

APPENDIX III

AUTISTIC'S SELF-ADVOCACY WORKSHEET/SURVEY

The purpose of this Worksheet/Survey is three fold:

- 1) It was modeled after the "step packets" given to members of the 12 Step support group that the author attended for codependency. The intent was to help the addict/codependent to see the impact that their addictive/dysfunctional behavior was having on their personal life.

Likewise, this Worksheet is designed to educate Autistics about their own Autism and the effects that it has on their lives. Just as with the 12 Step packets; the Autistic would greatly benefit by going over what they wrote in this Worksheet with a mentor, confidant, counselor, etc.

- 2) Help Autistics with self-advocacy by providing them with a "cheat sheet" that can aid them in explaining their autism to others.
- 3) Most surveys provide statistical data for those who advocate for policy changes and those who are in a position to change policies. However, there are those who recognize that there is more to understanding a situation than statistical analysis can ever provide. In fact, many consider it to be dehumanizing to base your views of another human being solely on statistics. There are even some that have little or no regard for statistical surveys of any kind because all data can be manipulated to suit the agenda of the surveyor.

For those who would be willing to volunteer to submit this Worksheet as a Survey, I was planning on providing a special MS Word version can be emailed to you so it can be filled out on your computer and emailed back. However, Dr. Woodruff expressed great concern about this plan.

"I would have very significant concerns about the potential privacy issues involved in someone completing such a survey and then emailing it to you to be stored in a potentially nonsecure location. The sensitive nature of the information you are collecting and the potential to identify the individuals providing the information would put you in a position of liability if such information somehow was inappropriately accessed while you were 'responsible' for it."

Dr. Woodruff brings up a valid point that I honestly had not considered, and I am not currently able to provide a solution for. Therefore, although I am still willing to email you a MS Word version for your convenience in filling out for your own personal use, please do not email it back to me for the purposes of the information being used in a survey until it is announced on the official AAC website that such security issues have been properly addressed.

WHO ARE YOU?

This first section is intended to give you some basic insights about yourself that can help you explain yourself to others. It especially focuses as much as possible with the positives that are often drowned out by the struggles that have come to define Autism in the eyes of many. It also focuses as much as possible on possible solutions in order to encourage Autistics & their loved ones.

- 1) **What are your autistic gifts?** It is both very frustrating and misleading for us autistics to be viewed solely by the things that we struggle with.

Please provide a list of special gifts that you believe that you have as a direct result of your autism. Make sure to include specific examples of how these gifts have benefited you:

- 2) **Which of your autistic struggles have self-corrected?** Science shows that the unique struggles autistics have are the result of some parts of their brain developing differently than a neurotypical brain does. As a result, these parts of the autistic's brain are more or less active than the same parts of the brain of a neurotypical. In addition, science also shows that the human brain is "plastic," meaning that our brain is constantly changing, enabling it to adapt in both positive and negative ways. This provides us with scientific evidence that some areas which autistics struggle with may be modifiable.

Therefore, please list your autistic struggles from the early years of your life that you believe may have self-corrected. Include any sensory processing issues that do not affect you to the same extent as they may have in the past:

- 3) Which of your autistic struggles have you learned to manage?** We autistics should never assume that we are hapless victims of our autism. Although autistics may object to everyone trying to change us, the fact is that there are things that we really would want to improve about ourselves because doing so would make life so much easier on us. Just because many of our struggles are neurological in origin does not necessarily mean that we are powerless to do anything about them. Many of our struggles can be managed through the use of proper strategies and coping skills by those who are willing to mentor us. Securing the cooperation of those that we interact with on a regular basis will make things a lot easier for us, but all self-improvement hinges on the choices of the person seeking to improve him or herself.

Therefore, please make a list of areas that you still struggle with that you have learned effective strategies for dealing with. This does not necessarily mean that you consistently implement these strategies in an effective manner, but that you do possess the knowledge to do so:

- 4) Which of your autistic struggles have you not yet learned how to manage?** I can provide no guarantee that every area that an autistic struggles with will self-correct or be managed. There is also the possibility that some of the autistics who are doing this worksheet simply have not yet gained sufficient neurological development. Others may not have learned effective self-management techniques due to a lack of age and/or experience.

Please list the areas that you still struggle with:

COMMON AUTISTIC ISSUES THAT YOU DEAL WITH

Although many of these issues may have been brought up in the previous section; sensory processing issues affect such a large portion of the Autistic community that they do need to be singled out here to make sure that they are addressed. The atypical neurology that autistics have can result in their brain having difficulties processing sensory input. This can make autistics hyper- or hypo-sensitive to sensory stimuli, as well as well as confusion in the brain's ability to interpret the information. As I said earlier, science shows that the human brain is "plastic," meaning that our brain is constantly changing. Because of this, it is possible for these sensory processing issues to self-correct in part or in whole.

- 5) What sensory processing issue(s) have you struggled with?**
- Please describe the sensory processing issues that you may have had, but have since completely self-corrected to the point that they are no longer a problem:
 - Please describe the sensory processing issues that have impacted you at some point in your life, but no longer impact you to the extent that they once did:
 - Please describe the sensory processing issues you still struggle with and what you do to better manage them:
- 6) Have you ever had problems with being touched?** It is an erroneous assumption that Autistics who do not want to be touched lack a desire for affection. In actuality, this is a sensory processing issue. Some Autistics have a negative physical reaction to touch due to the brain having difficulties processing sensory stimuli through the sense of touch.

If you have ever had problems in this area, please explain the physical reaction that you had to people touching you:

- 7) **Have you ever had problems with “aggressive” behavior (hitting, biting, etc.)?** It is understandable to assume that hitting, biting, etc. would be classified as “aggressive behavior.” However, if the intent of the Autistic is to prevent another person from doing something that would trigger a sensory processing issue within them, then should the behavior not be classified as self-defense?

I am not attempting to use these sensory processing issues as an Autistic's “get out of jail free card.” Nor do I support the notion that Autistics never engage in inappropriate and/or malicious behavior and therefore should never be disciplined. After all, Autistics are just as human as everyone else and are therefore as capable of engaging in inappropriate and/or malicious behavior as anyone else. Furthermore, Autistics are just as capable of being taught right from wrong as anyone else. Nevertheless, Autistics should be shown an appropriate amount of consideration when their sensory processing issues are a factor in their behavior.

Please describe any aggressive behavior(s) that you may have had at some point in your life that you believe was/were tied to specific sensory processing issue(s). Do you still have problems with this/these behavior(s) and sensory processing issue(s)?

- 8) **How do you respond to emotional situations?** The misconception that bothers many Autistics the most is that we lack empathy. This issue is being brought up in the sensory processing section because that is the true origin of this issue. Autistics will often [experience sensory overloads when faced with extremely emotional situations resulting in them losing their ability for self-expression](#). This complete lack of responsiveness to a highly emotional situation can lead to others to erroneously conclude that they lack the ability to feel empathy for others, which is the exact opposite what is actually happening inside the Autistic's mind.

[Please describe occurrences where you were falsely being accused of cold, uncaring, empathetic, etc. when you were in fact being overwhelmed by these very emotions:](#)

OTHER COMMON AUTISTIC ISSUES THAT YOU DEAL WITH

- 9) **Have you ever had bowel control issues?** The fact that many Autistics have problems controlling their bowel movements is a well-known fact. However, what is not widely known is what the Autistic was experiencing moments, minutes and even hours leading up to their accidents. It is understandable that most would assume that bowel control issues originate in the gastrointestinal tract, but it is erroneous for anyone to not consider the role that the brain plays in the defecation process and the problems that atypical neurological connectivity can cause.

Please describe the difficulties that you may have experienced with bowel control:

- 10) **What teaching techniques do you believe work best for you?** Those who have already graduated from high school can only theorize about what techniques might have worked better for us during our K-12 years. Nevertheless, teachers today can try some of these theories to see if they might benefit some of the autistic children in their classes today. If you are thinking about going back to school, but are apprehensive because of your struggles in K-12, they might help you gain confidence that you can have a plan that might enable you to fare better.

a. **Please provide some ideas of what kinds of teaching techniques work better for you:**

b. **What kinds of teaching techniques do not work for you:**

- 11) What have your employment experiences been like?** A lot of Autistics struggle to maintain employment for reasons that are directly connected to their Autism.

Please describe what, if any, problems you have had maintaining employment:

- 12) How do you respond to different social environments?** Although it is a fact that Autistics do struggle in many social environments, it is a misnomer that they struggle in all social environments. It is also erroneous to assume that just because Autistics struggle in, and are often reluctant to join, social environments that they have no desire to socialize.

Therefore, please describe the following:

- a. The kind of people that you find it easiest to socialize with:**
- b. The kind of people that you find it the hardest to socialize with:**
- c. What social environments are easiest for you:**
- d. What social environments are most difficult for you:**

WHAT EMOTIONAL/PSYCHOLOGICAL ISSUES HAVE YOU STRUGGLED WITH?

With all of the focus that is placed on the neurological aspects of Autism; the emotional and psychological aspects of Autistics are almost completely neglected. The fact that the way you treat a neurotypical child greatly affects their social development is irrefutable, but the idea that the asocial tendencies amongst the teen and adult Autistic could be connected to how they are treated is considered a radical concept by many. Nevertheless, no matter what therapies, treatments and/or cures that an Autistic may or may not receive, they will not develop effective social skills until their emotional and/or psychological issues are dealt with.

- 13) What needs of yours do you believe have gone unmet?** Our needs may go unmet due to neglect, abandonment, our inability and/or unwillingness to express our needs, etc.

Please describe your unmet needs:

- 14) What physical, emotional and sexual abuse have you endured?** The atypical social behaviors of autistics often times lead to destructive responses from those who do not understand us. The asocial tendencies of autistics can result in the kind of isolation that makes them prime targets for bullies and others who engage in predatory practices.

These are issues that we autistics must open up and talk about if we are ever going to overcome their consequences. Please indicate whether or not you have endured such experiences. If so, please indicate which types you have endured, the frequency you received such abuse and how old you were at the time of the abuse.

- a. Physical:**
- b. Emotional:**
- c. Sexual:**

- d. **Unwanted Sexual Contact** (This is listed separately from sexual abuse because some people, including many victims, perceive that there is a difference between the two. Nevertheless, one of the important issues that this question is attempting to address is the sexual vulnerability of autistics.):

15) Suicide thoughts and attempts. Have you contemplated and/or attempted suicide? If so, how old were you when you first started contemplating? How old were you at the time of each of your attempts? What was going through your mind as you contemplated such an irreversible solution?

16) What types of addictive/dysfunctional behaviors and character flaws have you struggled with?
We autistics also need to recognize that not all of our struggles have anything to do with our autism. After all, we autistics are fallible human beings, just like the neurotypicals. All people, including Autistics, need to do their best to improve in any area that would help us live more fulfilling lives; especially if it becomes clear that we may have character flaws.

Taking responsibility for our choices is mandatory if we are going to succeed in changing the aspects of our lives that have become a detriment to us and those we interact with. Furthermore, using autism like a “get out of jail free card” will cause us to lose the respect and cooperation of many of those who might otherwise be sympathetic towards us.

Please acknowledge what issues of this nature you need to overcome:

GETTING HELP

17) Name all of the diagnoses you can remember being given. Those of us who graduated from school prior to the 1990s went through our school years before most of our educators and counselors even heard of “high functioning” autism/Asperger’s. They attempted to explain our atypical behaviors and development by diagnosing us with the only conditions that they were aware of at the time. There are also other conditions that bear resemblance to Autism. Some are now being considered as possibly being an aspect or variation of autism.

Please provide as thorough a list as you can recall of every diagnosis you have ever received:

18) What types of treatments and/or therapies have been attempted with you and what were the results? Please list as many of the different treatments and/or therapies the experts recommended for you. Explain to the best of your ability the reasons that were given for why they believed these treatments and/or therapies might help you. What is your assessment of the effectiveness of these treatments and/or therapies?

19) What questions about yourself were answered when you were diagnosed with autism? Those of us who were diagnosed with autism later in life spent our lives asking, why do we struggle with some of the simplest things? Why can we not do things that everyone is expected to have mastered when they were much younger than we are? Why do people not believe us when we say we are trying our best? Why are we treated so differently than others?

Please tell us what specific questions that you had when you first learned about your autism that you had answers to. What questions do you still have that you have yet to have been answered?

WHAT IS YOUR OPINION ABOUT THE FOLLOWING?

20) Neurodiversity:

21) Research into a cure for Autism:

22) Biomedical treatments for Autistics:

23) "Normalization" of Autistics:

24) Vaccines causing Autism:

25) What do you believe is the best mindset to approach the subject of Autism with?

**OTHER INFORMATION THAT YOU WOULD LIKE OTHERS
TO KNOW ABOUT YOU AND YOUR AUTISTIC EXPERIENCES**