

Georgia Southern University

Digital Commons@Georgia Southern

Georgia Association for Positive Behavior
Support Conference

Dec 3rd, 4:30 PM - 5:15 PM

My Life as an Autistic

Eren Denburg Niederhoffer

Eren Kyle Denburg Niederhoffer, erenkn715@gmail.com

Follow this and additional works at: <https://digitalcommons.georgiasouthern.edu/gapbs>

Recommended Citation

Denburg Niederhoffer, Eren, "My Life as an Autistic" (2014). *Georgia Association for Positive Behavior Support Conference*. 27.

<https://digitalcommons.georgiasouthern.edu/gapbs/2014/2014/27>

This presentation is brought to you for free and open access by the Conferences & Events at Digital Commons@Georgia Southern. It has been accepted for inclusion in Georgia Association for Positive Behavior Support Conference by an authorized administrator of Digital Commons@Georgia Southern. For more information, please contact digitalcommons@georgiasouthern.edu.

December 2014 GAPBS Conference Proposal

My Life as an Autistic

By Eren Denburg Niederhoffer

Hello everyone. I would first like to thank Doctors Stacey Ramirez and Emily Graybill for having me here today. I am grateful to have been presented this opportunity by the both of you. Now before I begin discussing my life as a person with Autism, I will be going over positive observations I have discovered regarding what I felt school systems and family could have done for me do to improve my development as a child.

A. Behavior

- a. The changes in my behavior as a child took time, and could not be rushed. Suggestions I have that can be done to aid in the development as a child grows?
 - i. My therapy dog was important to my development. Dogs make for excellent therapy animals, and people on the spectrum have bonded well with dogs, particularly the Labrador and Golden Retriever Mixes...not to mention, as a socially overeager person, I found it easier to socialize with dogs than people because dogs were not pushed away if I tried to strongly to interact....rather, don't dogs love it when people want to be with them
 1. Canine Companions for Independence (CCI) is –one nonprofit (Canine Assistants is another) that raises dogs to assist children with special needs, and has a chapter in Atlanta. Thanks to CCI, I was given a yellow Lab Golden Retriever Mix named Letty, who was perhaps the first real friend I ever had.
 2. By interacting with Letty, I learned to pay attention to my own emotional state because while I did not care as

a child about what parents thought of my arguments, I did not like to see my dog upset

3. By walking with my dog, I could learn to spend time outside of the house, and get used to both physical activity and interacting with others using Letty as a way to get over my nervousness. I did have a problem with insects as a kid, and I still have an issue with wasps, having been stung by one, but I did love walking my dog Letty
 4. By learning to take care of Letty I learned personal grooming habits, for ex, brushing my teeth, brushing hair, washing up
 5. By feeding Letty, I learned to see myself as an individual and take steps to feed myself (for me, getting milk from the refrigerator for ex)
 6. Dogs follow calm strong leaders and get anxious if the child acts out. CCI and I assume Canine Assistants would have taken the dog back had I kept acting out and since Letty was my only friend, the potential to lose the dog is very powerful and can lead to behavior modification
 7. My bond with Letty was so strong, I humanized her as a member of the family, the one that I would get along with
 8. There are also dog parks that parents can take children to...
 9. If the family cannot own a dog for whatever reason, there may possibly be friends and family who own a dog who the child can interact with. When I interacted with family members and friends, my parents had to remind me not to want to go to their house simply for the sake of wanting to play with the dog.
- ii. Having a friend around my own age can also be helpful, but it was difficult because of the age difference and social skill

level...I didn't even know what it was like to have a friend for most of grade school. Not to mention, when I tried interacting, I tried too hard and desperately...you can push someone away without meaning to by not knowing how to interact, even if you want to.

1. Perhaps having a slightly older mentor can help. Why not search for volunteer groups which may try to pair younger adults with children to do activities together?
 - a. A program started in Gainesville Schools, Partnerships for Success, does a great job of connecting students with and without disabilities (to include autism). Lasting friendships have developed naturally through this program.
- iii. Not everyone with autism wants to be grouped, but it helped me to be in the same setting to interact with similar people. But for me, the problem was that I did not want to nor know how to interact with my fellow autistic peers.
 1. Why not having games for the children on the spectrum to play together, without using electronics, be a method? Like board games, role-playing games, word and guessing games, etc.?
 2. When I look back, I thought that games where we were forced to interact together might have helped me a lot in encouraging more interactions with others to build my social skills
- b. When I acted out there were many strategies that helped me learn what I was doing wrong or should not be repeated, without physically harming me but still got the message across?
 - i. I enjoyed role-playing . Some people with autism may try to repeat words, phrases, or actions they have seen in books, movies, or TV. Having them play this out may help them to distinguish between fiction and reality and that many things in movies and TV should not always be repeated or followed.

1. I learned this way not to do certain habits and how to properly do other behaviors. It helped me to think and ask questions...but you should be prepared to give an example of why something is wrong
 2. It's my opinion that TV shows like Family Guy, American Daddy, and Boondocks may NOT be good learning material for your kids...please try to keep an eye on what they read and watch...parental filters are there for a reason
- ii. A child on the spectrum, as with all children, can be difficult at times, even if high-functioning, but if you can use a method that the child won't like, the child may come to associate doing a certain action with the consequence
1. This is not positive behavior supports, but for me, a method that seemed to work on discipline was taking away certain privileges, like videogames, TV, or dessert (but not dinner or lunch, we need those, and taking those away is excessive). The goal was that I would equate doing the right thing or not doing the wrong thing with being allowed to hold onto those privileges
 2. Again, not positive behavior supports but another method was having me write "I will not" or "I will" a number of times, and increase the number each consecutive time there was an issue.
 3. A possible positive behavior support is to use positive reinforcement. Throughout the day or week, the child can earn or lose a number of stars (or other item of their preference) for their behavior or performance. At the end of the week, the child can use the stars earned to earn a treat, a toy, or use it to get a chance to go somewhere like the park or bowling (for this one, you may already be considering it, but let the child feel that he/she has proven that they have the right to do so)...if

they feel a sense of accomplishment, it helps to positively encourage good behavior

- c. These strategies helped me when I would be trying new things in life.
 - i. Positive reinforcement helped me to try something new. It made me feel proud in trying a new thing
 - ii. I liked when someone would make a game out of new things to try. When I “won”, I felt I had accomplished something tremendous. That sense of pride may help the child in trying similar new things
 - iii. For me, I was afraid of getting diabetes as a teenager from being too fat, so I dieted, tried new foods, and exercised...thank goodness I can now cook
- d. These strategies helped me avoid conflict between with my the neurotypical peers when at school:
 - i. A check in/check out room for transitions in the school day was helpful.
 - ii. Depending on the class setting, I found it best to sit at the front of the class
 - iii. It helped to role-playing classroom scenarios, having the teacher talk with me one-on-one first, having the teacher keep an eye on me
 - iv. It may not be right for every student with autism, but I had an assistant paraprofessional who helped.
 - 1. I had a counselor I could talk with throughout grade school regarding my social issues which was a big help. I had issues listening to my parents and I had difficulties with admitting the faults of my own self. Yes, one of the biggest problems I had was admitting my own responsibilities in the matter.
 - a. I learned that it’s not weak or stupid for me to admit my issues. I just have to be careful who they admit them to. A teacher or faculty, or a trusted friend is better than just any classmate

who might alienate me and discriminate me as someone different

- v. In order to minimize discrimination between neurotypical and students on the spectrum of any school level, I greatly recommend raising awareness of the Spectrum by educating neurotypical students and having training. No one wants to be discriminated against or judged for the way they look, the color of their skin, their religion, or their level of typical-ness. Try to include strengths about autism in addition to the symptoms so that the mainstream students will have less reason to treat the autistics as outcasts, or at least feel a need to reach out to them...students in social skills classes can definitely practice role-play with autistics

And now, a bit about my life's story, and how I have made it to where I am today, so you can do now, what I wish I could have done then.

For many of us with Autism or Asperger's, life after high school is extremely difficult, whether or not we enter college. There is the aspect of wanting friends, seeking activities to do, relationships, jobs, and even the issue for some of not wanting to take part in social activities due to introversion. Even before high school, I have struggled with these issues and overcome most of them. Even if you may not be able to enter college, there is plenty someone on the spectrum can do to enrich their lives. And it starts while you are still in high school.

When I look back on where I started out in self-contained classroom since elementary school, it wasn't until high school that I started transitioning out of

self-contained classrooms and attending mainstream classes. I learned to control my behavior and deal with the sensory issues to where it no longer affects me. By the time I entered college, I was going to classes on my own without needing a teaching assistant watching over me.

Before my final year of high school, I still suffered from a variety of difficulties. I had no friends whatsoever, I had no interest in getting out attending public events, I had poor social skills, and I refused to change who I was or listen to advice. The only good memories I had prior to college was my Service Dog, given to me from Canine Companions for Independence. Letty was my friend who had been with me for over 13 years she first came into my life back in 2000...she died last year. It was thanks to Letty that I had learned to take of myself in terms of having a degree of emotional control, and personal grooming habits, learned from taking care of her.

Then, before my final year started, my Mom sent me to a seminar in which an elderly couple on the spectrum spoke of their own transition from high school to college and onward, and how they had managed to overcome the difficulties in their lives. They said it wasn't healthy to be alone. It was at that moment that I realized, just like that couple had when they were young, that this was not how I wanted to be spending the rest of my life; I did not want to spend the majority of my life with a computer where there were so many amazing opportunities to be had with people, I did not want to remain someone who had such difficulties trying to socialize, I did not want to spend most of my life being interested in just a few things that I could get bored of and not have interest in anything else... and I realized that the sooner I started, the sooner I could improve my life.

I started my attempts to change by trying to sit with people at the cafeteria; In the past, I could not take the noise and stimulation of the cafeteria environment, and preferred to eat outside of the cafeteria...the first step was braving all that noise and commotion, which was very hard, before I could even begin to socialize with others there...every time it felt like I would suffer sensory overload, I reminded myself what I was doing this for, till finally eating in noisy public areas was no longer a problem. The next step for me, now that I could brave the noisy environments without help, was trying to converse and socialize with other people sitting at tables. This was hard at first, not only because I had little experience in doing that, but also since the people sitting together knew each other and had conversed before outside of class, and I was an outsider. This was where I learned conversation with people I did not know before, and trying to let them allow me into their conversation. Knowing what and what not to say and ask helps in trying to get on the good side of new people, but not having much experience with socializing then made me make quite a few mistakes, which happens to typicals just as it happens to people on the spectrum. One of the first things I learned was tact...honesty can be a virtue, but there are plenty of times where you need to watch what you say, or you will either hurt people's feelings, sound creepy and drive others away, or embarrass yourself. Life is not like comics, TV, movies, or anime/manga. In no way does life have some sort of script that you can follow, it's always open to unexpected circumstances. But Roleplaying with family and counselors can still help give you an idea of what might work...the more you practice beforehand, the less embarrassment you encounter later. You have to keep in mind everything you say, from compliments to answers. Also, the way you speak is important...even though making eye

contact is often difficult, it goes a long way to making a good impression. For me, both in high school and middle school, I said plenty of things that drove people away that I did not realize were creepy or rude at the time.

And Facebook, don't even get me started. I have been on Facebook for years, and learned that everything I said or did could have a negative impression on other people, especially in being overeager in trying to interact. Definitely, let me repeat that, definitely, check with friends, family, counselors, on how you should act on Facebook. I've had to learn that the hard way that if you want to keep those FB friends, stay away from politics and religion discussions. Facebook is not where you say what you want to say without thinking it through...that's what Twitter is for.

One other thing that I've finally controlled over the years is having conversations...we often have a lot to say, and want to go into detail....but I have to be able to let others talk, and let it be conversation of back and forth. I've learned that I can say a few things, but I must give the other person the chance to ask questions, and check to see if the person is interested...it was easier to understand people when I started observing their faces and behaviors while I was talking...body language is very important! I try not to look away from someone's face while they are talking! The more you get someone to talk about themselves, they'll appreciate you listening and that will improve your impression with them. Also, when someone asks "how are you?" it's not an invitation for 10 or more seconds of "how are you", they're just giving you a much longer way of saying "Hi There." So basically just say you're fine and you can try to build on that conversation starter.

Another hard part I had in that year of trying to interact with people was the setting for where I tried to talk with people. It may have been a bad time, I may not have known the person very well and trying to set up a conversation just to interact with that person....there are going to be times where there's this person you feel like speaking to, but there's no real good way to go about it. It may be better not to...learning to judge the situation helped me out with not getting rumors spread about me when I went to college. Not knowing any better in high school, I made plenty of mistakes and did plenty of things that would end up making things difficult for me.

The hardest thing for me in high school was making friends that I could hang out with outside of school. Sure, I could interact with people while I was in school, or speak to them in the hallways but that is completely different from people that you can hang out with outside of a required setting. One such opportunity for making friends was on school projects. Since for most of my time at school I isolated myself, my teachers changed the school projects so I would not have to work in a team. But for those who would be willing to work together in school projects, especially ones that require you to work together outside of school, it allows you to build a connection to each other that allows you to try to befriend them outside of the classroom and hang out. Once again, for me, I did not realize the importance of such an idea until I entered college. Thanks to my mother's advice, I worked up the courage to ask several people I knew for their numbers in order to hang around after high school graduation. Although most of them said no, there was one person who I had known throughout my entire time at school who exchanged numbers with me. If I had worked together with other people on school projects, built up some communication between us, that might

have gone differently, and if I could go back in time, I would certainly be willing to work with other people in school projects, because I no longer feel uncomfortable hanging out with others as I did back then. Even though most said no the fact was that I took the chance in spite of the risks and fears of being rejected. What's more, I was introduced to other friends as a result of knowing this friend, the original social networking that is still used even with Facebook around. Thanks to her, I was able to meet and make new friends in places outside of school, and most of them I still speak with to this day. Even though I only left high school knowing one single friend, it was enough to make an enormous impact in changing my life.

College was a new experience for me because I was going out-of-state and going from a school of about 2700 to a university of about 9000. It was a fresh start for me and I could present a "new" me. While I did not know **ANYONE** there, there was an autism support program (CPSAS) that helped me handle life skills, finances and social skills, workplace and interview skills and become more independent. I had a graduate assistant who was a sort of "guide" who would check in with me and be a friend of sorts. There were no special classes and no special dorms, but the support program was critical to my success and without it, my time at college would have gone much differently. In addition to the support program, there was also a college therapist, who helped the students out on many issues. Also, all students in CPSAS got single rooms. That was perfect for me because I had concerns about having a roommate, and was worried about living in the same room with someone else because I could not guarantee the safety of my belongings.

Upon entering college, I still had many issues with my social skills. When I started living in a dormitory I was placed in a suite; I shared a common bathroom and a living room with 3 other guys but we each had our own room. This allowed me to have some degree of interaction, despite it being forced. Actually, this was useful because I still had issues with the desire to socialize, AND it put me in the opportunity to interact with my suitemates at times. Still, other than us living in the same suite, I had nothing in common with these guys, and they didn't really interact with me. I was living with people without really living with people....It was at this point that I realized...I was alone, and it hurt. These suitemates, all typicals, had lives of their own. I could have taken the chance in later years, to get a roommate instead of having a suitemate, but I had such trouble trusting other people with my belongings in the same room, I could not do it. It was this point that I realized that the worst thing that could happen to me for the rest of my life was to be lonely...an empty feeling which caused me constant depression. It spurred me then to try to find clubs and organizations that I could be a part of, anything to get rid of the pain of alone while surrounded by people. One good thing that happened at the dorms was that the dorms had social events that allowed me to interact with people, and as time went by, I felt comfortable enough to open up to several people about my autism, and they helped me with some of my communication problems. There was even a guy there, let's call him Ques, who later in my college years would coach me in interacting with others as well as going to parties and events.

But my first year everything changed for me. In my dorm, there was another guy who did not have many friends, but saw how I wanted to be around others, and took pity on me. This guy, we'll call him Nick, was the guy who was

responsible for me becoming at least half of the man I am today. Of all the things he helped me in changing myself; the greatest was him taking the effort to force me into becoming open-minded into trying to expand my interests in activities and people. The first two years of college, I stayed in my dorms on Saturday night while people went out...Nick convinced me to try out fraternity parties and nightclubs. I eventually found myself enjoying them and started going out to clubs, parties, and fraternities on my own.

During that third year, I still was too eager but socially awkward, and caused people to keep away from me at first, but have managed to greatly improve over time, practice and advice must never end if one is to improve. If you could have seen me during college, the things you wouldn't believe. Make no mistake, at many parties, people will be cruel to those who stand out or seem unsure of themselves; and for me, they certainly were. That's why having friends around is helpful, because to have people who know you in a good way will back you up when there's a problem; more importantly, they can teach you how to better interact with other people and how to use FB as well. But having confidence when going to public places also gives you a level of security when dealing with others. The willingness to try new things carried over into many aspects of my life. Social Skills, hobbies, exercise, dieting....I still refused to do drugs, because there were still limits. But Nick was willing to take the time and effort to finally get me to open my mind to so many things in life...that willingness to try new things and be open to how I can change myself for the better is crucial to my development as a person.

Something that was helpful about Nick being there for me, is that he was able to listen to what other people said about me behind my back. By explaining to me what was being said and how I could change myself, I was able to improve my social skills and behavior to where people's comments about me became positive. The hard part was not letting anyone know that Nick had been listening. I had the desire to ask certain people to inform me when I did wrong...but learning not to speak my mind or confront people about certain issues was one lesson that was difficult, due to my wishing to fix all the problems that I had to deal with. Some of the kindest people we know, are those that are willing to give us constructive criticism, and tell us what we can do to fix our mistakes.

I also began searching for campus groups to become involved with and became involved with the SAPB, which planned activities for students across campus to get to know people, make new friends, and have fun. It was my first organization that I ever truly joined, and it allowed me to make new friends. It was really difficult at first, my autism still gave me social deficit issues, but these people were very understanding of Autism and in overlooking my social difficulties, they helped me overcome them. SAPB became an incredible source of development for me for my third and fourth year of college.

There was another group I took part in that had an effect on my life. But for me to go into detail over that topic, I must start with another one. My university had an event called a Day of Service, where you were expected to take part in volunteer non-profit activities. You would not get any rewards or points for them, but it was expected of you to be involved. I got involved at a church and had fun helping everyone. A woman who ran a program at Marshall

University was there and noticed my interactions and behavior. After talking to me and learning that I was autistic, she got me involved in Marshall University Multicultural Affairs, where I first began to speak about autism.

Marshall University Multicultural Affairs was an organization that gathered different people from unique backgrounds around campus, and had them to speak to different groups around Huntington, WV to help break down stereotypes about them. The group was comprised of an Orthodox Muslim Girl, a foreign Japanese girl, a gay man, and a student whose family has criminal history. The group presented to children, student-teachers, and finally our University's Board of Governors (the people who made decisions for our university); speaking about my difficulties with autism and how I overcame them gave me a sense of purpose, and was yet another step towards self-improvement and development. Another benefit of the autism support program was connecting with nonprofit groups in the city to get me internships. This was big for my future because even though I was Marshall University's first ever Honors Student from the Autism Program, and would even graduate Cum Laude (an academic award), that would mean nothing for my future if I could not work on building social skills, learned how to dress for the workplace and, critically, what not to discuss—religion, politics and sex! My employers worked with the autism program to help teach and guide me through mistakes.

It was in my final year that I moved out of the dorms, and into an apartment complex. My interaction with the other students in the complex was extremely limited, but it was a transition to more independence. I did go out on a few dates. It was difficult just like learning social skills. But even though I made

mistakes on several dates, I still learned from them. Some of the mistakes made included: not asking to pay the whole bill, talking about sensitive issues such as religion and politics and talking too much about myself. Fortunately, even though some of the dates went wrong, the people I asked out never talked negatively about it with other people – that I know of. I've learned that what others say about you in school or campus affects how you will be treated.

Upon graduation from college, everything changed for me. Back in GA, I had to start fresh. I had almost no friends, nobody to interact with, and almost no events which interested me. It was worse than being alone at the dormitories, and this feeling lasted for months. Eventually, someone showed me to social networking site Meetup.com to attend events, and thanks to that, not only was I able to meet people and make friends at last, but I was able to feel like I had a chance at making my life in Atlanta wonderful. In fact, today I even find myself enjoying dating, in addition to being a host for a monthly lunch social for young adults.

Thanks to disability support programs in Atlanta, I was able to interview and get jobs with two places that would give me job experience and skills. I was set me up with a non-profit group I worked as an administrative assistant with from October last year to May. Today, I serve in an internship with an eye towards higher skilled services for the Piedmont Financial Group thanks to my disability support groups.

In the past, I was very introverted, hating this world because I never knew what it was like to experience people accepting me with kindness. I never wanted to get out as a result. It was thanks to my cherished memories with my dog, and

the kindness of others that has allowed me to realize that there are so many good things in the world to enjoy, that there are many good people, and that life, is full of opportunities, if you are willing to embrace it.

So much has happened in my life. There are too many things that happened which could have gone differently. By taking chances, by being open to change, I was able to reach progress with my life that has enabled me to live independently. I am still learning, still developing, but I have come so far, it seems like a miracle. It is my hope that what I have said here today will help all of you in moving forward in life while on the spectrum. Each step you take will help you move forward, and each of you can inspire others to reach great heights along with you.

So I have a few last pieces of advice for everyone here...

Next time at school look at your classmates and how they interact with their friends....for those of you who try to get by on your own....being alone does not help that much, does it? Being alone without anyone to talk to is not just unhealthy it's painfully lonely. Without friends, you have nobody to stick up for you, nobody to express yourself to or talk to when you need help.... I learned that painful lesson well through childhood...that's why I began making the steps to grow right after the couple helped me realize that spending my life without any friends was not how I wanted to do this....it was hard, because I feared change, I feared going into a situation where I didn't know what was going to happen or have control over it...but once I took the first step forward in setting goals for myself and accepting change, I learned to face those fears and grow as a person in so many ways...and you can too...

So ask yourselves, what type of changes in your life are you willing to try reaching so that you can set goals for yourself in order to grow as a person?

Setting goals to reach will be hard, that's life itself for you generally, but once you take that first step forward by trying, the steps after that will all get easier not just for that goal, but other goals as well. Also, you've gained a useful resource to help with your growth when you walked in here tonight....take a look around you...to your right, to your left, behind you, in front of you....what do you see? Actually, who do you see? You should understand now, that you don't have to be alone in struggling to reach your goals. Each of you here came for the same purpose of trying to find a way to grow as a person...why not speak with your peers here to find it? Ways to find solutions, friendships, growth as a person...all can be made by you folks working together....you're not just families with children having developmental disabilities, you're all a community itself, and a community is supposed to help their people. So talk together, work together, build a future for your families together....I went through so many of my struggles with a lack of that community....that's why I know, that if you all go through this as a community, you won't need to go through nearly as many challenges....because together you will have already found a way through them....I've given you my story and the lessons from past to present....now it is your turn to make the decisions from the present to the future, and it starts now...I believe in each and every one of you to have the ability to take those steps...

Good Luck!

So from the children here in the audience to the adults...Come, let's build a future for the state of Georgia; Together. THANK YOU