

## Autism e-mailing lists

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*A discussion, from a subscriber, of the pros and cons of autism e-mailing lists for people with Asperger's syndrome.*

The Internet has the ability to unite small groups that are so thinly spread across the world, meaning that special interest groups, including health-related groups, can be found 'clustered' in the form of online communities. In the case of people with Asperger's syndrome, Internet access has not only brought people who form part of a sparse population together, but has also enabled the Asperger's syndrome population to discover itself. From the Asperger's syndrome population's recognition of itself, 'self-advocacy' movements for the condition have also emerged. Much of this has been achieved through a medium of communication with which many people with Asperger's syndrome appear to be comfortable.

Asperger's syndrome is a diagnosis given to high-functioning individuals who have autism but who are at the end of the autistic spectrum that shades into normality. Many individuals with Asperger's syndrome often display characteristics associated with autism but without severe language problems. Such characteristics can include problems in interpreting non-verbal signals such as facial expressions, literal interpretation of metaphors and difficulty with social skills.

As a result of such characteristics, many people with Asperger's syndrome often find themselves socially isolated. However, the emergence of autism e-mailing lists has helped reduce this to some extent. After early autism e-mailing lists became dominated by parents and professionals, discussion lists specifically for people with autism and Asperger's syndrome started to emerge. Such lists include Autism

Network International's list (ANI-L), Independent Living on the Autistic Spectrum (INLV) and Autuniv-I, a list for university students with autism and Asperger's syndrome.

avoid using the term 'normal' to describe people who don't have autism or Asperger's syndrome, members of the ANI-L list started using the term neuro-typical (NT).

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According to INLV's owner Martijn Dekker: 'the Internet is for many high-functioning autistics what sign language is for the deaf'. Problems that people with Asperger's syndrome can often encounter within face-to-face and verbal communication is 'sensory overload' resulting from the presence of too many people and voices combined with the added stress of having to balance eye-contact, facial expressions and voice tones simultaneously. The 'one-channel' nature of Internet communication removes these barriers, making communication more manageable. Another problem that people with Asperger's syndrome can have in these situations is being able to think quickly enough of what to say as an appropriate response, which sometimes leads to them saying something that is unintentionally offensive and can cause the offended person to jump to conclusions that they don't like them, even if the person with Asperger's syndrome is trying to get along with them. The ability that Internet communication provides for users to go along at their own pace is of great benefit to people with Asperger's syndrome as they have time to think about and structure an appropriate reply.

Autism e-mailing lists have developed their own 'language'. To

Opposite terms include 'Aspie' which refers to people diagnosed with Asperger's syndrome and 'Autie' which refers to a person diagnosed with autism. A more generic term referring to autism culture is 'AC', meaning 'autistics and cousins' or people with autism and related conditions. Such terminology is analogous to similar words used in other online communities, thus helping to shape an online community.

As well as being beneficial to the social lives of people with Asperger's syndrome, there are also suggestions that Internet access has helped to improve some aspects of their general quality of life. For some people with Asperger's syndrome, shopping online is far easier than going out into a crowded store and the user can take more time in making their decision without being pressured by salespeople. Similar benefits include being able to find information without having to go to a library and the possibility of being able to find employment through telecommuting.

In some cases, people with Asperger's syndrome who subscribe to autism e-mailing lists to correspond with like-minded others can eventually get frustrated by the limits that the medium presents, particularly as they can't see or hear the person at the other end of the line,

unless they have a Webcam. This can lead to the person with Asperger's syndrome wanting to go beyond the monotone nature of text and meet respondents in person. This desire has encouraged some individuals with Asperger's syndrome to make journeys abroad to meet fellow list subscribers in person. It has been noted that verbal communication between people with Asperger's syndrome, who initially met on autism e-mailing lists, almost resembles written communication. Interactants mainly use words with very little body language and facial expressions. In addition to this, the interactants often say what they have to say in its entirety before stopping and waiting to hear the other person's response, whereas NT conversations are often more fast-paced with short exchanges back and forth.

Despite the opportunities that Internet communication has provided for people with Asperger's syndrome to interact with others who have the condition, there are some negative aspects. Currently, there is much concern about the reliability of self-diagnosis of autism, Asperger's syndrome and other related conditions. The number of people being self-diagnosed with such conditions online is increasing. This is of particular concern to professionals specialising in Asperger's syndrome, bearing in mind there is a lot of misinformation available online. Unless people self-diagnosed online have obtained their diagnosis from a genuine and well-policed site, they may well turn out not to have Asperger's syndrome at all. A problem that this can have for people with Asperger's syndrome when interacting on autism e-mailing lists is that they might be vulnerable to non-genuine, self-diagnosed people who may have personality disorders rather than Asperger's syndrome.

As many people with Asperger's syndrome often appear to have obsessive-compulsive tendencies, they can become very over-reliant on the Internet as a means of social interaction, allowing little scope for development of social skills in

verbal and face-to-face situations. However, there are many people with Asperger's syndrome who believe that NTs can learn a lot about Asperger's syndrome from online communication with people who have the condition, believing that NTs are more likely to learn about the qualities of people with Asperger's syndrome in an environment where they are most comfortable.

Although many people with Asperger's syndrome find themselves more comfortable with Internet communication, it is possible that over-reliance on the Internet for social interaction can lead to a reduction of the already limited amount of human contact they may have. This can result in

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further weakened abilities among people with Asperger's syndrome in terms of facial expressions and body language that, in turn, could lead to the person with Asperger's syndrome finding him/herself in trouble in social situations from misinterpreting people. Also, selective talking may take the place of impromptu speaking and inappropriate social cues may develop. In response, though, some people with Asperger's syndrome think that such arguments are often put forward by NTs who believe that, to be happy, people with Asperger's syndrome need to be interacting in ways that NTs enjoy.

A further problem for people with Asperger's syndrome is having difficulty in making valid judgements about the truth of what they read on autism e-mailing lists, due to their often literal interpretation of sources. In Internet conversations, it can be particularly difficult for a person with Asperger's syndrome to be able to tell if a respondent is lying. Sometimes, subscribers to autism e-mailing lists can feel depressed when respondents gain the wrong impression of them after

they have unintentionally posted something to their list that another subscriber has interpreted as being offensive.

Current problems that autism e-mailing lists are experiencing include e-mail overload and, in some cases, reliability. As numbers of subscribers to autism e-mailing lists continue to increase, so does the volume of mail. Such e-mail overload can be overwhelming for both the subscribers and list owners who find themselves having to manage excess amounts of messages. To try to keep the mail down to a manageable level, list owners often encourage subscribers to use private e-mail for a list conversation of interest to just two or three people or discussion of an

obsession or interest that isn't shared by others on the list. As there is much misinformation (and in some cases fraud) online, it is perhaps reasonable to assume that there could well be some autism e-mailing lists that are not genuine. As the Internet is a difficult medium to control in terms of being able to develop a central authority, it is important for people to be sceptical when researching online autism resources, including e-mailing lists.

Although it has been suggested that NTs can learn more about people with Asperger's syndrome through Internet communication, autism e-mailing lists also have to keep separate spaces strictly for people with Asperger's syndrome where they have a chance to interact in privacy.

Although many autism e-mailing lists are open to NT parents of people with autism and Asperger's syndrome and professionals specialising in these conditions, many autism e-mailing list owners believe in maintaining the intimacy that autism e-mailing lists have had as small special-interest groups.