

# Evolution of Autism Support and Understanding Via the World Wide Web

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For many autistics, the Internet is Braille.  
—Blume (1997)

Internet technology has radically changed society, widely affecting communication and the availability of information. The digital age holds unique significance for autism spectrum disorder. In this article I explore the interface between autism and the World Wide Web by reviewing evolving virtual communities pioneered by individuals with autism, exploring the online growth of advocacy organizations, and considering the positive and negative consequences that arise from autism's fledgling voices.

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## Features of the Internet and Their Relevance to Autism Spectrum Disorder

In 1990 Tim Berners-Lee, a scientist working at the European Organization for Nuclear Research, coined the term "World Wide Web" (Opfer, 1999). The Web today is a network of billions of documents, or "Web sites", on which millions of Internet users communicate and share information through e-mail, mailing lists, live online chats, discussion boards, and personal websites and blogs (a contraction of the term web-log). The Internet presents a unique opportunity for individuals with autism spectrum disorder when considering both their exceptional abilities and their impairments. Martijn Dekker, founder of the e-mail list, "Independent Living on the Autistic Spectrum," wrote, "The Internet is for many high-functioning autistics what sign language is for the deaf" (Mitchell, 2003). Work with computer technology is amenable to systemizing, spatial reasoning, and engineering skills, which are often strong in high-functioning individuals on the autism spectrum (Baron-Cohen, Richler, Bisarya, Gurunathan, & Wheelwright, 2003). Blume (1997) described the Web as an extended metaphor of the autistic brain, writing, "The mental processes of autistics can stand in as

symbols of the associative hyper-linking graphic chaos of the World Wide Web." Baruch (2001) proposed that Western cultures are developing "autistic society syndrome" as a result of the widespread use of online communication, suggesting that skills practiced on the Internet are the same exceptional abilities, and impairments, exhibited by individuals with autism spectrum disorder.

Discussion boards and chat rooms allow individuals with autism spectrum disorder to interact without the anxiety that often accompanies face-to-face interactions. Many individuals with autism desire social relationships but have difficulty engaging in rewarding interactions (Wing & Gould, 1979). Online communication is devoid of several components of face-to-face conversations, such as typical motor expression, tone of voice, and interpretation of conversational partners' emotions, with which individuals with autism have some difficulty (Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001; Gabriels & Hill, 2002; Rutherford, Baron-Cohen, & Wheelwright, 2002). Eliminating these conversational demands can reduce anxiety, enabling the individual with autism to focus on the context of the discussion and to engage in reciprocal conversation. The Internet also allows individuals with autism spectrum disorder to interact within a familiar setting, such as on a computer in their home, which further reduces the anxiety that pervades an unfamiliar situation (Happé, 1991; Mitchell, 2003). Individuals with autism who converse in an environment of their choosing can also control hypersensitivities to noise and light (Frith, 1991).

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## Virtual Communities

The benefits conveyed by the Internet for individuals with autism spectrum disorder are often

addressed on online discussion boards intended specifically for individuals with autism and their families. Such discussion boards, or forums, are frequently designed by individuals with autism and feature a general topic with corresponding *threads*, which are questions and thoughts posted by a forum user to initiate conversation. Users respond to threads by writing *posts*, answers and commentaries to the thread question. *Moderators* are forum users that review threads to ensure that other users are respectful and engage in appropriate discussion.

WrongPlanet is one such public online forum for individuals with autism spectrum disorder. WrongPlanet has been open since 2004 and claims over 25,000 members who have made over 2 million posts (Plank, 2004), indicating a very active community. WrongPlanet users are from around the world, living primarily in the United States, Europe, and Australia. Most WrongPlanet users are diagnosed with Asperger syndrome or high-functioning autism, though some have pervasive developmental disorder, not otherwise specified (PDD-NOS) or are self-diagnosed, and neurotypical individuals who are friends or family members of people with autism often participate in discussion. Discussion boards on WrongPlanet are numerous, including a general discussion, a “Getting to Know Each Other” section, love and dating topics, and sophisticated debates about politics, philosophy, and religion.

The social support that the WrongPlanet community offers is a frequent subject of discussion. Many users feel that conversing online is a way to socialize without experiencing the demands associated with real-life conversations. One person with autism spectrum disorder wrote, “I find that my conversational skills and general ability to cope with socializing do far better while communicating over the Internet.” Contrary to the awkwardness that is sometimes perceived in a face-to-face interaction with a person with autism (Frith, 1991), the conversations found on WrongPlanet and other forums reveal eloquent, empathetic individuals. Conversing online does not require interpretation of a conversational partner’s emotions from social cues, and conversations do not require an immediate reply. These benefits are illustrated in one WrongPlanet user, who wrote, “I am better online because I can think of things to say [first].”

The social anxiety encountered in face-to-face interactions is reduced in online communication,

as one man diagnosed with Asperger syndrome wrote:

Chatting on line allows me to use the best parts of my social skills; my intellect, and my deep sense of empathy; without having the anxiety of talking to someone face to face. Without the anxiety, my communication is much clearer. (Plank, 2008)

This individual also described an intimate online conversation with a neurotypical friend, discourse that may not occur readily in face-to-face interactions. The anonymity and privacy offered by an online setting facilitate personal disclosure that could otherwise be upsetting in daily conversation. As another WrongPlanet user wrote, “I do love the Internet, because at least I get SOME social contact this way. For whatever reason I’m much less scared with it than in real life.”

SpectrumForums, like WrongPlanet, is a public online discussion forum for individuals with autism spectrum disorders. SpectrumForums opened in 2002 and currently has 130 members, who have made over 15,000 posts on the forums at about 100 posts per day (SpectrumForums, 2009), indicating a very active community. SpectrumForums offers a variety of discussion topics, including an “Introduce Yourself” topic; autism in the news; interest topics about items such as movies, music, and games; and special sections just for teenagers with autism spectrum disorder and their parents. The supportive SpectrumForums atmosphere is exemplified in an exchange between a forum moderator and one mother of teenage boy with autism. The mother wrote, “Hi everyone! I am new to the site and I came looking for a safe place for my son to meet people and feel comfortable.” She received a warm welcome from the moderator, also an individual with autism spectrum disorder, who replied, “Welcome. This is indeed a safe lively and packed forum...for making like-minded friends or just sharing experiences and thoughts. There is also sections for jokes and good old aspie observations like weird expressions.” Like on WrongPlanet, the benefits of online communication is a popular topic on SpectrumForums. One girl diagnosed with Asperger syndrome wrote, “I have social anxiety. Things that make me anxious are school...using the phone, and new places and situations. For some reason, I have no problem, as far as anxiety goes, with talking (typing) to people online.”

The Internet provides individuals with autism spectrum disorder and their families an opportunity to converse with other affected individuals across the

globe. Whereas support groups for individuals with autism and their families do not always exist in their local community, people with similar lifestyles are located easily online, providing new sources of companionship and support. In response to a thread about loneliness, one mother of a child with autism wrote on WrongPlanet, “I know that the Internet is where I find many connections through commonalities without the awkwardness of the social interactions.” Likewise, on SpectrumForums, a user wrote, “There isn’t any support group close to me...but I survive with friends and talking to you guys online.”

Parents of children with autism spectrum disorders can find welcoming communities offering support and advice about caring for their child. TogetherForAutism is a forum opened in 2000 used primarily by parents. TogetherForAutism has around 24,000 members and 14,000 posts (TogetherForAutism, 2009). Discussion threads feature topics addressing the difficulties parents encounter in caring for children with autism, from sleep issues to gastrointestinal problems, as well as school placement, health services, and how to introduce a child with autism to a church community. Parents on TogetherForAutism also enjoy celebrating their children’s progress together; one mother described her child making his first requests for “more”, while another discussed her son’s graduation from high school and acceptance to college, writing, “I am Proud Proud Proud that he got himself to this point!”

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## Autism Advocacy

The Internet is a medium for self-advocacy. Individuals with autism, formerly characterized by isolation (Asperger, 1991), acquire a voice of their own on the Web (Brownlow & O’Dell, 2006). Osteen (2007) observed that a “flourishing” online community of individuals with autism is seizing the opportunity to represent themselves. Whereas publishing work in a magazine or newspaper is difficult, any Internet user can discuss their opinions on Web sites where all Web users can read and respond to them. High-functioning individuals with autism and Asperger syndrome create blogs and Web sites, such as *Aspies for Freedom*, to insist that autism is not a disease (Aspies for Freedom, 2009). “Autism Diva,” a young woman with autism studying engineering and psychology in college, created her own blog online to discuss her opinion on media portrayal of

autism, in addition to many other political issues. Reminding her readers of the exceptional ability that accompanies autism spectrum disorder, Autism Diva wrote, “Sometimes in conveying the ‘tragedy’ of autism, the media loses sight of the unique and special individual behind the label” (Autism Diva, 2005). Other blogs offer advice about coping with autism spectrum disorders. *Life with Asperger’s* is the blog of an Australian man with Asperger syndrome who provides insight to readers based on his own experiences, with the purpose of increasing “the amount of first-hand knowledge about Aspergers” (Bollard, 2007).

Parents of individuals with autism spectrum disorder also find a voice online through personal blogging. Kristina Chew, a classics professor and mother of a young boy with autism, founded a parents’ blog called *Autism Vox*, which features articles by parents of children with autism and guest commentators writing about life with autism and current political and media perspectives on autism (Autism Vox, 2009). Chew also has a personal blog, *Autismland*, where she describes daily experiences with her 10-year old son who is autistic. She describes one moment of her son’s behavior, “He was asking my mother to watch his photo show with him...The experts call this ‘joint attention.’ I call it, Charlie, you’ve come so very far and I can’t even see where you might be going” (Autismland v.2, 2009). Fleischmann (2004, 2005) conducted reviews of narratives posted online by parents of children with pervasive developmental disorders, including autism and Asperger syndrome. Fleischmann noted that many parents at first view their child’s diagnosis as an immense challenge but cope positively by publishing their stories on the Web and finding other parents in similar situations online. Together, the parents overcame their feelings of isolation; as one mother wrote, the families were not victims of autism but rather “daring mountain climbers.”

Beyond individual communication, the Internet enables many larger foundations to raise public awareness of autism. Autism Speaks is a large advocacy organization founded in 2005 by Bob Wright, former chairman of NBC Universal, whose grandson was diagnosed with autism. Autism Speaks promotes autism awareness through their Web site, by organizing fundraising and community events and funding biomedical research on autism spectrum disorder (Autism Speaks, 2009). Like Autism Speaks, the Autism Society of America is

an advocacy organization that operates online, to “increase public awareness about the day-to-day issues faced by people on the spectrum” (Autism Society of America, 2009). The Web allows foundations to promote community fundraising and outreach programs, such as Walk Now for Autism. Web sites also provide fundraising opportunities. Autism Speaks features an online donation option on their Web site, where donors can choose specific research and educational programs to fund. Today, online fundraising is often more effective than any other medium for collecting donations. For example, President Barack Obama’s 2008 campaign raised \$32 million in January 2008 alone, \$28 million (88%) of which came from online donations (Arrington, 2008).

Clinical and scientific research has improved through the use of Internet resources. The Interactive Autism Network (IAN), funded by Autism Speaks and run by the Kennedy Krieger Institute, provides a vast network for researchers to connect with parents of individuals with autism spectrum disorder (Hamilton, 2007). IAN maintains an online database of longitudinal data on diagnosed individuals, who can register with the Web site to learn about ongoing research studies in which they can participate. Researchers frequently implement online surveys for parents of children with autism (e.g., Green et al., 2006). Online surveys convey several benefits, including increased anonymity and convenience (Schmidt, 1997), a feature that is especially important for parents of autistic children who often require constant supervision.

Legislation to support families of children with autism and to provide health care and education for affected individuals is now advanced online. The petition to the Ontario, Canada, legislature to fund treatment for children with autism (Anello, 2006) and the petition for an amendment to the Michigan insurance law for autism (Coffey, 2002) encouraged politicians to acknowledge autism spectrum disorder and to introduce positive legislation.

## Negative Consequences

Despite the manifold benefits the World Wide Web bears for autism, there are also negative consequences. Among the Web’s greatest attributes in the Western world is the sharing of information, free from censorship, although inac-

curate information is perpetuated as easily as accurate information. Wisdom about specialized diets claiming to cure autism pervades Google searches about the disorder, and many Web sites advertise expensive therapies to parents of children with autism. One such site offers “Peptizyde” and “Zyme Prime,” enzymes designed to help digestion that cost up to \$180 (Autism Coach, 2009). There are no controlled studies verifying the effectiveness of such supplements, yet Web sites are decorated with testimony from parents claiming that their child’s symptoms vanish after taking the “vitamins.”

Autism’s newfound self-representation by individuals online may lead to splintering within the autism community (Caruso, 2009), potentially slowing the progress of the autism movement. The opposition of *Aspies for Freedom* to finding a cure for autism is antithetical to that of Autism Speaks, which is “dedicated to funding global biomedical research into the...cure for autism” (Autism Speaks, 2009). The vaccine controversy is another example of splintering, as many well-known autism advocates have expressed firm beliefs in vaccines as the cause of autism even though scientific research does not support this conclusion. Following *The Lancet’s* retraction of Wakefield et al.’s (1998) article, which has been often cited as sparking the vaccine controversy, Jenny McCarthy and Jim Carrey, actors and autism activists, released a statement admonishing the retraction, writing, “The work of Dr. Wakefield and his colleagues deserves to be shared with the world to further, rather than censor, scientific progress” (Generation Rescue, 2010). Websites such as K.N.O.W. Vaccines (Kids Need Options With Vaccines, 2009) continue to post direct comparisons between autism and mercury poisoning without differentiating between the form of mercury that is known to have toxic effects and the separate form that is used in vaccines (Baker, 2008). Fortunately, there are many Web sites dedicated to providing accurate information on the vaccine controversy, such as articles supplied by online news Web sites and information posted on discussion boards and individual blogs, although this is not yet the case for specialized diets. Regardless of the consequences of splintering, the Internet has opened discourse, allowing greater “democracy” in the autism community rather than exclusive voices.

The availability of online information fosters a sense of self-understanding, particularly within online autism communities. Parents find the Internet a helpful resource in answering questions about their child who demonstrates abnormal behavior and are encouraged to seek clinical help after learning about autism spectrum disorder. Adolescents and adults benefit from online information. A SpectrumForum user wrote, “I already knew from the Internet that I had AS [Asperger syndrome]. When I got diagnosed it was just a confirmation. When I read about it on the Internet, it was an explanation of my entire life.” Blume (1997) quoted one individual with autism as saying, “It was through the Internet that I discovered [Asperger syndrome] and the whole concept of neurological differences. Without the Internet, I’d still be seeing myself as the cause of my own ‘failure’ (failure to be NT [neurotypical]).” Diagnostic criteria that are available online can also lead to incorrect self-diagnoses (Mitchell, 2003), which is dangerous both for the individual and for the autism community. A WrongPlanet user illustrated this possibility, writing:

One day you find an article about Asperger’s...You read it and you are surprised, because it is all about you...you FINALLY found people like you...You go to the doctor...And doctor doesn’t mention Aspergers. You’re not an aspie anymore. And your obsessions don’t make sense anymore.

Only clinicians possess sufficient training to provide an autism diagnosis. Self-diagnosed individuals can be particularly damaging to properly diagnosed individuals in the Internet environment, as it is difficult to discern who is trustworthy online. Mitchell (2003) noted that one problem for individuals with autism participating in online discussions is that they could be interacting with “people who may have a personality disorder rather than Asperger syndrome.”

Individuals with autism spectrum disorder can find supportive social communities online, but some researchers fear that “chronic” Internet use may foster feelings of loneliness and inhibit real-life social interactions (Markoff, 2002). Although empirical studies have not yet been conducted examining the effects of Internet use on face-to-face interactions, it is possible that excessive time spent online might discourage individuals with autism spectrum disorder from initiating conversations in real life, given that online discussions may be more rewarding. The opposite effect, however, is

equally likely; online communication can help individuals with autism develop and practice important social skills that can increase confidence in real-life interactions.

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## Coevolution of Autism and the World Wide Web

The question of whether there is an “autism epidemic” often arises in public discourse. There has been an almost 13-fold increase in autism prevalence rates in the past 20 years (Wallis, 2007). This rise is generally attributed to broader diagnostic criteria and increased awareness of the disorder, although some advocates postulate theories about environmental causes of autism (Manning, 2005). Interestingly, the increasing prevalence rate of autism spectrum disorder appears to coincide with the rise in Internet use in U.S. households. One study estimated that Web use grew by over 2 million users per month throughout the last decade (A Nation Online, 2003). Given the vast body of information available online, the coincident rise in autism prevalence and Internet use may reflect a growing public awareness of autism spectrum disorders. Today, concerned parents and interested individuals can access hundreds of documents on the Web about autism. Jayne Lytel, founder of the Early Intervention Network, hopes that if parents are made aware of the disorder early, their children will have increased opportunities for treatment exposure that may prevent more severe symptoms from developing in later life (Newswise, 2008).

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## Conclusions

The development of the World Wide Web has important consequences for autism spectrum disorder. The increased availability of information is raising public awareness of autism and providing knowledge and support for concerned parents and other affected individuals. Online discussion forums function as supportive communities, helping to alleviate symptoms of autism spectrum disorder and reducing the isolation experienced by parents and individuals with autism. The Internet offers fundraising opportunities and increases research efforts. The Web has empowered individuals with autism

and their families to advocate for themselves, through the use of online blogs and forum groups. Although the Internet carries the danger of spreading false information, the benefits of the World Wide Web appear to outweigh negative impact. However, concern should be raised for individuals with low-functioning autism and of families of low socioeconomic status. Families living close to the poverty line are quickly left out of autism discourse if they do not have access to the Internet and other resources, and individuals on the low-functioning end of the spectrum are less capable of self-expression. Advocacy groups risk leaving low-functioning individuals behind in their effort to oppose treatments and “cures” for autism. Fortunately, the availability of Internet technology allows nonverbal yet intelligent individuals to reveal their unique experiences of the world. Carly Fleishmann, a 15-year old nonverbal girl with autism, was unable to effectively communicate until she discovered a computer keyboard. She now posts frequently on her online blog and is writing an original novel (Goldberg & Putrino, 2009). Autism spectrum disorder’s impact on individuals and their families is evolving today through the World Wide Web, progressing toward improved quality of life for them and promoting tolerance and understanding between neurotypical individuals and those with autism. Understanding the benefits provided by Internet technology can help further promote autism advocacy as well as aid in the development of educational programs and treatments for individuals with autism spectrum disorder.

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