

Behavior as Communication – When all else Fails  
By Sue Rubin

Hello everyone and thank you for having me here today. My name is Sue Rubin I am a 31 year-old college student and I have autism. Assume many of you viewed my film, *Autism is a World* last night and therefore have some idea of what my life is like but for those of you who didn't, I'd just like you to know that I have autism. When I say that, I mean the real deal. The autism outlined by Leo Kanner himself, what many of you may call low-functioning or severe autism, the kind that comes with all of the wonderful behavior problems that we are so famous for.

Today I want to discuss autistic behaviors and how complicated this subject is. Sadly behavioral psychologists think awful behaviors are exhibited on purpose. They think we use behavior to avoid a difficult situation, to gain attention, to harass a teacher or parent or just to be stubborn. It is true that behavior helps in these situations, but they are very rarely the reason for the behavior. Really rest assured that the friends who spend time with me realize that unusual behavior is due to decidedly more complicated causes.

Testing a new staff member has resulted in the most egregious behavior I've demonstrated in the past five years. You think I do it to test the person's ability to keep me safe if I have a melt down. I really am quite able to judge a person's ability to manage behavior without testing. The reason my behavior is so bad is because I am anxious about a new person entering my life.

Actually almost all of my nasty behavior is caused by anxiety. Whatever killer behavior is not caused by anxiety is usually caused by movement problems. When I am asked to do something, you want me to respond at once. You repeat yourself if I don't move. You actually used to think I didn't understand the request. You now know I do

understand but my body won't move. The behaviorists see non-compliance but it is actually a movement problem.

People who interpret behaviors as communication would also be wrong. They would say I didn't want to do something or go somewhere but I really did want to do the thing or go where I was asked. I was just stuck. Ann Donnellan and Martha Leary have done a lot of work in this movement area.

Sometimes behavior is a reaction to incorrect sensory information. Quite a few autistic people perceive sensory information differently. The overload can cause a reaction. Libraries and bookstores assault my visual senses. I have learned to tolerate them over the years and now can do research without behavioral outbursts. Behavioral psychologists and people who see behavior as communication would interpret my behavior as wanting to avoid doing research and they would be wrong. Assume similar things can happen with all the senses.

Nasty autistic behavior sometimes occurs for no reason at all. Great psychologists invented the ABC of behavior – Antecedent, Behavior, Consequences. This sadly is useless when there is no antecedent. It is also unfair to have a consequence. In my case I sometimes have an urge to bang my head. There is no antecedent, just a compulsion. The urge is rare now, but when I was young I did it every day.

Autistic behavior sometimes is triggered by an event that had meaning in the past. When you look for an antecedent it might have been something that happened a long time ago. Figuring out the trigger is difficult even for the autistic person. Sometimes the behavior is the last event in a string of events so you just have to interrupt the string to get the behavior to stop.

When I am stuck in a behavior cycle I sometimes need a staff person to interrupt the cycle. Keeping my spoons keeps me aware of the task I am doing so I don't let myself succumb to the autism.

Really horrible behavior sometimes can be caused by pain. Work by the Autism Treatment Network is causing people to take another look at behavior. Sometimes the way a person with autism shows pain is not the same way a person without autism would. We often can't tell where the pain is. We just react to it. We also don't always exhibit the same symptoms as a person without autism and we often react differently to medications. A normal dose may be too strong, but sometimes a huge dose will do nothing.

The supposition that behavior is communication could be misleading with pain. Instead of people reading the behavior as communicating pain, they may read the behavior as avoidance of task or as attention getting in the absence of a task.

I would kill not to have people stare at me. I don't know who came up with the idea that autistic behaviors are done to get attention. We would love to quietly blend into society. We appear to want attention when we yell and misbehave. That really is the furthest from the truth as possible. We yell and misbehave because we are trying to be social but don't have the ability to do it appropriately. In some circumstances it is anxiety causing the inappropriate behavior.

You can see from this discussion that behavior can be misinterpreted both by behavioral psychologists and well-meaning people looking at it as communication. There is only one way to answer the question of what function the behavior is serving or what its cause is. That is to ask the person. If he talks, ask him the same way you would ask a non-disabled person. If he doesn't talk, teach him to communicate using AAC

(Augmentative and Alternative Communication) and if that is unsuccessful teach him to use AAC with facilitation so he can communicate as I do.