**

We are all aware of the potential dangers of communicating with others over the Internet. False identities, sexual predators, and bullying are all serious concerns with online activities. Our participants identified harassment in terms of bullying and “trolling” as a key problem they encounter online. “Trolls” are people who create unnecessary conflict on message boards and blogs by posting comments that are often irrelevant and potentially hurtful to other participants. Harassment may also occur when people who do not have or understand autism make negative remarks about individuals on the spectrum. All of these issues must be taken into consideration when using the
Internet, as they demonstrate that not all AS experiences online are positive.

Despite the potentially negative effects of Internet use, most participants feel that, overall, the Internet is a safer space for them than offline environments. They regard most of the incidents of harassment online as less threatening than being in public with people who do not understand the social challenges of autism. Furthermore, the more controlled sensory experience of personal Internet use decreases the likelihood of being overwhelmed to the point of “stimming” or breakdown. Participants explain that “stimming” means self-stimulating or soothing behaviours such as rocking or hand flapping. They told us they feel safer and more secure if they have a breakdown while using their computers at home. They know that their actions cannot be seen (and so cannot be judged) by other people.

Another way the Internet may be a safer space for people on the spectrum relates to issues of disclosure, or “coming out,” as a person with autism. Our participants felt similar to members of other minority groups like D/deaf and LGBTQ (lesbian/gay/bisexual/trans/queer) communities, because many individuals within these groups view disclosure as an important personal decision, not one that should ever be forced on them or made on their behalf by others. Because people can use the Internet without revealing their name or location, it becomes a potentially safer space for those who wish to disclose their autism without
being identified. For many participants, this is a liberating experience that also allows them to practice coming out, to see how it feels to reveal that they are autistic before telling people in offline spaces, where there are greater risks of negative consequences. It also allows people the opportunity to share their experiences with others on the spectrum, find useful contacts and resources, and perhaps also discover different ways of understanding what it means to be on the spectrum.³

**KEY FINDINGS - 4: Mediated Isolation**

Much has been written about how people interact with each other in different places, and the kinds of strategies they use to control these interactions. One idea that has emerged from social theory and media literature is that people often want to be in the presence of others but also like to have their own personal space. In their 2002 book, *Perpetual Contact*, James Katz and Mark Aakhus support this idea and state that individuals in Western societies typically enjoy being—as they put it—“alone, together.”

³ For a more in-depth discussion of “coming out” on the spectrum, please see the article written by Joyce Davidson and Victoria Henderson in the references section of this booklet.
Michael Bull, a media scholar, tells us that many of our interactions could be called “mediated isolation,” because we often try to find ways to isolate ourselves through our technologies (like MP3 players, laptops, and phones) when we are around other people. It is one way that many people feel more comfortable being in public and in the desired presence of others. This controlled social interaction is similar to what Katz and Aakhus refer to as being “alone, together.” Like people with autism, most individuals are somewhat anxious about being noticed by others for doing something that doesn’t fit into what is understood as “normal” behaviour. The difference is that people on the spectrum tend to have less control over their heightened anxieties, and face multiple challenges that go beyond just being social (for example, sensitivities to sound and light, uncontrollable “stimming” behaviours, or fatigue). For people like our participants, mediated isolation through an MP3 player or even a newspaper that they can hide behind on the bus may help. But these tactics are often not enough to make them feel comfortable in other offline environments like shopping malls, public transport, or school.

We did find that mediated isolation is practiced by our participants in distinctly different ways. Michael Bull observes that people start in a public space and use technology to create a private bubble. Our participants describe an alternative form of mediated isolation. They most often start in a very private space (linked to a personal computer in a
bedroom), and then use the Internet to enter a more public world full of interaction with other people. This kind of mediated isolation allows them to participate in online activities, communicate with others, build friendships, and feel a sense of belonging without having to worry about face-to-face interaction. As one participant stated:

I use the internet as a form of social interaction, as I do not have to deal with eye contact and I can limit what people are saying to me I find this is a LOT easier.

(Male, 20, aspie)

Of course, this does not mean that participants only have meaningful interactions online, but many of them explained that their more recent offline social experiences have benefitted from “test-driving” their communication skills online first.

**KEY FINDINGS - 4:**
**Information, Activism, and Advocacy**

Increasing online communication has also created more space for social and political organizing. The Internet has played a key role in raising awareness about autism as well as providing resources for people in more accessible formats. Websites are typically free to visit and host a variety of accounts and explanations from people with first-hand experience of autism, as well as
from medical professionals, family members of people with autism, and many interested others. The information presented by these different groups comes in a variety of formats, including websites, forums, blogs, and videos. This means that the ways we can learn about autism have increased dramatically since the days of having to visit a clinic or learning about autism through a pamphlet at school (which is not to suggest that these sources of information are not valuable). Having forums in which people post about their experiences of autism is useful because it allows others to think about their own condition in relation to others, often learning that they are not alone.

When we think of activism, we tend to think of people getting together to raise awareness for a political cause as a large group in a public space, like a street. However, this form of activism is not very accessible to, or inclusive of, people who find it hard to be in large groups in an overwhelming environment. Our participants indicated that they value the Internet because it provides the opportunity to raise awareness, engage in debates, and challenge taken-for-granted ideas about autism without feeling quite so exposed. For some, the Internet becomes a space for building communities of people who might otherwise be unable to come together in person. As one participant explained:

...autistics can communicate, find new friends, help each other, exchange ideas and experiences, discuss and fight for their rights
together via internet. This is important because normally there are not many people on the spectrum in one place, so the internet is a good way to communicate.

(Female, 18, autistic)

The Internet also allows individuals to participate in diverse ways, at different times, and provides the time needed to think about how they would like to communicate. One challenge that a few participants noted was that people with certain types of autism have difficulty completing tasks. One participant spoke from his own experience of political organizing online:

The problem is that autistic people are individuals, mostly lack a collective sense, and more often than not have problems finishing what they start.

(Male, 43, Aspie)

This person raises an important point, and reminds us that moving from offline to online environments does not necessarily remove all the challenges that people on the spectrum might experience. However, the Internet does provide a meeting place in which more resources and support groups are available that might allow people to share strategies for how to manage social, cognitive, or sensory difficulties. In doing so, barriers to political organizing might be diminished, and the feeling of being able to participate can rightfully make people feel more valued in their broader societies.
KEY FINDINGS - 6: Using Technology to Feel More Human

As a result of my use of the internet, I’m a person, not ‘ontologically a freak.’

(Gender unspecified, 45, Asperger’s syndrome)

One of our most intriguing findings is that when people on the spectrum use the Internet and its associated devices, they actually feel more social than they do in public, offline environments that do not involve technology. Some even associate this sense with feeling more human, reflecting the common (but restrictive) idea that being sociable is an important – even “normal” – part of being human.

Many of our participants told us that because they don’t express emotion or socialize in the same ways as other people, they are often labelled as anti-social. Such labelling has made many participants feel “less human” (Female, 27, Asperger’s, or HFA), and often even more isolated from the rest of the world. Some have unfairly been made to feel as if they are “freaks,” and that this is somehow their own fault. One participant said,

It’s always been very difficult for me to make friends, but I just assumed I was a ‘freak’ and found ways to deal with it.

(Female, 29, aspie, or autistic)
When participants communicate with others online, many of them describe starting to feel less isolated and more connected:

I don’t feel like a freak, when communicating online with others on the spectrum.

(Gender unspecified, 45, Asperger’s syndrome)

The most positive aspect of communicating with anyone [online] is just that: communication. Expressing ideas, learning from each other, in some ways becoming more human through that interaction.

(Female, 43, aspie)

Although we might think that using computers makes people more anti-social because there is less face-to-face contact, our findings suggest that for many people, the Internet is a crucial tool for obtaining a sense of belonging and community. Our research is helping us to learn that there are more inclusive ways of thinking about what it means to be social, and perhaps even about what it means to be human.

Using technology to feel more human blurs the boundaries people commonly draw between categories like human/non-human, offline/online, and real/virtual. As our participants explained, the relationships built online (often described as virtual) are just as – if not more – real to them than the often uncomfortable interactions with people in
Many of our respondents stated that they don’t seem to have a social filter like most other people. However, their computers can act as extensions of their body, thereby helping to achieve this filtering effect.

**Conclusion: Future Directions**

Generally, I feel that my world has expanded because of the Internet, and I have grown to meet it.

(Female, 50, aspie, person on the spectrum, person with autism)

Our research project was guided by the sense that if we want to learn about autism, it is most valuable to listen to people who actually experience first-hand what it is like to live on the spectrum. This is not to deny the importance of knowledge and resources provided by medical professionals, but it is clear that much of what most people know about autism tends to be based more on explanations by medical professionals and representations in popular media than accounts provided by autistic people themselves.

To understand how people on the autism spectrum use and value the Internet, it is essential to hear the voices of those for whom the Internet plays a vital role in their daily lives. As we learned from our participants, the reasons and ways they use the
Internet are varied, and this highlights the fact that while people on the spectrum share some things in common, they each have individual experiences and opinions that cannot be lumped together under the term “autism.”

Like other groups who are marginalized or even completely excluded for not fitting a specific “model” of normalcy, our participants explained that the ability to meet with others who share similar struggles can lead to real breakthroughs for autistic cultures. For people on the autism spectrum who are unable or simply prefer not to meet face-to-face in more public locations, the Internet provides a space for them to fulfill the desire to communicate with others and share experiences, support each other, and as one participant put it, give practical advice on how to “compensate for the difficulties” (Female, 38, on the autism spectrum). The Internet also creates opportunities to experience the benefits of community participation by allowing the voices of individuals on the autism spectrum to be heard and valued. As the following participant explained, finding resources and a voice to make a difference has empowering effects:

The internet has been very empowering to me. That is where I learned most of what I use to get through a day.

(Male, 54, autistic)

Interestingly, it seems that many of the concerns our participants had about social interaction are really
not so different from the stress that non-autistic people experience when engaging with others in social spaces. This is not to deny the intensity of the struggles experienced by those on the spectrum. However, if we acknowledge that almost everybody has some discomfort or engages different “façades” to survive in social situations (to varying degrees) then people might be more understanding of those on the spectrum.

Overall, our findings showed positive associations with Internet use. Benefits include: establishing lasting friendships and finding people who share similar experiences, gaining confidence through less threatening forms of interaction, and finding coping strategies and developing skills that can be transferred between online and offline spaces. As one respondent said:

I have become 1000 times more confident since becoming computer literate... I feel the respect of others for what I do, and I understand myself and the world around me better than I did before.

(Female, 43, aspie)

The Internet should not, however, be viewed as a “cure” or solution to all of the difficulties that people with autism might endure. The idea that people with autism need a “cure” is, in fact, what many on the spectrum are asking researchers like us to try and move beyond. As we learned, however, some participants feel that their increased reliance
on the Internet makes it even harder to go into public spaces, and they fear that they might be spending too much time online, even becoming “addicted” to the Internet. Furthermore, the spaces of the Internet are not immune to bullying and other forms of harassment. Generally, though, our participants suggested that they feel much safer using online forums than they do when they go to places that require in-person interaction.

One of the most promising findings that came out of these accounts is that using the Internet to learn and meet others has made our participants feel more human. The Internet’s humanizing potential fills us with hope that we - people with and without autism - can find new ways to engage with each other and appreciate the differences that make us unique.

Our understanding of autism can be neither complete nor universal. However, this study has allowed us to gain better insight into how autism touches people’s lives in very personal ways and how the Internet - mostly for the better, but sometimes for the worse - helps to mediate the lives and worlds of those on the autism spectrum.

We would like to close this report by thanking our participants, once again, for sharing their stories, and thereby helping us to learn about both their personal experiences of autism as well as how the ability to communicate these experiences online is leading to the emergence of new autistic cultures.
References


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