

ON BEING AN AUTISTIC

By Joel Smith

INTRODUCTION

I am extremely thankful for the friendship that I've found in a handful of special people. I'm not an easy person to know, but these friends have extended their friendship to me. I cherish these friendships and consider myself to be very blessed, as I have the chance to know some truly wonderful people.

Autistics want the same things that others want in their friendships. We want to have friends who are loving, honest, and kind. I'm writing this with the assumption that the reader is a non-autistic who wants to be a friend to an autistic person.

Note that while many autistics may agree with the thoughts expressed below, not everything expressed here will apply to every autistic. It is best to talk with your friend about these things and find out what each of you could do to become closer friends.

Be Clear

Autistics aren't always "subtle" individuals. We experience the world very deeply, and often have very deep emotions. However, most non-autistics live in a world with tremendous amounts of subtleties and shades of gray.

This world is often foreign to an autistic, as we often think very clearly in black and white terms. We don't always understand shades of gray, nor do we understand why someone would want to live in a world filled with shades of gray! So, we appreciate any effort that a friend makes to be clear. For example, if you grow tired of a subject we are discussing, tell us that you are tired of it! Just say, "I'd prefer to talk about something else."

If we overstay our welcome, let us know in a clear and direct way, since many subtle cues are lost on us. Non-autistics often assume it is kinder to say something indirectly then to say it directly. Autistics sometimes miss subtle statements. You can be kind and direct at the same time - in fact, most autistics will appreciate your clarity.

We Don't Always Understand Social Rules

We often have a very definite sense of right and wrong, and believe that the rules should apply to everyone. We often can only follow the rules that we believe are sensible. So, we might not follow a "social rule" because we don't know the rule or because the rule would require some sort of performance that we are unable to give (ex: eye contact, remembering people's names/details, etc). We might not follow a rule if it doesn't make sense to us, either. For example, indirection and hints seem inefficient and dishonest to some of us.

We Don't Like Crowds!

Often, autistics don't like to be part of a crowd. We usually prefer activities with one or two people we know well. For example, rather than going to a movie theatre, we might prefer to

watch a movie at home with a couple of other people.

In addition, people that we don't know well can make us uncomfortable. If, for example, we are invited to a friend's house for dinner, we would usually prefer to know who else will be there so that we can "prepare" ourselves for the social situation. We might also choose not to go if we don't think we have enough energy to handle the situation. If we choose to say "no" when you invite us to spend time with you and your other friends, please don't assume that we don't like you or your friends.

Sometimes it is simply too much effort to interact with more than one or two people at a time. Please do keep inviting us, though, as we might have the energy and desire to meet a new person another time.

Don't Be Easily Offended

Autistics can sometimes say things more directly than a non-autistic might prefer. This is often misinterpreted as the autistic trying to insult the other person. A good rule-of-thumb for understanding my directness is that I almost never intend to insult anyone. I am who I am and I can't change that. I only know how to speak directly. You may find that I don't follow "unspoken" rules and, as a result will break them - sometimes hurting you. Chances are, I did not know that there was an unspoken rule. I'm not trying to insult you! A way that someone could be a friend is to ask me about my intentions when I offend. I probably don't realize that you were offended.

Sometimes We Just Want to be Alone

There are times when it is difficult for us to be around other people. If you invite us to spend time with you and we decline, it may simply be one of these times when we want to be alone. Please don't be offended, and please continue to ask us to be involved in your life!

You Are Strange To Us!

Just as the autistic personality seems strange to a non-autistic, the reverse is also true. Please help us understand who you are and how you experience the world! Share your thoughts and emotions as clearly as you can, so that we may better understand your special personality. Please remember that it helps to be very clear as you translate your thoughts into words, so that we can understand.

I Can See and Hear Fine!

We may miss social cues and have difficulties expressing ourselves, but that doesn't make us less of a person. I don't like people to shout at me or talk slowly, even though I sometimes have auditory processing problems. My actual hearing is fine (better than most people's, actually). But, my brain has problems processing the input in some situations. Shouting or talking slowly doesn't usually help. It also makes me feel bad, as it feels like I am being treated like a child.

Don't tell me to "look at you," either. I can't look you in the eye most of the time. Realize that I have to watch you out of the corner of my eye, and not directly. Telling me to do something that I can't do only makes me feel bad. Because I don't look people in the eye, it can be hard

for them to figure out if I am listening to them or not. The easiest solution is to ask me if you are unsure, as I don't have any problem admitting if I wasn't.

Let Us be Autistic!

Sometimes, an autistic will engage in some sort of repetitive motion or strange behaviour, such as rocking, hand flapping, strange postures, or humming. This is one of the ways we cope with a confusing world. These behaviours also give us comfort and relieve our stress. Please don't try to take them away from us or become embarrassed if we should engage in these behaviours in public - it is simply the way we are. When I am with understanding friends, I'll often tap/bounce my foot or wrap a blanket around myself. These are the ways I deal with stress, and by allowing me to do them you help me to enjoy your company.

Help Me When I Ask

Sometimes I just can't do something that other people can do. I have to rely on my friends to help me. I'm learning that it isn't wrong to need someone else's help. One of the areas I need help in is at social situations, like parties or meetings. When I'm with friends, I rely on them to mention the names of someone I am talking to (I don't recognize faces) or to "translate" another person's subtle cues into language that I can understand. This can be done in a very kind way by an understanding friend. For instance, a friend can say, "Hi, Bob" as we approach Bob, so that I will know right away that he is Bob. Or my friend could say, "It was nice chatting with you, Bob! We'll let you get back to talking with your wife." This lets me know the conversation is over. But, always let us decide if we need the help or not. We know our limitations much better than even a good friend can know them. Don't assume that we have a particular limitation because you might be wrong. If done by a good friend out of concern, I don't mind a friend asking if I need help. But, please ask in private.

Answer Our Questions

Autistics can have a naivety or innocence in their understanding of the world. We don't learn the same way others do, so we need to be told about a lot of things others seem to intuitively understand. Sometimes we need to ask a "dumb question" to someone we trust. If we ask you a question, we really don't know the answer.

Don't read more into our questions than is there. If I ask, "Are you cold," don't assume that I am asking you to turn up the heat! I probably don't know if I'm cold or not, due to my autism, so I am trying to figure out which sensation I am feeling - so I really want a yes or no answer!

Ask Us Questions

Let us know you are interested in us and who we are. This is the easiest way for me to explain who I am. Autism isn't a four letter word. If you are curious about autism or how it affects our lives, please ask. Most of the time we would be glad to answer the question. Many of us wish more professionals asked autistics about their lives before drawing conclusions! Ask about other parts of our lives as well, as it shows you are interested in us as people.

Allow Us Alternative Forms of Communication

Some of us have great difficulty with speech. Often, we have alternative ways we prefer to

communicate. For me, that means I use email, text chat, a portable speech synthesizer, writing, and other non-speaking ways of communicating with my friends much of the time. The best way to respond to my use of these techniques is to continue to speak to me normally, realizing that you may need to modify your conversational style to a more rigid "turn taking" style where you say something and then wait for me to respond, as some of these techniques make interruption difficult for me and take more time than speech does. Simply listen to me and allow me to speak in whatever way is comfortable.

Let Us Be Silent

Some normally verbal autistics sometimes have trouble speaking, either because of overload or simply because they don't have the energy at the time. I am one of these autistics. If it is an emotionally charged situation or lots of people are talking at once, I might not be able to talk to you. If I don't answer you, I'm probably not ignoring you - realize that it is just too much for me right now and I just want you near me. Don't touch or hug me, as I don't enjoy that (some autistics do, though, so ask if you are unsure). Some others might just want to be left alone.

In addition to this, I find it is much easier for me to express my deep feelings in writing than in speech. Please allow me to use this form of expression - I only use it because I want to tell you something that is very important to me and because I trust you as a friend.

Don't Ignore Us

Like any friend, we may get upset if you ignore or exclude us. Please ask us if we would like to participate in an activity or outing before deciding that we wouldn't enjoy it. For example, we might not normally like to go to a party, but we would feel bad if we weren't invited when all your other friends were. We might say "no, thanks" if you ask us if we want to go. But, by asking us, you show that you are interested in our company. In addition, sometimes we even surprise ourselves with the kinds of activities we enjoy!

Our Past

Some of us have had a very difficult past. Please don't pry, but let us tell you if and when we decide we want to. It will mean more to both of us this way.

Forgive Us

We will wrong you at some point in our friendship. Autistics often miss signs and rules that say some subjects are forbidden. We say things directly and sometimes seemingly with the wrong emotions (sometimes my facial expression doesn't reflect how I feel). I know that I often need the forgiveness of my friends, probably more than most people. But, I'll also forgive you when you don't understand something about me.

TRY NOT TO REFER TO US AS 'AUTISTICS' - THAT IS A LABEL FOR US TO USE ABOUT OURSELVES WITHIN OUR COMMUNITY.

INSTEAD CHOOSE TO USE 'PEOPLE WITH ASPERGER'S' OR 'PEOPLE ON THE SPECTRUM' OR A SIMILAR PHRASE THAT ACKNOWLEDGES WE ARE FIRSTLY PEOPLE AND INDIVIDUALS OF VALUE... LIKE YOURSELF.

Contributors to this Document

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