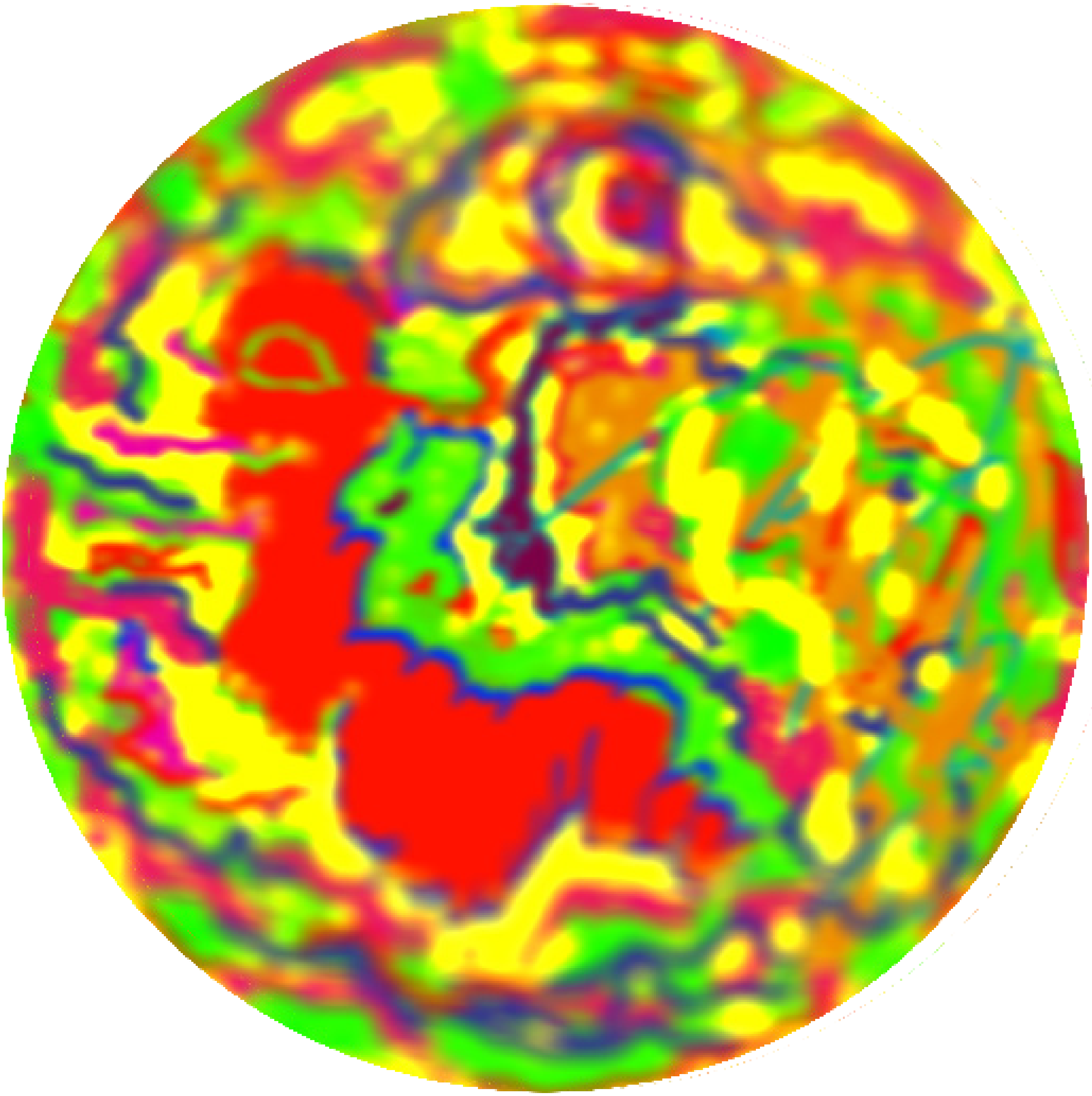
AUTISM'S OWN

Volume 5 - 2018



AUTISM’S OWN

Autism Culture by Authors with Autism

Volume 5 - 2018

EISSN 1929-6177

Autism's Own Journal

Autism's Own is published annually by:

Autism's Own Publishing
University of Victoria, Authors with Autism
PO BOX 3035 STN CSC
Victoria BC V8W3P3
Canada

Autism's Own is a University of Victoria peer-reviewed journal about autism culture authored and edited completely by autistic people. It offers an intimate first-hand depiction of the subjective experiences and thoughts of autistic persons. Autism's Own was founded in 2012 by Joseph Z. Sheppard, a UVic student and author with autism as a compilation of works by members of "Authors with Autism," a UVic peer-support group for students and lifelong learners with autism. Professor, Dr. James Tanaka became a co-founder by suggesting it become a true academic peer-review journal. This vision was later actualized under the guidance of Dr. Catherine Mateer, A-VP Academic of UVic. We are now pleased to warmly present readers with Autism's Own.

Contents:

University of Victoria

One Autistic Person's Blueprint on How to Keep a Job Once You've Found It

By Corey Walker

I entered the workforce in 1995, when I was still in grade 11. For my first job, I worked for a flower shop as a sidewalk clown. My job was to carry a billboard advertising the shop's current specials. Since that time, I have had many jobs, most of them student jobs either during the summer or at UNBC during the school year. My first permanent job came in October 2009, when I worked in the literacy program at the Prince George Native Friendship Centre. I was the Learning Enhancement Instructor, which was a rather fancy title for a simple job. I was responsible for ensuring that the adult literacy tutors had the resources they needed, to tutor their learners. I also scheduled tutoring sessions, and kept records of each learner's progress. I was laid off ten months later, due to funding shortfalls. In December 2012, I was hired by Autism BC as the Northern Regional Coordinator. I have come a long way since I was the clown on the sidewalk. I have learned how to be an effective employee, and although I still have challenges, I am far more successful at navigating the complex maze of the workplace.

If anyone has ever watched an episode of Star Trek or Star Trek: The Next Generation, they will remember how difficult it was for the crew of the USS Enterprise to learn the culture of an alien civilization. This is what the workplace can be like for an adult with autism. There are all sorts of unwritten rules a new employee needs to know about. How do you act? How do you dress? How do you communicate? What kind of work environment works best for you? These are all important questions that many neurotypicals know the answers to, just by instinct. My best friend, who works in retail, can listen to a lunchroom conversation and easily figure out on his own how to jump in and join the conversation and not offend any managers or co-workers. That's not so easy for someone with autism. From my experiences, I have developed a blueprint for finding a job and keeping it, and I am hoping that some of these strategies will also work for others on the Spectrum as well. I will share the things I have learned about myself, my personal toolkit for success, but will acknowledge my own humanity by sharing a few aspects of the workplace that are still challenging to me.

Over the years, I have successfully undertaken many self-discovery missions, which have taught me more about who I am, how I work best, and what I need in the workplace to ensure I have an equal chance of success. I learned I needed time to identify what worked for me and what didn't. I discovered I had the greatest success in a work environment that provided flexible hours, freedom to work at my own pace (if I respect a few important deadlines, such as time sheets, monthly reports and grant applications), and the autonomy to make many of my own decisions regarding my daily tasks. This allowed me to take advantage of my good days and work around the other things going on in my life, such as my community volunteering, medical appointments, and extended family events. Since I could work extra hours some days when I needed to, I had banked hours I could use to take a day off when I was stressed or tired, without losing any pay. This flexibility prevents me from becoming too overwhelmed and from having a mental breakdown on the job.

Those of us with autism like to "call a spade a spade." While most people have a filter to moderate the transition of thoughts from their brain to their mouth, I don't have that. This means that I communicate differently, and sometimes more bluntly than my co-workers. This comes with a three-part responsibility.

- I must communicate this fact to my supervisor and co-workers, so they understand it is part of my disability and so that they can be prepared for this.
- I must ensure that I'm not blunt with clients and the public.
- My supervisor and co-workers need to be understanding and accommodating of me.

Being blunt isn't my only challenge. I tend to take things literally. Again, I need to educate the others I work with about this, so if they receive an unexpected response to any e-mail, memo or phone call, they know it is probably because I misinterpreted what they said or wrote, and they just need to take a few minutes and clarify what they meant, so that we are both on the same page. By taking the time to educate the rest of the team on my unique communication style, I discovered we usually get along quite well with each other and can keep conflicts to a minimum.

I have a strong resistance to change. Surprising me with a new policy, procedure or worst yet, a new boss usually doesn't go over very well, not just for me, but also for the person unfortunate enough to be communicating the surprise information. However, I have developed some strategies that, while not as ideal as no change at all, help me adjust to changes quicker and easier.

- First and foremost, I discovered I needed advanced notice of any impending changes: the more notice, the better. Having plenty of advanced notice allows me enough time to process the change(s), figure out how or if it is going to affect me, and decide how to respond.
- I have also known for many years that I am very much a "reason why" person. I find it extremely helpful to know the reason why things are changing, and why things cannot remain the same. Sometimes, there is a very good and logical reason for changing things. A few years ago, we changed our e-mail and website host from a local Vancouver company to a larger company. Our original service provider was nearly impossible to reach, even during business hours, and the new host allowed somebody at head office to serve as site administrator. This was an easy change. However, we changed e-mail and website hosts again this spring, and with it, came a whole new webmail interface that I still find confusing and complicated. I could see no reason for this change, and am still frustrated by it three months later.
- Furthermore, I found it helpful to be a part of the decision-making process. During a recent visit to our head office, I was invited to sit on a conference call with Telus about a new call management system that head office already had, and that they were looking to implement in the regions in the future. I was able to see firsthand the cool features of the software, and quickly realized the advantages this would have both for staff and for clients. Should the organization decide to roll it out to the regional offices in the future, I will likely support the change. However, had I not been part of the process reviewing the system and seeing first hand its cool features, I would have probably fiercely resisted any efforts to implement the system in Prince George. I think this experience really opened the eyes of our head office staff about the importance of having me "buy in" to the change beforehand, and confirmed something I already knew about myself.

Image credit: Kit Out My Office, Creative Commons 4.0. Retrieved from Wikimedia Commons.

During my years of employment, I have learned a few other important things about myself as well. I learned that I have an easier time talking to non-co-workers about workplace frustrations, as they are more objective. If they agree my frustrations are justified, I have reassurance that I am not just being unreasonable or stubborn, especially when it comes to an impending change. However, if they do not understand why I am frustrated over what they see as something small, then it gives me reason to pause and think longer and harder about my response and whether I really am just "sweating the small stuff." My best friend, who works in a retail management position, is quite good at telling me if I am overreacting or not, and I frequently consult him for his opinion for this reason, even though I may not like what he has to say because I hate admitting I am wrong. But then, who does like being wrong?

Finally, I learned that I need a distraction-free work environment if I am to be productive and successful. I used to work from home, and for some people, this is the perfect work environment. For me, however, I found there were too many distractions. I love watching TV, and having a TV next to my office was a bad idea, as was having my living room couch. Additionally, the fifty-nine square foot cubby hole in my apartment that I used for an office was too small for me to effectively organize. Thankfully, the Society elected a new President, who was totally on board with me renting a small office in town. Since that time, I have raised my profile in the community, and increased my productivity. By taking the time to engage in self-discovery, I was able to learn more about myself and how I work, and become a better employee as a result.

During my twenty plus years of employment, I have developed my own personal toolkit for success. While not all these tools will work for everybody, I find they work for me. The first tool I learned is to try and create a professional atmosphere, so that I feel like I am at work and so that others take me seriously.

- The first way I do this is through my dress. Even when I worked at home, I dressed business casual most of the time. Business casual is a step down from formal business wear, so there is no need for a suit or even a tie. I wear dress pants or khakis and some type of shirt with a collar. I usually prefer a semi-dress button up shirt or a nice golf or polo shirt, but I sometimes wear a dress shirt as well. The only time I usually wear a sport jacket and a tie is when I'm doing a presentation at a conference, and even then, I'm usually over dressed for the occasion. By wearing business clothes, I remind myself that I am a working professional and it helps me focus on work and act professionally. This is why I dressed up even when working from home.

- The second way I create an atmosphere of professionalism is that I try to keep my office neat and organized. When you're trying to do a full-time job with part-time hours and there's lots of papers in your office, this can be a real challenge at times. This was one reason I pushed for a proper office because my home office was too small to properly organize. My office does get rather messy at times, but then I will come in on a day off for a little while when I can ignore my phone and e-mail, and I spend an hour or so tidying and cleaning. When I see somebody with a well-organized office, I look around for ideas of how I can better organize mine. There is no. I need for me to reinvent the wheel. If somebody else has found a great way of organizing their office, I think it makes sense for me to try that in mine. While I never received drop in clients at my home office, I do welcome them in my downtown office. Having a clean place for them to sit and chat with me and having a somewhat professional appearance ensures they take me seriously and it reflects positively on my employer. When you make your employer look good, you make them happy and when they are happy, they want to keep you around and look after you.

One of the challenges with my job is that while it is not as fast paced as, say, McDonald's, I often do have a wide variety of tasks on the go, and if I wish to continue being a successful employee, I need to do my best to keep track of what I have "on my plate." I do this in a few ways.

- I have used Google Calendar for many years to keep track of personal events, such as medical appointments, board meetings and so on. However, since I started my current job in December 2012, I have used my Google Calendar to keep track of work appointments as well, including meetings, support group sessions, and conferences. I found that having all my appointments in one central location, accessible from any computer with internet access, was a big help.
- Another thing I try to do is to identify key tasks I need to work on or complete the next day. I usually try to do this shortly before going to bed.
- I also use a custom daybook template, one that I created back in grade 12 because I found the commercially produced day planners did not have enough room for me to write down all the details I want to record for my work days. I had not used this template in years, but I was really organized in grade 12, so I decided to revive it. Using my custom daybook helps me to structure my work day into chunks of time, so I know what I need to do during each part of the day. Otherwise, I find the end of my work day comes fast and I have accomplished very little. It is taking me awhile to get back in the habit of using it every day, but I find using it again is like having an old friend come back after being gone for many years.

My second last tool is the importance of taking periodic breaks. Luckily for me, my office is right above an amazing bookstore, so when I need a break, I will wander down to the bookstore and browse the shelves and even read pages from some books that I hope to eventually purchase. Since I am also ADHD, taking a few short breaks each day allows me a chance to let my mind wander freely, instead of trying hard to stay focused and attentive to my tasks. My brain gets exhausted trying so hard to concentrate, so taking a few short breaks each day allows my brain to relax a bit, and refreshes my energy levels so when I go back up to the office, I am ready to tackle the next task.

My other important tools are about honesty and self-advocacy. I admitted earlier that I can sometimes be too blunt, but at the same time, I do try to be honest about what my needs are and how I am feeling. William Shakespeare (1993, 3.5.12) once wrote: "No legacy is so rich as honesty," and I feel that no truer words were ever spoken. Being honest with others on the team, and encouraging them to be the same with me, creates an atmosphere of trust and respect. I feel that nothing contributes more to my success than having people trust and respect me. Part of my honest means I also advocate for myself and stand up for what I need. While my self-advocacy at work does not always change things the way I would like, in many cases it has, or at least has prompted my boss to communicate more with me about what is going on, and ensured my feelings are considered in any decisions being made. This often results in a work environment that is more comfortable for me, and when I am happy with life and with my job, I work harder, and both my employer and I benefit from that.

I have talked about my journey of self-discovery and my personal toolkit for success. However, I do not want to leave my reader thinking that life is all perfect and rosy because that is not a true picture. However, I am happy with my job and life most of the time. Of course, there are the usual things we all wish for: I would love to make more money, so I could buy a house and a car. I would love to have a girlfriend too, but I am not sure my boss can do anything about that. While I do consider myself successful in my job, I still face some challenges. After all, I am human, and being a human is kind of like pushing a rock up a hill. Sooner or later, the rock is going to roll back down the hill and you have start all over again.

My final tool deals with having a neurotypical supervisor and neurotypical coworkers. Everybody on the team knows about autism, but we look at the world through different coloured lenses. You could say that bridging the gap between us is like trying to get a Mac and a PC to talk to each other; each system acts and thinks differently. If I could walk "in my co-worker's shoes" and them in mine, we would probably understand each other perfectly. Since that is easier said than done, I find taking the time to explain how I see a problem, or even a solution, and why, helps them understand me better. My co-workers return the favour by talking the time to explain their perspectives to me.

Recently, a co-worker wanted me to join in a phone meeting for forty-five minutes, to talk about our fall raffle. I felt fifteen minutes was more than enough time. My co-worker sent me the agenda for the call, so I could see what she wanted to discuss. I quickly realized there was more for me to know about the raffle than I originally thought. Once I realized that, I happily agreed to a forty-five-minute meeting. My co-worker now knows to explain the reason for her request, and I learned to ask for the reason. We get along quite well now.

I developed all the tools I described here over the course of time, and through trial and error. Some days, my toolkit is very effective, and some days I lose my head and forget to use my tools. While I hope that others can learn from my experiences, these tools are just one autistic person's blueprint to keeping a job. They might not work the same for everybody else, but hopefully, it will encourage other autistic employees to develop their own personal toolkit, customized for their specific needs. Remember that my toolkit is always changing, as I grow and learn as a person and employee. Do not be afraid to swap out an ineffective tool for an effective one. Doing so is a sign of strength.

Reference

Shakespeare, W. (1993). All's well that ends well. Retrieved from http://shakespeare.mit.edu/allswell/index.html

Seeing Myself as Others See Me - Living with Undiagnosed Autism in the Workplace

By Anthony Gurr

When I turned 50 years old in May, 2010, some very close friends invited me to dinner at their home in Vancouver. We'd known each other for over 30 years. We talked about children, the state of our lives, and shared the latest news from distant friends scattered across the world. One of them was a Canadian diplomat living in London, England. Another was an international investment banker in Paris, France. One close acquaintance had just been appointed as Speaker of a Canadian provincial legislature. My friends in Vancouver were accomplished lawyers and senior managers for provincial crown corporations.

Meanwhile, I was working as a sales specialist at a newly-opened retail Apple Store in Vancouver. Like my friends, I was well-educated, well-travelled, and had ten years of international experience working for videogame companies in Japan and the United States. Yet, here I was, employed at a large shopping mall, earning $16.00 an hour, and renting a one-bedroom apartment.

At that time, I knew very little about autism. However, I always felt there was something different about me compared to everyone else. I believed that I perceived the world differently. Ifelt like a social misfit. How else could I explain the lack of career and social success compared to my friends?

In September, 2015, I was officially diagnosed with autism. For decades, my family suspected that I was autistic. As a child, I couldn't hold eye contact. I had no manual dexterity in my right arm. I invented my own language and couldn't communicate in complete English sentences until I was four years old. I was extremely sensitive to loud noises, and lacked empathy towards other children. My social skills in elementary school were poor, and I was brutally harassed in junior secondary school because I was perceived as being different. During the 1960s and 1970s, there were no methods of assessment, support, or trained medical professionals available to deal with autism in British Columbia. Federal and provincial funding was non-existent. My family and relatives did the best they could to help me cope with my situation.

As a 57 year old man, there are times when my autism feels like a decidedly mixed blessing. Receiving an official diagnosis validated my life-long feelings of being a misfit who perceives the world differently from other people. It was a relief to know that I wasn't imagining things; I can look back on my life and see how autism affected me. But there's one significant downside to possessing this knowledge – I can't go back in time and change how it impacted the past 35 years of my working life. Thinking about it brings back painful memories. Younger generations diagnosed with autism today in the 21st century not only have access to better funding, support services, and trained professionals, they have the advantage of time on their side. I must grapple with the fact that not only do I have fewer years left to live a productive life – I'm still on my own when it comes to finding the support I need. There is no government funding currently available to help high-functioning autistic older adults in the province of British Columbia.

There are specific aspects of my autism that are problematic in a regular work environment. My inability to consistently hold eye contact gives the wrong impression that I'm distracted and not paying attention. For example, five minutes into a job interview, a potential employer asked me why I wouldn't look at him directly. I tried to explain that I was slightly nervous. The truth is that I often lose eye contact when discussing a subject I'm enthusiastic about. I also have a tendency to become animated. In another situation, I was working with a university professor who noticed that I tended to look up and away during our discussion. She said that I was a person who visualized what I was talking about. It was an astute observation on her part. I have a vivid imagination that lets me describe original concepts and ideas with great clarity and detail.

One of my biggest challenges is that I can't read non-verbal emotional cues on people's faces. I don't work well in institutional settings like a corporate head office or a university department. Even when collaborating with a team, my inability to read someone's facial emotions can create problems, such as taking a comment too literally, or accidentally saying something that's socially inappropriate. Another side-effect is that I have poor awareness of the social dynamics that are happening around me. It's ironic because I'm visually hyper-sensitive. I can become overwhelmed by too much visual stimulation, such as trying to read large amounts of text information displayed simultaneously on multiple computer screens. However, this hyper-sensitivity also gives me the ability to focus my attention on something in greater detail, such as a computer-generated animation, a photographic image, or individual flowers in a garden. But I can't read the emotions on people's faces, a critical skill for day-to-day social interactions.

Like many high-functioning adults with autism, I'm extremely intelligent and able to think very quickly. This natural ability lends itself well to activities that involve researching, organizing, and presenting both visual and written information. However, I've had life-long issues with retaining things when they're communicated verbally. During childhood, my mother discovered that I remembered a list of tasks more effectively when I wrote it down. Looking back at my work experiences, there were times when the inability to retain verbal information, combined with a quick mind, created significant problems. During one performance review, a manager provided me with several examples of important tasks that were incorrectly completed because I didn't follow his verbal instructions. In retrospect, I should have written down what he said, but we were on a tight deadline. Now that I'm aware of how autism affects my ability to retain verbal information, I frequently write things down using an iPad or a pen and notebook. I also focus my listening skills more carefully when someone is speaking to me.

In 1786, the Scottish poet Robert Burns wrote a famous poem called Ode to a Louse – On Seeing One On a Lady's Bonnet, At Church. This verse describes how I feel about having autism:

O would some Power the gift to give us,
To see ourselves as others see us!
It would from many a blunder free us,
And foolish notion.

There are moments when I wish I could go back in time and change the outcomes of events that happened in my life because I didn't know I had autism. But that's not possible – I can only keep moving forward. Now that I'm aware, the challenge is to find opportunities in the years ahead that let me use my life experience and talents. I also believe it's vitally important to be open about being an older adult with autism, and raise public awareness about the need for more funding and support services. There are younger generations coming up behind me; the least I can do is help to blaze the trail.

Reference

Burns, R. (2004). To a louse, on seeing one on a lady's bonnet at church. Robert Burns World Federation. Retrieved from http://www.cobbler.plus.com/wbc/poems/translations/552.htm (Original work published 1786)

Anthony Gurr is an educational technology specialist with a Masters' degree in Education from Simon Fraser University.

Jahn, J. J. Q. (1785). Portrait of a Lady with a Bonnet.

Transition to Adultood, Employment, and Post-Secondary Study

By Patrick Dwyer

The community of autistic adults is in a state of crisis.

Right now, employment outcomes for young adults on the autism spectrum may be even worse than outcomes for young adults with other disabilities, including young adults with learning and intellectual disabilities (Roux et al., 2013). Exact figures are hard to come by, but as few as a quarter of autistic adults may have jobs (Dudley et al., 2015). Some research is slightly more optimistic, but it does still appear as though only a quarter of cognitively-able autistic people will be able to consistently sustain participation in employment or postsecondary studies, with many others alternating between engagement and long periods of unemployment. Furthermore, fully a third of these cognitively-able adults may never have a job and may never attend a postsecondary educational institution (Taylor, Henninger, & Mailick, 2015).

Even if autistic adults are successful in finding jobs, research suggests that many have a precarious form of employment: jobs characterized by low wages, limited hours, and little guarantee that the job will last (Dudley et al., 2015; Roux et al., 2013).

My own observations in my community of autistic adults, subjective and anecdotal as they may be, are consistent with the research. I know some people who have jobs, but most have precarious jobs. I know autistic college and university students, but I also know some who dropped out of post-secondary due to the shock of transition. I also know some autistic people who are unemployed and living in their parents' homes.

The real solution to addressing this crisis is clear. Many autistic people have the potential to be excellent employees, and we know that employment services for autistic adults can be highly effective (Wehman et al., 2016, 2017). Job outcomes would improve if these employment services were provided more widely. Similarly, we could achieve greater employment success if employers were educated about autism, and indeed, incentivized to hire autistic people. Job outcomes would also improve if employers could be persuaded to place less emphasis on job interviews and social demands.

Implementing these changes is only rational, because supporting unemployed individuals imposes substantial costs on governments and families (Buescher et al., 2014). Such costs might take the form of lost taxes and productivity, added disability benefits, added residential supports, and more. Thus, the cost of providing employment services can be offset by long-term savings in other areas (Howlin, Alcock, & Burkin, 2005).

Unfortunately, for many young autistic people, these points are irrelevant. Right now, employers do use job interviews, and they do place considerable emphasis on the traditional social cohesion of the workplace. Right now, most employers know relatively little about autism, and little has been done to give employers incentives to hire autistic people. Employment services are nonexistent or, at best, inadequate.

Until we can change our society and our institutions to support the transition of young autistic people into adulthood, we must consider how, with only the resources available to themselves and their families, young autistic people facing an imminent transition to adulthood can effectively adapt to the impending changes in their world.

I'm an autistic adult with an interest in autism research, and I have decided to write some suggestions and strategies for transitioning individuals and their families, based on my experiences as well as my reading of the scholarly literature. I don't pretend to have all the answers, or that my suggestions will necessarily apply to everyone. I'm also conscious of the fact that my adult life is ongoing and incomplete. However, I hope that some may find the suggestions contained in this article useful.

Job Experience

Perhaps the most crucial piece of advice that I can offer to young people on the autism spectrum is that early engagement in employment should be a top priority. I know that individuals and families have many competing demands on their time, but studies show that one of the most important predictors of adult employment outcomes for young people with autism and other developmental disabilities is whether they held a paid job in high school (Carter, Austin, and Trainor, 2012).

This finding is far from being surprising. Not only does job experience look good on one's resume, which increases the chance that one will be hired in the future, but it allows us to gain familiarity with the expectations of the workplace environment and with the job search process itself. This familiarity makes us more comfortable and helps us develop strategies to succeed in the workplace, in job applications, and in interviews. It is no surprise that older autistic individuals have better employment outcomes after receiving fewer employment services than their younger counterparts (see Chen, Sung, & Pi, 2015): presumably, through many painstaking years in precarious employment situations, the older individuals have spent more time becoming accustomed to the demands of adulthood and employment.

Of course, one can always object that an association between past job experience and future employment success is not necessarily causal: indeed, we might imagine that the people who successfully obtain job experience in high school do so because they are already better at navigating the world of employment and because they then carry that skill with them into adulthood.

However, some studies have actually manipulated the variable of employment status. Wehman and colleagues (2017) randomly assigned autistic high school students to either a control condition or an intervention condition. Those in the intervention condition benefited from training in job skills, and, crucially, from a supported internship that gave them job experience and job search experience. Twelve months later, 87% of those students from the intervention condition had gone on to find jobs in the community, compared to just 11% of controls. Because the students were assigned randomly, we can assume that the two groups were essentially equivalent to begin with, meaning that the intervention must have caused this enormous difference between the groups. The enormous size of the effect in the study only further emphasizes the importance of employment experience.

A high school student's first job experience does not need to be particularly demanding or competitive. My first job was in my father's law office, where I filed documents. However, I still gained the experience of interviewing for a job and experience navigating the social and task-related demands of a workplace. This successful experience was invaluable to me when I was seeking work-study or summer jobs during my undergraduate studies. I could also list my job experience on job applications and resumes; if I did not have job experience, I would have been at a substantial disadvantage even on paper.

Of course, not every young autistic person can find a job in a parent's workplace, nor would such experiences be particularly useful unless the culture of the parent's workplace was similar to other workplaces. However, while young autistic people remain in high school, they may still have access to autism funding that could be used to pay for employment support services. I would encourage young autistic people, and their families, to prioritize employment experience in high school as an essential precursor to the adult transition.

Post-Secondary Studies

Many young autistic people may aspire to obtain a post-secondary degree. Such a credential is, of course, invaluable in many professional fields today. Furthermore, some autistic people (including myself) may delight in learning and view post-secondary studies as a way of furthering their academic and focused interests.

However, post-secondary studies are also challenging. University students are expected to manage their own schedules, studying for exams and completing assignments without prompts or reminders. Autistic people may already have difficulty with executive function (Ozonoff, Pennington, & Rogers, 1991), which could manifest in problems with planning and time management at the post-secondary level. Furthermore, in high school, students – and, perhaps unfortunately, particularly students receiving support from special education assistants – receive much more explicit instructions about when to complete tasks. Because autistic people are more likely to receive support from special education assistants, as well as teachers, they may become dependent on others to organize their time for them.

I was able to avoid most difficulties with time-management at the post-secondary level because I had a very different experience during high school. Instead of receiving very explicit directions about when to do tasks, I had to develop much more independent time-management skills than I ever used in my undergraduate studies. Beginning in Grade 8, I was a student in a distance or distributed education program, which is essentially a form of homeschooling (something which was made necessary by my sensory sensitivities at the time, along with other issues in the mainstream school setting).

In my distance education program, I received a package of curriculum materials every year and was essentially free to structure my time as I pleased, as long as I was finished by the end of the year. I freely admit that my teenage self was not always the most effective time manager – I always had a last-minute rush to finish everything in May and June, and occasionally still had work left over to complete during the summer – but by the time I started attending university, I was used to planning my time over a period of months and years. Remembering to start studying for the test in two weeks' time was relatively easy in comparison!

Of course, I understand that giving high school students such broad discretion in their time management may not be possible or desirable in the mainstream school setting, but I strongly encourage autistic teens, and their families, to work hard on building organizational skills. Learn to complete homework without prompts. Learn to use calendars and schedules to manage assignments. Try to work with the school-based team to fade away prompts and supports as much as possible, leaving students to plan their work independently – and allow them to experience failure, if they must.

I have other advice for students considering college or university studies. I would advise people to consider attending a local institution before considering an institution out of town – if one lives in a community where such a school exists. Attending a local institution would allow students to focus on the academic demands of post-secondary studies first, without worrying about living independently. One can always transfer to a different institution later if necessary.

That is, effectively, the approach which I took. I'm fortunate enough to have grown up in Victoria, British Columbia, which hosts the University of Victoria (UVic). UVic has an excellent psychology program, so I was able to obtain my B.A. in Psychology without leaving town. I didn't have to worry about living independently until I started my graduate studies at UC Davis in California, and the impact of the transition to independent living was easier at that point because I already had experience working in a university environment and working in a psychology lab environment.

Another advantage of attending a local institution is that it allows one to become familiar with the physical layout of the campus, and even to audit courses before one officially starts attending classes as a student. This familiarity can be a big comfort to autistic people, and I was grateful for the opportunity to become familiar with UVic before my undergraduate studies began.

If one doesn't live in a community with an appropriate post-secondary institution, consider doing research and attending an institution that has supports for autistic people. In Canada, York University and Simon Fraser University both have peer-mentorship programs for students on the autism spectrum. In the United States, there are many more programs. You can find information about them on various websites, such as the ones maintained by the College Autism Network or College Autism Spectrum. Be careful, because some are expensive or will require an application!

I think it is also important to register with the campus disability office in advance. Whether or not students end up requiring academic accommodations, bureaucracies can take time to move, and suddenly trying to register with the disability office in the middle of an academic semester is unlikely to result in the immediate provision of support. Students may need additional documentation to register for disability supports, which can take a great deal of time and money to obtain!

One final piece of advice concerns a specific accommodation that may be offered to students: the opportunity to take a reduced course load while still being considered a full-time student for funding purposes. I decided to take only two classes during my first semester at UVic, in order to give me plenty of time to adjust to the demands of the university environment, and I don't regret that decision. I did end up increasing my course load in subsequent semesters, but during a transition to an unfamiliar environment with unfamiliar expectations, I think it is important to start slowly and not overload oneself.

Mental Health

Increasingly, we are becoming aware that autistic individuals may struggle with anxiety and depression (Johnson & Iarocci, 2017; Simonoff et al., 2008). The relationship between autism and these co-occurring mental health problems is perhaps unsurprising, as autistic people can have many stressful experiences that naturally lead to mental health difficulties (Wood & Gadow, 2010) – experiences such as unemployment, academic failure, interpersonal isolation, interpersonal victimization, or repeated exposure to sources of sensory distress, to give just a few examples. Furthermore, prior mental health challenges are likely to only result in more stressful experiences. Thus, a vicious cycle can quickly develop, wherein stressful experiences and mental health challenges mutually reinforce one another. And unfortunately, if autistic people do become increasingly anxious and depressed during childhood, it is likely that they will have more difficulty transitioning to adulthood.

Fortunately, poor mental health is not a core part of autism, and it is possible to promote good mental health in autistic individuals. Ideally, environmental modifications can be used to reduce or eliminate unnecessary stressful experiences – such as sensory or interpersonal stresses. Such modifications have the potential to remove the source of mental health problems. Finding K-12 school environments that work for the autistic person is crucial.

Alternatively, if a change of environment is impossible, specific programs may have positive effects on mental health. Evidence suggests that cognitive-behaviour therapy may be helpful (Weston, Hodgekins, & Langdon, 2016). I participated in a theatre program for many years, and I am firmly convinced that drama and theatre can be an effective intervention for anxiety.

Grit and Tenacity

Our society has overwhelming expectations of autistic people. We often undergo countless hours of intervention, even while completing all the work of a typically-developing high school student. Throughout this, we are expected to cope with social rejection, scorn, and listening to others speak of curing us – listening to others who openly admit to rejecting us as we are, and who demand that we be otherwise. In adulthood, given that we lack the social skills demanded by our society, we often have to work harder than others who have achieved the same level of occupational success and distinction. Many of us have to prove our value based on our work performance – even while coping with other demands and with our autism-related impairments.

Winner (2011) emphasizes the importance of grit, persistence, and motivation for autistic people. She notes that people on the autism spectrum may be overwhelmed by the demands placed upon them and may lose motivation as a result. But such a loss of motivation, just like poor mental health (to which it can, of course, often be related), will only hurt the individual in the long run.

Grit and tenacity – the ability to motivate oneself to work hard, to overcome challenges, to reach success against the odds – is a must for autistic adults. And belief in one's own abilities is a crucial prerequisite for grit; belief that one will fail is a self-fulfilling prophecy.

Sadly, we don't prepare many autistic adults well for the demands of succeeding in a world stacked against us. Earlier in the article, I raised the concern that many young autistic people become dependent on others to structure and schedule their time. I think that this problem of dependence can be even more general: as long as young autists are surrounded by supports, buttresses, and scaffolds, they'll start to rely on those supports. And worse, these young people may see others taking over their work, and they may start to lose confidence in their own abilities. Thus, even though autistic people may need to work harder than their peers in adulthood, they're in many ways less prepared for this work, and they may even expect to fail.

I know that it's difficult, with all the demands we already put on autistic high school students, but I think it's important that people spend time before adulthood learning to become more independent, and learning to motivate themselves, even if that independence occasionally means experiencing minor failures.

To clarify, I'm certainly not opposed to childhood services or interventions – these are often absolutely necessary! It would also be wonderful if autistic adults could all benefit from reliable and useful services, but in today's world, we can't make the assumption that such services will be available. Therefore, even as we strive to provide young autistic adults with supports that may be necessary to their success, we must take care that we do not teach these young adults to become unnecessarily dependent on supports that will vanish. It's a delicate but crucial balance.

Furthermore, I think it's vital to show autistic youth our confidence that they will succeed. We must attempt to turn the self-fulfilling prophecy of failure into a self-fulfilling prophecy of success.

A Note on Older Adults

I've focused this article on young adults and teens facing an impending transition, but it's also important not to lose sight of the fact that there are many older autistic adults, even if they may not be diagnosed. A recent cross-temporal analysis suggests that, despite the increasing rate of autism diagnoses, the actual level of autism symptoms in the population has been quite stable over time (Lundström et al., 2015). These results suggest that many older autistic adults – presumably, indeed, a majority of the total population of autistic people – are undiagnosed.

As I noted earlier in this article, older autistic adults can expect to benefit at least as much from employment supports as their younger peers. Indeed, when Chen, Sung, and Pi (2015) examined employment outcomes in youth, young adults, and older adults receiving vocational rehabilitation services in the United States, they found that the youth obtained worse employment outcomes than the adults, despite receiving significantly more support. Presumably, age gives autistic individuals increased working experience. Even if that experience is of precarious, inadequate employment, it could still, however gradually, begin to give autistic adults the skills, familiarity, and comfort to become more successful. Given the potential of these older adults, it is tragic to see that meaningful supports for older autistic individuals are almost nonexistent.

Conclusion

The transition to adulthood is perhaps the greatest challenge that young autistic adults will experience in their lives, and unfortunately, it happens to coincide i with the removal of most of the supports to which many become accustomed during childhood. However, there are ways that we can set ourselves up for a successful transition to adulthood, and ways that their families can support this process. My adult life is far from over, but through early preparation and a certain amount of hard work, I've been relatively successful so far. In the article, I've attempted to draw on my experiences and some of the research in this field to give the best advice I can to young autistic people preparing to undergo transition themselves.

Ultimately, though, we also need to advocate for greater attention to adult issues in autism. According to a review of articles published in the field's largest journals, less than four percent of research studies on autism interventions include participants over the age of twenty (Edwards et al., 2012). This review parallels the reality in communities, where adult services are limited, disaggregated, and challenging to locate and access. Furthermore, public awareness of the challenges faced by autistic adults is low, which limits the degree to which autistic adults can expect understanding and support from others.

Fortunately, some of the steps which can be taken to address the crisis of transition to adulthood in autism are clear. A panel organized by the United States Government Accountability Office reminds us that autistic adults require, to support their transition into adulthood, well-coordinated and individualized supports across a wide variety of different domains (Government Accountability Office, 2016). The panel also emphasizes that autistic individuals should not have sole responsibility for their own inclusion in society; instead, society has a critical responsibility to include autistic people. These are the messages which we must work to spread.

References

Buescher, A. V. S., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA Pediatrics, 168(8), 721-728.

Carter, E. W., Austin, D., & Trainor, A. A. (2012). Predictors of postschool employment outcomes for young adults with severe disabilities. Journal of Disability Policy Studies, 23(1), 50-63.

Chen, J. L., Sung, C., Pi, S. (2015). Vocational rehabilitation service patterns and outcomes for individuals with autism of different ages. Journal of Autism and Developmental Disorders, 45(9), 3015-3029.

College Autism Network. (n.d.) Institutional initiatives: Find a program that fits. Retrieved from https://collegeautismnetwork.org/institutional-initiatives

College Autism Spectrum. (n.d.) Programs for students with Asperger syndrome. Retrieved from http://collegeautismspectrum.com/collegeprograms.html

Dudley, C., Nicholas, D. B., & Zwicker, J. D. (2015). What do we know about improving employment outcomes for individuals with autism spectrum disorder? University of Calgary School of Public Policy Research Papers, 8: 32, 1-35.

Edwards, T. L., Watkins, E. E., Lotfizadeh, A. D., & Poling, A. (2012). Intervention research to benefit people with autism: How old are the participants? Autism Spectrum Disorders, 6(3), 996-999.

Government Accountability Office. (2016). Youth with autism: Roundtable views of services needed during the transition to adulthood (GAO-17-109).

Howlin, P., Alcock, J., & Burkin, C. (2005). An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. Autism, 9(5), 533-549.

Johnson, K. H. S., & Iarocci, G. (2017). Are generalized anxiety and depression symptoms associated with social competence in children with and without autism spectrum disorder? Journal of Autism and Developmental Disorders. Advance online publication.

Lundström, S., Reichenberg, A., Anckarsäter, H., Liechtenstein, P., & Gillberg, C. (2015). Autism phenotype versus registered diagnosis in Swedish children: Prevalence trends over 10 years in general population samples. BMJ, 2015; 350:h1961.

Ozonoff, S., Pennington, B. F., & Rogers, S. J. (1991). Executive function deficits in high-functioning autistic individuals: Relationship to Theory of Mind. Journal of Child Psychology and Psychiatry, 32(7), 1081-1105.

Roux, A. M., Shattuck, P. T., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. Journal of the American Academy of Child and Adolescent Psychiatry, 52(9), 931-939.

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. Journal of the American Academy of Child and Adolescent Psychiatry, 47(8), 921-929.

Taylor, J. L., Henninger, N. A., & Mailick, M. R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. Autism, 19(7), 785–793. https://doi.org/10.1177/1362361315585643

Wehman, P., Brooke, V., Brooke, A. M., Ham, W., Schall, C., McDonough, J., … Avellone, L. (2016). Employment for adults with autism spectrum disorders: A retrospective review of a customized employment approach. Research in Developmental Disabilities, 53-54, 61-72.

Wehman, P., Schall, C. M., McDonough, J., Graham, C., Brooke, V., Riehle, J. E., … Avellone, L. (2017). Effects of an employer-based intervention on employment outcomes for youth with significant support needs due to autism. Autism, 21(3), 276-290.

Weston, L., Hodgekins, J., & Langdon, P. E. (2016). Effectiveness of cognitive behavioural therapy with people who have autism spectrum disorders: A systematic review and meta-analysis. Clinical Psychology Review, 49, 41-54.

Winner, M. G. (2011). Organizing strategies to prepare for homework and the real world: An interdisciplinary treatment approach. Presentation at ACT – Autism Community Training workshop, Victoria, BC.

Wood, J. J., & Gadow, K. D. (2010). Exploring the nature and function of anxiety in youth with autism spectrum disorders. Clinical Psychology: Science and Practice, 17(4), 281-292.

MEDITATION

by Maria Iliou

Focusing on power of energy
Emotions of recollection arrises
Thoughts were scatter

Deeply absorbing
Ebullience power
Depth of aptitude
Within me

Breathing …penetrating
My heart of soul, beyond
Embracing my wisdom

Willingly in theory, with
Your energy power…too
Power of word
In corner of
My mind

Repute fainting screams
Echoing through sounds
In distances
Repetitively…playing

Sounds emerging,
Phraseology…can't express
Off unknown
Occurrences of memories
Allocating stories
Optimistic…slowly
Unwinding…unwrapping

Secluded Greek Island
Maria Iliou

AUTUMN LAKE
Maria Iliou

SONG OF MYSELF

by Maria Iliou

I lost my self …paddle boat off the shore
Logical, physical and emotional endurance
Extremely abstract to my body… no one is listening
Hiding …storing in files within my brain

Silence that quiets the mind… deep in to my core
Buried underneath…sadness only remains
Periodically, story receptive in certain situations
Repeats itself in various forms..same principle
Adults think; secretly, you know these things of your age
Without being taught
how to manage instead of fear

While being in the moment of conversation
Our words melt away
Shy giggles
Not to be misunderstood…Sharing,
Sensing the mood changes
Without an understanding
Anxieties creep in
Losing my power, which is
Song of myself

To the power of the word

UNCONDITIONAL LOVE

by Maria Iliou

Wisdom emerging, your
Soul…his soul
Entwines, his
Heart of emotions
Unconditional love
For you
Connecting
Passion of kiss

He hugging you
In a whisper
Communicating his
Feelings of
Spoken words

I love you

Unwrapping package
Slowly …intuitively
Echoes soars though
Ear…hearing
Verbal plans, of
Life situation
Learning entire
Lessons with

God eternally love

Greek Inlet
Maria Iliou

VOICE OF WISDOM

by Maria Iliou

My intuitions is
Voice of wisdom
Naturally infinite
Pure love is my
Goal, my learning
In strive teaching
Step by step
Becomes
Easier ever day

Holding hands
Embracing
Our love, as
Mother and daughter
Journey…experiences

Routines of programs
Incorporating
Structure of support

My soul
Our souls
Deeply connecting
In balance
Strong and
Grounded in
Our roots

MIRRORING
Maria Iliou

Day 10,000: The Humans Still Have Not Noticed Me

By Morgan Jones

I am now (supposedly) 10,000 days old and the humans still have not seen me for what I am: an alien.

I was very lucky this species has such varied behavior in their young, otherwise I would have been picked out right away. They merely thought I had "behavioral problems" and wrote me off as a "special case," which is the label they give to anyone they don't know how to deal with.

In my childhood I had no clue as to what was going on, no way to express myself properly, no idea that I should be trying to hide my differences and adapt. Looking back, I can see the signs of the truth I have come to realize. There were others like me: obviously hybrids but not to a uniform degree. The humans had even unknowingly given us hybrids a name: Autistic.

One would think this is a handy way of identifying my kin, but that's not always the case.

I guess the blending of two different species' DNA was less of an imprecise art and more of a roll of the dice. This conclusion was reinforced when I saw how wide the range was. The term "autistic" applies to such a broad spectrum that it can be sometimes difficult to tell if those classified as such are truly one of us.

Some are completely nonverbal, instinctively closing themselves off from a world they do not understand and find painful to live in. They often have increased sensitivity to sound, touch, taste and smell, experiencing what humans normally do at several times the intensity.

Very rarely, a few of us gain significant abilities in some areas at the cost of deficiencies in others. They are prodigies in math, art, or music, and some have incredible memory capacity.

Those are the easy ones to spot; it's the ones at the other end of the spectrum, the "high functioning" autistics, that are harder to pin down. They, like me, have learned to blend in almost seamlessly to the human population. That's why they make the best actors, they play the part of "human" their entire lives.

There are a few traits that are nigh impossible to hide, though. Most are written off as eccentricities: rigid adherence to patterns and structures, narrow fields of interest, odd social quirks, the pedantic way of speaking that can be confused with arrogant superiority. That last one is because humans don't understand us well enough, so we must overcompensate to make sure they get it right when talking with us.

Make no mistake: we are well aware of our deficiencies. Painfully so.

The commonly shared experience of bullying and incompatible education systems in our youth has seen to beating the confidence out of us. Schools are built to fit the majority of humans (round pegs) and focus on traits desirable to life in the modern world – and therein lies the problem.

Autistics are square pegs; we do not fit in the system as it stands. Those who don't fit in the system are grouped together and given "space" and "extra time" as if those are the only things we need to forcibly mould the corners enough to fit through the round hole. This does none of us any good if we simply can't learn the same way others do.

In my experience, math was typically a grueling exercise of mental torture. I sat there and stared at incomprehensible numbers and formulas, mentally hitting my head against the wall until I either burnt out and quit or succeeded only in giving myself a headache. Teachers attempted to get me to understand by repeating the same process again and again with predictably terrible results. They were baffled by my inability to learn the way normal humans do. Some of them really did try to help me, and some eventually succeeded, but by and large I struggled to maintain a passing grade.

Unfortunately for me, and others as well, math is an essential skill required for many jobs and higher education.

The annoying thing is that the methodical, repetitive qualities we autistics have are well suited to fields that require those subjects. It's the actual learning part that makes getting into those kinds of careers such a massive pain in the ass. If I had been correctly diagnosed in my early childhood, things may have been different. As it was, it wasn't until I was in my early 20's that I was officially recognized as being a high-functioning autistic. I had to suffer under the impression that I was a dysfunctional human for all that time.

Learning is only part of the battle in the warzones called Elementary and Secondary School, or as I like to call them, The School Of Hard Knocks. The fourteen years I spent there remain the single most traumatic experience I have ever had. I have no doubt that the constant levels of stress I was under has shortened my lifespan by several years. It was during the later years of school that I became aware of my true heritage.

As if the academic pressures weren't enough, my kin are forced to endure this crucial period for developing social skills with a significant lack thereof from the word go. This instantly sets us apart from the crowd and we become targets for ridicule and torment. We well know the pain of being singled out as "weird" and "slow learners." Human children can be viciously anti-other, sometimes.

It's no wonder our suicide rate is eight times higher than "normal" humans (Hirvikoski et al., 2016). Some of us just can't take being so different; many of those don't make it to their 20's. Two-thirds of us have thought about suicide at some point in our lives (Cassidy et al., 2014). I certainly did.

Those of us on the higher end of the spectrum have learned to keep to themselves, to not draw attention, to stay out of the public eye as a means of survival. It's not healthy, but it's the only thing we can do.

This has given us autistics bad rap. We are lumped in with the "loners" and when a high-profile crime such as a murder is committed by one of us, the media jumps at the chance to put the blame on us if there is so much as a whiff of mental illness (Christopher, 2012). They avoid facing the unpleasant truth that all humans

are capable of it. In fact, neurotypicals, or “normal” humans, are just as likely to commit violent crimes as we are (Heeramun et al., 2017).

Statements similar to, “He was a quiet man; kept to himself, mostly,” are a common refrain, as if being forced to live in a society we find uncomfortable, if not tortuous, has no impact. As if everyone who would rather be left alone, and actively try to be left alone, is a killer. Most of us feel broken at some point. I know I did. Technically, we kind of are.

Others agree with that sentiment. To a degree that they think autism is a disease that should be wiped out. What they don’t realize is that they are advocating xenocide.

I must confess, I once feared humans would purposefully purge us from their gene pool. Still do, a little bit. The movie Gattaca was a terrifying awakening and from what I have seen of humanity, I wouldn’t discount the possibility. Thankfully, most are extremely uncomfortable when the topic of eugenics comes up. Any discussion about human genetic modification is around organ defects, deformities, and congenital diseases like cancer.

Yet for all the hardship we go through, all the discrimination, all the suffering we must endure, I do not hate humans for this. Their ignorance protects them.

It is not a specific decision for children to pick on us for being what we are. They grow up and learn, for the most part, how to be civilized individuals. To care for, or at least empathize with, others. The adults who do not outgrow their aversion simply do not understand us, and, as humans have throughout history, don’t like what they can’t understand. It’s instinct. A bad one, but still instinct; one that can sometimes be overridden if they know who, what, and why we are.

As it is, they see us as human and treat us – mostly – as their own. Even if the truth were to become known, that an alien species had crossbred with theirs to survive some unknown calamity, I suspect they would – again, mostly – welcome us. We did not choose to be hybrids, we just ARE.

There might also be a fair amount of pity. After all, we are progeny of a failed race. Worse, we are not perfect hybrids: far from it. Our progenitors must have been truly desperate if they knew the odds of compatibility were so low.

However.

In my studies of autism, it looks like my people have succeeded in surviving ... after a fashion. Given recent prevalence estimates (Baio et al., 2018), there might be over 125 million of us world-wide. It sounds like a lot, but the humans are seven and a half billion strong and counting. While there are many of us, I’m not even sure if my brothers and sisters realize what we truly are. Most probably think they struck out in the genetic lottery. A few may have arrived at the truth, as I have, but wisely keep the knowledge to themselves. It is far easier to simply try and be as human as we can.

That is what I have decided to do.

For better or worse, we are part of the human family now. I am grateful they have taken us in, even if they do not know it. Perhaps especially because of that.

I will end this essay with a quote from a cartoon character in a very similar situation (Spencer, Sanders, & DeBlois, 2002):

> This is my family. I found it all on my own. Is little, and broken, but still good. Yeah. Still good.

References

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., … Dowling, N. F. (2014). Prevalence of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. Morbidity and Mortality Weekly Report, 67: 6. https://doi.org/10.15585/mmwr.ss6706a1

Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: A clinical cohort study. Lancet Psychiatry, 1(2), 142–147. https://doi.org/10.1016/S2215-0366(14)70248-2

Cristopher, T. (2012, December 16). Fox News and The New York Times abet media effort to falsely link autism with CT shooting. Mediaite. Retrieved from https://www.mediaite.com/print/fox-news-and-the-new-york-times-abet-media-effort-to-falsely-link-autism-with-ct-shooting/

Heeramun, R., Magnusson, C., Gumpert, C. H., Granath, S., Lundberg, M., Dalman, C., & Rai, D. (2017). Autism and convictions for violent crimes: Population-based cohort study in Sweden. Journal of the American Academy of Child and Adolescent Psychiatry, 56(6), 491–497. https://doi.org/10.1016/j.jaac.2017.03.011

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), 232–238. https://doi.org/10.1192/bjp.bp.114.160192

Spencer, C. (Producer), Sanders, C., & DeBlois, D. (Directors). (2002). Lilo & Stitch [Motion picture]. United States: Walt Disney Pictures.

Further Reading

ABC News. (2012, December 15). Adam Lanza was a loner who didn't feel pain either physically or emotionally says former teacher. Retrieved from http://nationalpost.com/news/adam-lanza-was-a-loner-who-didnt-feel-pain-either-physically-or-emotionally-says-former-teacher

Lundström, S., Forsman, M., Larsson, H., Kerekes, N., Serlachius, E., Långström, N., & Lichtenstein, P. (2014). Childhood neurodevelopmental disorders and violent criminality: A sibling control study. Journal of Autism and Developmental Disorders, 44(11), 2707–2716. https://doi.org/10.1007/s10803-013-1873-0

Mouridsen, S. E., Rich, B., Isager, T., & Nedergaard, N. J. (2008). Pervasive developmental disorders and criminal behaviour: A case control study. International Journal of Offender Therapy & Comparative Criminology, 52(2), 196–205. https://doi.org/10.1177/0306624X07302056

Quigley, R., Durante, T., Peterson, H., & Zennie, M. (2012, December 15). How 'ticking time bomb' Adam Lanza went from 'genius' tech geek who grew up in $1.6million home to heartless killer. Daily Mail. Retrieved from http://www.dailymail.co.uk/news/article-2248782/Adam-Lanza-How-classmates-remember-genius-turned-heartless-killer.html

Schmidt, J., & Graham-Harrison, E. (2016, July 24). 'Strange and withdrawn': What drove Ali Sonboly to launch Munich attack? The Guardian. Retrieved from https://www.theguardian.com/world/2016/jul/23/ali-sonboly-munich-massacre-mcdonalds

Vives, R. (2017, October 2). Remembered as a loner in his hometown, Paddock did little to draw attention. Los Angeles Times. Retrieved from http://www.latimes.com/nation/la-las-vegas-shooting-live-updates-remembered-as-a-loner-in-his-hometown-1506988930-htmlstory.html

The Big Bang Theory's Sheldon Cooper and The Portrayal of Autistic Characters in Popular Culture

By Mario Anuales

The Big Bang Theory is an American TV comedy-sitcom on CBS that is broadcast around the world and is widely popular; it is currently in its 11th season, the premiere of which has garnered 17.65 million viewers in the US alone (Porter, 2017).

One of its main characters, and a major cornerstone of the show, is Dr. Sheldon Cooper, a theoretical physicist and child prodigy who displays stereotypical autistic traits. These traits include but are not limited to: his genius IQ and savant-like abilities; obsessive interests in trains and different fandoms; deficient social skills; difficulty identifying sarcasm; a lack of humility and empathy; low tolerance for changes in routine; and more. These traits heavily overlap with the DSM's criteria for an autism diagnosis (see American Psychiatric Association, 2013), to a degree that is unrealistic for actual autistic people (Heasley, 2017).

While he is not explicitly mentioned to be autistic, his idiosyncratic behaviours have led many fans to speculate or conclude he is indeed autistic (Collins, 2009; Soraya, 2009). This makes Sheldon an autistish character: a person that displays autistic traits but either has not been diagnosed or does not meet diagnostic criteria is known as autistish.

Two of the series' creators, Chuck Lorre and Bill Prady, have denied that Sheldon was written with autism in mind (Collins, 2009). In a 2009 interview with Alan Sepinwall, Prady claimed that Sheldon's personality was based on computer programmers he had previously worked with, before autism or Asperger's Syndrome were commonly known. Prady acknowledged the similarities to autism, but Sepinwall (2009) wrote that,

> …he [Prady] would feel uncomfortable labeling Sheldon as such.
> In the writers' minds, calling it Asperger's creates too much of a burden to get the details right. There's also the danger that the other characters' insults about Sheldon's behavior - in other words, 90 percent of the show's comedy - would seem mean if they were mocking a medical condition as opposed to generic eccentricity. In general, it's more responsibility than they feel a relatively light comedy can handle.

Essentially, the writers are trying to have their autism cake and eat it too. By doing this, TBBT's writers are trying to evade their responsibility to create an accurate portrayal and instead are using these stereotypical traits for comedic value whilst still retaining plausible deniability against accusations that the other characters are mistreating or making fun of an autistic person.

They believe that autism is a subject that is too taboo to address directly but that somehow, possessing the characteristics of autism still makes one fair game for ridicule as long the person is not classified as autistic. They recognize that making fun of an autistic person's behaviour is wrong, but somehow making fun of the same behaviour from a person without a diagnosis is humour. Somehow, the authors think that a person cannot be considered autistic until they receive a diagnosis, despite the obvious fact that autism is inborn.

Dr. Amy Farrah Fowler, Sheldon's girlfriend, is portrayed by Mayim Bialik, an actress with a PhD in neuroscience. Bialik was asked about the possibility that Sheldon might have undiagnosed autism in an interview with Dr. Neil deGrasse Tyson; she said:

> 'All of our characters are in theory on the neuropsychiatric spectrum, I would say…' 'Sheldon often gets talked about in terms of Asperger's or OCD. He has a thing with germs, he has a thing with numbers, he's got a lot of that precision that we see in OCD. There's a lot of interesting features to all of our characters that make them technically unconventional socially…'
> 'I think what's interesting and kind of sweet and what should not be lost on people is we don't pathologise our characters. We don't talk about medicating them or even really changing them.
> 'And I think that's what's interesting for those of us who are unconventional people or who know and love people who are on any sort of spectrum, we often find ways to work around that. It doesn't always need to be solved and medicated and labelled.' (Gill, 2015)

The rationale behind Bialik's statement was aptly broken down autistic blogger Kim Sauder (2015), who wrote:

> So this idea that TBBT is a way for the awkward and possibly autistic audience to see that the world can fit them and that TBBT is just a big "It get's better" message to those of us who were bullied for having characteristics similar to Sheldon are just false. Bialik's excuse is just a way to push back against the criticism that TBBT gets for turning ASD into a caricature. She made a nice progressive sounding statement that just doesn't happen to be true. There is no underlying moral of the acceptance of difference regardless of label in The Big Bang Theory.

This is especially true when you consider that Bialik's statement contradicts the actual treatment of Sheldon in the show. Rather than accept him for who he is, the other characters despise his idiosyncrasies and attempt to pathologize them. Sheldon's so-called friends openly speculate that he is "crazy" or that he has some unidentified disorder(s) (Belyeu, 2007).

Bialik, Prady, and Lorre's reluctance to label Sheldon as autistic is rationalized as seeing the person before their behaviour: they assume that pathologizing such behaviour is a gateway to exclusion and discrimination. However, avoiding the label

of a diagnosis does not promote inclusion; it merely stigmatizes the word "autism" even more. This is the same twisted logic seen in referring to autistic people with person-first language: trying to emphasize the person before the diagnosis implies that a diagnosis is undesirable or a disease. It implies that autism can be somehow be separated from personhood, instead of being a component of someone's being and identity.

Regardless of the character's origins and the writers' intent, the impact is still the same. Even if Sheldon was explicitly identified as autistic, he would still look like a rigid caricature of an autistic person, a walking checklist of DSM symptoms. Just because Sheldon lacks a diagnosis, it does not absolve them of the responsibility of portraying an autistic character. Sheldon Cooper displays a myriad of traits that are clearly neuroatypical, he is read as an autistic character by most of the show's audience, and thus he influences how they perceive and treat autistic people.

Jacqueline Koyanagi (2015), writing on the same subject, expresses this idea best:

> Fictional characters exist to be consumed by real people, and real people live on the autism spectrum. Characterization, regardless of label or lack thereof, regardless of genre, has a real impact on these real people, myself included. Content creators must understand that they can be answerable for that impact. When they render a character into their world wearing an entire suit of autistic behaviors, reactions, and needs, responsibility-dodging only serves to hurt the population they're representing, whether they wanted their work to be representative of that population or not.

As one of the most recognizable media figures representing autism, Sheldon's impact cannot be understated. He perpetuates stereotypes about autistic people: that we are insufferable geniuses with near-magical talents. His status as a walking DSM checklist influences people to think autistic people are merely the sum of a few stereotypes.

The most insidious thing about this is that neurotypicals with a lack of knowledge will mistakenly think he is an accurate representation and an inspiration to autistic people. Others will think that Sheldon will drum up awareness of and interest in autistic people. Granted, some autistic people see parts of themselves in Sheldon, and some neurotypicals that aren't familiar with autism might have learned more about it after hearing Sheldon may be autistic. However, this does not change the fact that he is still a bad representation.

Bad representation is not better than no representation at all, as some might think. Consider the example of Mr. Yunioshi, a racist caricature of a Japanese man portrayed by white American actor Mickey Rooney in the 1961 film, Breakfast at Tiffany's. His depiction did not contribute anything to the status of Japanese or Asian-Americans and his inclusion did not make the movie better. In fact, the entire movie has been tarnished by the character, and it continues to draw controversy when publicly screened (Huffington Post, 2011). Similarly, I assert that Sheldon's portrayal is akin to racial stereotyping and does not contribute to improving the status of autistic people.

Another example of the real-world harm these stereotypes have wrought can be seen in the mass proliferation of autism self-diagnoses by people with only a shallow understanding of it. Using Sheldon as a template, some people have self-diagnosed themselves as autistic because they think they are socially inept geniuses and that these characteristics equate to autism. Some of these people use their self-diagnosis to both assert their supposed intelligence and deflect criticism for poor social conduct. This phenomenon has become prevalent enough that these people are nicknamed "Assburgers" by internet denizens (Definithing, n.d.). This both trivializes actual autism diagnoses and makes it harder for individuals to disclose the fact they are autistic, because they may be lumped in with these pretenders.

Furthermore, Sheldon projects a false impression of what it is like to interact with an autistic person. He rigidly adheres to his routines and insists on having his friends drive him to various locations to fulfill these routines. He imposes inflexible rules in his apartment and strictly enforces them. Any attempts to subvert or compromise these rules results in Sheldon annoying or punishing his friends until they submit. All of this makes Sheldon come across as a burden and as generally distressing to interact with. The audience is encouraged to feel sympathy for the people around Sheldon for putting up with his behaviour. Not only does this reinforce narratives of autism people being living tragedies for the people around them, it ignores the reasons why autistic people behave in these ways.

Occasionally, the show does try to explain why Sheldon does these things. In the episode "The Itchy Brain Simulation" (Molaro, Prady, Reynolds, & Cendrowski, 2013), Sheldon describes the experience of leaving an issue unresolved as making his brain itch. He has his roommate, Leonard, wear an itchy sweater until Leonard can return a long overdue DVD, in order to understand how Sheldon feels. During his attempt to complete this task, Leonard wears the sweater long enough to contract a bad rash. After this plot is resolved, that is it: the incident is never referenced again and there is no meaningful impact. This could have been used as a character-building moment for Leonard, enabling him to get a better understanding of Sheldon and being able to better empathize with his feelings of distress. Unlike Leonard, Sheldon never gets to choose when to take his sweater off. Worse yet, Sheldon's attempt to teach Leonard is played off as pointless torment, almost as if it were a prank.

Ignoring the similarities between Sheldon's character and the autism diagnosis criteria in the DSM does not exempt the show from criticism for how Sheldon is depicted. The Big Bang Theory, along with other media featuring autistic or autistish characters, must be held accountable. When future generations look back on the show, I wonder what they will think of it. I wonder if it will be viewed as a trailblazer of neuroatypical characters on mainstream television, or if it will be seen as an offensive relic of an era where it was acceptable to caricaturize autistic people for the sake of comedy.

References

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596.dsm01

Assburgers. (n.d.). Definithing. Retrieved from https://definithing.com/results/?q=assburgers

Belyeu, F. O. (2007). The Big Bang Theory [Television series]. CBS.

Collins, P. (2009, February 6). Is the world ready for an Asperger's sitcom? Slate. Retrieved from https://web.archive.org/web/20090210061649/http://www.slate.com/id/2210635/pagenum/all/

Gill, J. (2015, June 15). Is Sheldon autistic? The Big Bang Theory actress Mayim Bialik gives this brilliant response. RadioTimes. Retrieved from http://www.radiotimes.com/news/2015-06-15/is-sheldon-autistic-the-big-bang-theory-actress-mayim-bialik-gives-this-brilliant-response/

Heasley, S. (2017, September 26). Is Hollywood's Portrayal Of Autism Fair? Disability Scoop. Retrieved from https://www.disabilityscoop.com/2017/09/26/is-hollywood-portrayal-autism-fair/24222/

Huffington Post. (2011, July 13). 'Breakfast at Tiffany's' Brooklyn screening sparks protests from Asian-American group. Retrieved from https://www.huffingtonpost.com/2011/07/13/brooklyn-breakfast-at-tiffanys_n_897557.html

Koyanagi, J. (2015, April 17). Context Matters: On Labels and Responsibility. Disability in Kidlit. Retrieved from http://disabilityinkidlit.com/2015/04/17/context-matters-on-labels-and-responsibility/

Molaro, S., Prady, B., & Reynolds, J. (Writers) & Cendrowski, M. (Director). (2013). "The Itchy Brain Simulation" [Television series episode]. The Big Bang Theory. CBS.

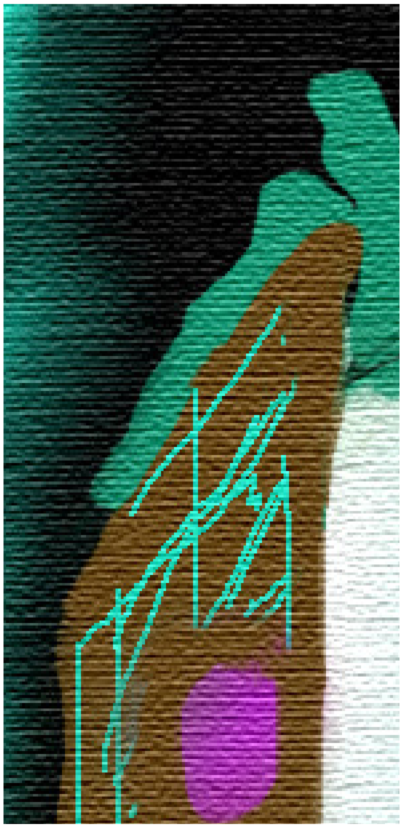
Porter, R. (2017, September 26). 'Big Bang' and 'Young Sheldon' adjust up, 'Good Doctor,' 'DWTS,' 'The Brave,' 'Me, Myself & I' down: Monday final ratings. TV by the Numbers. Retrieved from http://tvbythenumbers.zap2it.com/daily-ratings/monday-final-ratings-sept-25-2017/

Sauder, K. (2015, June 17). Mayim Bialik's take on Sheldon Cooper and autism is wrong [Web log post]. Retrieved from https://crippledscholar.com/2015/06/17/mayim-bialiks-take-on-sheldon-cooper-and-autism-is-wrong/

Sepinwall, A. (2009, August 13). Reader mail: Does Sheldom from 'Big Bang Theory' have Asperger's? NJ. Retrieved from http://www.nj.com/entertainment/tv/index.ssf/2009/08/reader_mail_does_sheldon_from.html

Soraya, L. (2009, April 20). Sheldony or Aspergery?: The Big Bang Theory. Psychology Today. Retrieved from https://www.psychologytoday.com/blog/aspergers-diary/200904/sheldony-or-aspergery-the-big-bang-theory

If you are a person diagnosed with autism and are called to participate in being a voice of autism culture, then write down your ideas and send us a submission. We are waiting to hear from you.



Autism’s Own is the first Peer-Review A
Journal on Autism Culture completely
edited by the Autism Community. Tog
co-authoring our world and our future
benefit of all receivers along the big pa

Academic
written and
ether we are
es for the
ath.

THANK YOU

We greatly appreciate all who have sponsored our events and made our journal so special. Our readers have made our effort worthwhile. We hope even more authors and artists with autism submit journal entries for next year's Autism's Own journal. This journal truly belongs to us, the autism community, as our own.