

## APPENDIX II

### WHEN SHOULD AUTISTICS SELF-DISCLOSE/SELF-ADVOCATE?

To self-disclose/self-advocate or not to self-disclose/self-advocate, that is the question that weighs heavily on the minds of many of us Autistics. There is a legitimate reason for Autistics to fear discrimination if they reveal their Autism to a public that has been told that it is a horrible blight. However, the fact that there is something inherently different about us is so obvious to non-Autistics that it is impossible for us to hide. So if we do not help non-Autistics understand us, then they will look to their own preconceived notions about people in general to interpret our actions and behaviors. So I ask all Autistics who are struggling with whether or not they should self-disclose, are the pre-conceived notions that people currently have about you any better or worse than the stereotypes that they currently have about Autism?

Nevertheless, I have an Autistic friend who has had negative experiences some of the times when he attempted to self-disclose/self-advocate. Having listened to his accounts, I believe that much of this had more to do with the way he did it rather than with what he was trying to do. It is my desire to help Autistics be more effective in their ability to self-advocate that has led me to present these basic insights for self-disclosure and self-advocacy. All of these points transcend the subject of Autism and apply to anyone who is advocating their views on any subjects that are personal, political, social, religious, etc.

### GENERAL FACTS TO BE AWARE OF WHEN SELF-DISCLOSING/SELF-ADVOCATING

- 1) Most people do not want to hear about someone else's personal matters that do not affect them:** This was something that my previously mentioned self-disclosing Autistic friend did not understand at the time. The fact that those who do not know us do not want to get drawn into our personal problems is not a lack of empathy or act of rejection of us personally on their part, but a matter of practicality. Although we do need and want to have a circle of friends with whom we give and receive mutual support, there simply is not enough time in the day to deal with the problems everyone we cross paths with as well as our own.

A major aspect of "Codependency," a type of a dysfunctional relationship, is the inability of the Codependent to accept the fact that they cannot fix the problems of everyone they meet. They, driven by the obsessive needs for approval of others and to feel good about themselves, are constantly causing themselves extreme emotional stress by trying to fix problems that they cannot fix. This not only includes them trying to help those who do not want their help; but also trying to help more people than is humanly possible. This is why someone with this variation of Codependency may be referred to as a "FIXER," "RESCUER," "ENABLER," "HERO," etc. Therefore, the disinterest that people have towards the problems of those who they do not have a close relationship with is actually the ability to have healthy relationship boundaries.

Another aspect of Codependency may be referred to as the "WOUNDED PUPPY," "LOVE ADDICT," "DOORMAT," "PLACATER," etc., is the variation that is often times guiding those who do go overboard in telling everyone about their issues. Such individuals, who are also driven obsessive needs for approval of others and to feel good about themselves, go to obsessive lengths to find someone who will demonstrate that they care about them. The reckless nature of their search will eventually suffocate those who try to help them. This will not only force those who want to help them to reduce or eliminate their involvement, but also leave them extra vulnerable to those who will reject and hurt them.

While working on issues of my own Codependency, I have dealt with both aspects. When things are going good, I believe I can help anyone fix any problem they might have. When things are going bad, I feel massively inferior to everyone around me and desperately want someone to show me that they care about me. Rapha (the Hebrew word for "*one that heals*"), a Christian Counseling Ministry, refers to this as "The Judas/Savior Cycle." With all of the progress I have made in making healthier decisions in my personal life, I find it very easy to slip back into these old roles.

The most extreme individuals who are enslaved to the second aspect may be referred to as the "victim," "martyr," etc. These individuals not only want to feel sorry for themselves, but also want

everyone to feel sorry for them as well. I invented the term “VICTIMITE” because such individuals, who most likely were indeed victimized in the past, are now letting their past experiences define who they are today. This results in them doing things that range from believing they are being victimized any time things do not go their way, to provoke negative responses from others that amount to self-provoking victimization. Most Autistic self-advocates, as well as non-Autistics who advocate on behalf of Autistics, present Autism in what I would describe as a “victimite” manner. If you come across as being a victimite, the majority of the very people that you are trying to reach out to will respond negatively.

- 2) **Those who do not know how to respond to someone’s uniqueness may keep their distance from such individuals in order to avoid doing something wrong:** This roadblock, which is common when dealing with any element of a society that would be considered “atypical,” was one that I failed to overcome when trying to recruit volunteers to help me tend to the needs of the local refugee community. I am not going to go in depth about this; other than to say that most people were so scared that they would do something wrong that they left the refugees alone to struggle with some of the simplest aspects of American life.

Many Americans believe you have to be an educated “expert” before you can attempt to do anything about anything. This is not to say that I am opposed to learning all you can before you start a project, but most just cannot grasp the effectiveness of approaching those from a different culture as a humble student wanting them to be their teacher. Those who are willing to use this approach will learn things about that culture that the cultural “experts,” who are actually foreigners of the very culture(s) that they are trying to educate others about, are clueless about.

Not only are many of us Autistics capable of educating others about Autism, but I believe we do a better job because we explain Autism from every angle. This not only includes the scientific and clinical viewpoints that most non-Autistic “experts” of Autism focus solely on, but also the viewpoint that most of them never bother to take the time to learn, the viewpoint of Autistics themselves. I am not saying that I want you to avoid going to these experts for information, but that I do not want you to think that you can go to them as an alternative to giving us the opportunity to speak for ourselves. The few that do will not only find out that some their interpretation of the unique aspects of Autistics are flawed, but that it is possible to understand and remedy many of the issues that most non-Autistics view as mysterious aspects of Autism that no one can do anything about.

- 3) **Avoid conducting yourself in a way that will get you lumped in with those who have manipulative, controlling, angry, arrogant and/or combative personalities:** So many individuals who advocate on behalf of issues that they are passionate about, especially those advocating their religious, social and/or political views, have these character flaws. People like this develop a reputation of just looking to pick a fight with someone. These reputations are usually far more accurate than most of them are willing to acknowledge. Most people will eventually get to the point of realizing that trying to have any dialog with those who have these character flaws is a complete waste of time. If you develop a reputation of being one of these people who just want to fight all of the time, then no one will take any of your needs and grievances seriously.

- a. **Many individuals come across as being angry when they advocate views that they are most passionate about:** This is something that I have to be careful of as much as anyone else, especially when my normal talking voice is about twice as loud as what is typical for most people. Those who know me will tell you that I am not exaggerating this in the slightest.

Some people I try to explain this to erroneously think that I am saying that they should learn to completely suppress their emotions. No, our emotions help others fully understand the magnitude of what we are trying to convey to them. However, if our emotions are dominating what we are saying, then the wisdom and/or substance of what we are saying can and will get drowned out. This can cause others to misconstrue our message as a product of emotion, rather than of wisdom.

- b. **The more things you complain about, the less validity your complaints will be in the eyes of most people:** There is a saying, “The squeaky wheel gets the grease.” However, there are people who live to “squeak” who need to realize that if the wheel continues to squeak after it has

been drowned in grease, it gets discarded. This is another problem that is by far worse for political and social advocates.

I once was very displeased at a church's singles group when I observed what I first interpreted as them alienating an Autistic at a social event she had invited me to attend, until I got to know her better. She uses her Autism as a license to manipulate people into letting her have her way all of the time. There is big difference between self-advocating to get your needs met, and manipulating others to get your way because of your obsession to being in control of your surroundings. If you do not understand this difference, then you need to deal with the underlying issues of this self-created blindness.

- c. **Do not treat anyone who disagrees with you as your mortal enemy:** This is the number one thing that political and social advocates do to alienate those who might otherwise be sympathetic towards their cause. It is OK for someone to have a different assessment of a situation and believe that a different solution might work better. As long as they are willing to dialog with you about the issues that you are trying to address, then take your assessments and recommendation into thoughtful consideration, you should not treat them as your enemy.

#### **PERSONAL PREPARATIONS TO MAKE BEFORE YOU SELF-DISCLOSE/SELF-ADVOCATE**

- 1) **Work on your own self-improvement as much as humanly possible:** One of the favorite analogies that Autistic self-advocates like to use is that they are cats and non-Autistics are dogs. When neurotypicals try to get them to conform to the "normal" way of doing things, they say that you cannot turn a cat into a dog. Nevertheless, these same Autistic self-advocates then turn around and demand so many accommodations from the non-Autistics that they are essentially trying to turn dogs into cats. Although they may demand that non-Autistics give them the benefit of the doubt when it comes to them reaching their goals, many Autistic self-advocates refuse to give themselves the benefit of the doubt when it comes to them overcoming their personal struggles so can they require few accommodations from non-Autistics.

Social harmony between Autistics and neurotypicals requires mutual cooperation. Yes, just about every Autistic does need some special accommodation in some area(s). However, the more special accommodations that Autistics (or anyone else with a disability) demand, the more of a nuisance they become. Eventually, the non-Autistics (especially in social groups) will try to avoid Autistics as much as possible in order that they can accomplish things that they can never accomplish if their #1 priority is providing special accommodations to a single individual.

On the other hand, people respect those who try their best to overcome their own problems and only ask for accommodations if it is clear that they are required. This makes them more accepting of your request for accommodations instead of questioning whether or not you just using your Autism to get your way. If they believe that you are just using your diagnosis in this manner, some will scrutinize your every move to try and prove it.

Furthermore, self-improvement gives you a level of self-confidence that can be contagious. If you demonstrate confidence in your own abilities, most people believe in you enough to give you the benefit of the doubt and give you the support you need to try to order to accomplish your goal. In most cases, at least one such person will even stand up to the naysayers on your behalf.

Therefore, if Autistics can learn to overcome their struggles so they require few accommodations, then they will be able to start contributing their unique strengths and personality to the group. In the process, the group will gain respect for the Autistic (or anyone else with a disability) for their determination to not allow anything to hold them back. Such groups will then have no problem giving the Autistic (or anyone else with a disability) whatever accommodations they need to so they can continue to contribute their uniqueness to the group.

- 2) **Develop a quality support system:** All human beings need older adults, including but to limited to their parents, to provide them with guidance throughout their lives. This is especially important when dealing with difficult situations which provoke a strong emotional response in us.

- a. A Mentor/Life Coach who shares the wisdom they have learned from...
  - i. ...their past struggles and mistakes.
  - ii. ...have personal experience "walking in your shoes."
  - iii. ...someone who mentored them.
- b. Friends who, along with your Mentor/Life Coach...,
  - i. ...understand...
    - 1. ...that their job is to help you make informed decisions about what choices you should make, not run your life by pressuring you into making the choices that they think you should make.
    - 2. ...just because a problem may seem insignificant to them, does not change the fact that it can be major to you.
  - ii. ...tell you what you need to hear, even if it is not what you want to hear.
  - iii. ...do not tear you down when you fail and/or make mistakes.
  - iv. ...cheer your victories.

### 3) Learn...

- a. **...how to explain Autism in an effective manner:** The conventional way of explaining your Autism to others, "I'm wired differently and here's a list of all the things I can't do," DOES NOT WORK! Yes, you can get away with such a shallow explanation when giving a formal presentation to a friendly audience. However, if you try to use it when trying to resolve a real world dispute with someone who's frustrated with you, IT WILL FAIL EVERY TIME!
  - i. It is fundamentally unsound to present any position on any topic that does not provide you with a solid foundational truth that you can build upon. Starting off by saying, "I'm wired differently and here's a list of all the things I can't do," will always result in a dead end conversation.
  - ii. You need to be able to explain the difference is between Autistic and non-Autistic neurology.
  - iii. The concept of people being "wired differently" is now being used by Hollywood to absolve any responsibility for everything from rape to mass murder. Whether or not people are trying to use this defense in real life, the fact is that many law abiding citizens are sick and tired of hearing about it. It is possible for an Autistic to receive a "backlash" response if they use that term, especially by those who believe Asperger's is a "fake illness" because they do not understand the paradoxes associated with Autism.
  - iv. If all you can tell others about your Autism is all the things you cannot do, then it's going to sound like you are just making excuses.
  - v. Your method of explaining the struggles your Autism causes you needs to lead to solutions. This does not mean that you need to be able to come up with solutions to all of these problems, but that you need to provide enough information to others so everyone can work together to find solutions.
- b. **...what your struggles are and what can be done, not only by second and third parties, but especially by yourself to minimize your dependency on others:** Doing so improves your quality of life by...
  - i. ...enabling you to achieve more of your personal goals in life.
  - ii. ...building your personal dignity, self-esteem and self-confidence.
  - iii. ...gaining the admiration and respect of others.

c. **...what areas you excel at:** This can be especially challenging for Autistics because their weaknesses can often drown out their strengths. Just because your weaknesses are easier to spot than your strengths does not mean that your strengths do not exist. When you do figure out what your strengths are, you can then look for employment and social opportunities that tie into them rather than your weaknesses.

d. **...what is likely to lose your audience:**

- i. Talking over the head of who you are attempting to communicate with. This not only includes talking to someone with a professional vocabulary when they are not part of that profession, but also taking overly in depth to people in subjects that they are not familiar with.
- ii. Talking about issues that are irrelevant to the person you are attempting to communicate with. Example: Your boss does not have time to listen to a two hour seminar about your Autism and all the way it affects you when you are not at work. The only questions your boss wants answers to are, what is your problem(s) at work and what is/are the solution(s)/reasonable accommodation(s) required for you to be an effective employee.
- iii. Taking up more of a person's time than they have to give you. Example: Again, your boss does not have two hours to deal with your problems. Instead, he/she will probably only be able to allot a maximum of 15-20 minutes to find a solution. If you do not convince the boss within two minutes that there is hope for you, you have probably already lost. Furthermore, you will probably have about two sentences to actually engage your boss' mind in order that he/she will still be paying attention to what you are saying after you have completed those first two sentences.

Therefore, what you say to your boss needs to be well thought out in advance in order that your conversation with your boss is a constructive dialog rather than a vain monolog, or worse.

4) **Understand how Autism affects you in your day-to-day life so you can be opportunistic when your Autism is relevant to the conversation:** The basis for this is what many Christian churches refer to as "friendship evangelism." Instead of forcibly bringing up the subject to an audience that does not want to listen to what you have to say, you make a comment that is both casual and non-threatening. If they respond with extreme hostility, then drop the subject. So how does this apply to Autism? Avoid bringing up the subject in a combative self-advocating manner unless absolutely necessary.

- a. Do some constructive community service with your free time that benefits the Autism community. When someone asks you what your plans are for a certain time and day, and you happen to have a community service activity planned at that time, tell them about it. With as active as I am in serving the Autism community as much as humanly possible, such opportunities for self-disclosure happen all of the time and it is always positively received.
- b. Instead, talk about the uniqueness of your Autism in a casual "no big deal" manner whenever the situation presents itself. Example: The night before I wrote this, I was waiting at the bus stop pacing. A young lady commented that I, "must be going a long way," when I moved my groceries so she could sit on the bench while I continued to pace. I told her that I was naturally hyper active and that it was a part of my Autism. Although that particular encounter did not lead to prolonged dialog on the subject of Autism, I have had such dialog in the past when I happen to make such a self-disclosure to someone who happens to be the loved one of an Autistic.