

THE CANADIAN JOURNAL OF AUTISM EQUITY
LA REVUE CANADIENNE DE L'ÉQUITÉ EN MATIÈRE D'AUTISME
VOLUME 2 | ISSUE 1 | APRIL 2022

The challenge of meaningful work for adults with ASD

Kirk Winter, *Independent Author, Canada*

RECOMMENDED CITATION: Winter, K. (2022). The challenge of meaningful work for adults with ASD. *The Canadian Journal of Autism Equity*, 2(1), 47–56.



The challenge of meaningful work for adults with ASD

Kirk Winter

Abstract

Individuals with autism spectrum disorders (ASD) face many challenges during their lives that range from decoding the public school system, understanding social cues and surviving the challenges inherent in higher education. Perhaps the most significant hurdle for those with ASD to overcome is obtaining meaningful employment upon finishing school. The levels of unemployment and underemployment for those with ASD is scandalously high and despite some efforts being made by a handful of well-meaning employers, too few individuals are given a fair shake in both the hiring process and the workplace once hired. This reality unfortunately leads to far too many talented and innovative individuals with ASD facing working lives of unmitigated frustration and unfulfilled potential.

Résumé

Les personnes ayant un trouble du spectre de l'autisme (TSA) doivent relever de nombreux défis au cours de leur vie, qu'il s'agisse de décoder le système scolaire public, de comprendre les signaux sociaux ou de survivre aux difficultés inhérentes à l'enseignement supérieur. L'obstacle le plus important à surmonter pour les personnes ayant un TSA est peut-être de trouver un emploi intéressant à la fin de leurs études. Le taux de chômage et de sous-emploi des personnes sur le spectre de l'autisme est scandaleusement élevé et, malgré les efforts déployés par une poignée d'employeurs bien intentionnés, trop peu de personnes bénéficient d'un traitement équitable tant dans le processus d'embauche que dans le milieu de travail une fois qu'elles ont décroché un poste. Cette réalité fait malheureusement en sorte que beaucoup trop de personnes autistes talentueuses et innovatrices sont confrontées à une vie professionnelle faite de frustration et de potentiel non réalisé.

Keywords

autism, employment, underemployment, strategies, role of caregivers

Mots Clés

autisme, emploi, sous-emploi, stratégies, rôle des soignants

^{1,2,3,4} Independent Author

As an individual with ASD who has a son with ASD and has worked with hundreds of individuals with ASD as a high school history teacher, I believe that we can help the next generation of young people with ASD by recognizing our role as parents in preparing our children for meaningful employment.

While this paper is not scholarly in the truest sense of the word, I believe there is much useful information contained here on how to prepare your child with ASD for the all-important world of work. The lessons I have learned are certainly not easy, but they are worth the effort and tears that have been shed. My son with ASD successfully defended his PhD thesis in November 2021, and is celebrating almost 15 years of employment which put him through school, working a variety of jobs in the challenging and fast-paced service industry.

What do the numbers tell us?

It has often been said that statistics don't lie. If that axiom is still true, then the numbers regarding employment of individuals on the autism spectrum are worth a sober second look.

A study from Drexel University in the United States concludes that individuals on the autism spectrum are less likely than any other disability group to be employed or pursue post-secondary education. (Long and Kearon, 2018) The numbers cited are very stark with 58% of people with ASD working for pay, 74% of people with intellectual disabilities working for pay, and 95% of those with learning disabilities working for pay. (Psychology Today, no date listed)

The Drexel study suggests that young adults with ASD have the highest risk of being completely disengaged from any kind of post-secondary education or employment after high school. (Long and Kearon, 2018)

A British study commissioned by the Office for National Statistics suggests that as many as 78% of adults with autism are underemployed or unemployed. (National Autism Society, 2021)

An American study finds relatively similar data to the British research when they conclude that 85% of Americans with ASD are underemployed or unemployed. (Sparrow, 2018) The American research also indicates that only 53% of young adults with ASD have worked for pay outside the home in the first eight years following high school. (Ciccocioppo and Taylor, 2018)

How can we change this sorry situation? What can we do to better prepare our children with ASD to get a leg-up in the ultra-competitive job market?

Be a good role model

The elephant in the room on the issue of employment for young people with ASD is the role played by the individual's parents/caregivers in preparing them for the world of work. Assuming a young person is living with their birth parents, genetics tell us that one or both of their parents are likely on the spectrum. What are their experiences like in the work world? Do they find themselves frustrated, angry and underemployed? If they have not been successful in the work world what skills, tips, and knowledge do they have to pass on to the next generation? What have they modelled for children about the importance of work?

Young people learn by listening and watching role models they respect, and if their parent(s) have found the work world fraught with disappointment because of their diagnosis, this will most certainly have an impact upon the next generation's outlook on work. Some of those same young adults have also seen parents never work because they have been deemed disabled by being on the spectrum. One wonders what message about their condition young adults take from growing up in those households.

I was very lucky growing up. My father, who worked outside of the family home, was not the parent with ASD. I watched my dad go from promotion to promotion with ever increasing responsibilities. He began his career with one of Canada's largest retailers as an entry-level management trainee and retired 40 years later as a national manager. While my father mastered many different skills, he was a human resources person at heart. He was an expert hirer and his ability to interview, select and retain good people was legendary. Work, for my father, meant providing for his family, a message I took to heart.

I learned at a very early age that “work made the man” and carried the “need” to work with me for decades after leaving the family home. There was never any question about me working; the only question was at what. Not working was a sign of failure for both of my Depression-raised parents, and I wasn't going to be a failure.

From a young age I was expected to help at home. I loved shovelling snow and working in the yard and wondered at other friends who had no chores. As someone who was not identified as having ASD until my son was, my condition manifested first as anxiety and an obsessive need for order. I worried too much about too many things. My desperate need to control the world around me often ended in abject failure.

I watched how hard Dad worked. Work was important to Dad, and that importance was clearly modeled for me when I saw my father put in 60-plus hour weeks and travel across Canada on a regular basis.

When I told my parents as a high school student that I wanted to teach, they were both very supportive and encouraged me in every way they could. They both knew I loved history and hoped that teaching would be my outlet for that passion.

Both my wife and I are retired career teachers, and we consciously modelled a better balance for our kids between work, family and community service than my parents did. We always emphasised that whatever the undertaking, if you gave it a real effort, it was something worthwhile. My son with ASD was brought up in a world where not working because of his condition was never spoken of. We knew he would likely need some time to choose a realistic job plan based on his areas of interest.

Start them young

My father knew I was happiest when I was busy, and as soon as I could I began the world of work with a paper route which soon grew to two different routes. Dad had delivered papers growing up and decided this was a positive way to experience work, get out of the house and earn a little bit of extra money.

I was initially very unsettled about everything that could possibly go wrong with a route. I feared bad weather, vicious dogs or being robbed in some of the seedier apartment blocks I delivered to. There were times I wanted to quit because it was too cold, or the walk was too long. That was not an option in my family. I had made a commitment to my employer and that was sacred in my father's eyes. I delivered those routes for over two years. I experienced every hiccup that a paperboy could face, like papers arriving late or not at all (I thought my customers would blame me). I found the routine of the job was quite relaxing and the seniors, particularly on my route, became friends whose generosity at Christmas was often unexpected.

Our oldest was identified with ASD in grade two. We talked to other parents who were going through similar experiences and as the years went by conversations of applying for a

disability pension became more commonplace. My nephew, also on the spectrum, qualified for and received a monthly pension for his ASD and will receive it for the rest of his life while he lives in Ontario.

My ASD-free wife and I talked for hours about what to do regarding pensions and medications, and whether these were paths we wanted to pursue. We made a conscious decision that our son at 18 could and would make informed decisions for himself about being medicated and applying for the provincial pension. Until then we would try to give him every opportunity to experience life as his friends and neighbours did.

All our children had chores to do beginning with making their beds in early elementary school. They then moved on to doing their laundry. Sometimes it wasn't done until they discovered they were out of underwear, but it was the beginning of taking on work-like responsibilities. My son quite enjoyed shovelling snow and took pride in helping clean our two driveways all the winter long.

We also asked our children to clean their rooms once they reached grade three or four. Two did a relatively decent job but my son with ASD struggled mightily. I will be the first to admit that occasionally I went in and cleaned his room when my OCD dominant ASD could no longer stand the disorder he lived in; but for the most part he was expected to take care of his space.

At the same time the local newspaper advertised that they were looking for carriers and we encouraged my oldest to take it on. He was as hesitant as I was at a similar age, but in some form or another, often with assistance from a brother or two, the papers were delivered. It was a once-a-week commitment, so the workload was not onerous. Not once did Mum or Dad have to deliver the papers and they got to their allotted homes without much complaint. Chores at home and a paper route provided my oldest many of the building blocks that made his entry into the work world much smoother than it would have been otherwise.

Interview preparation

Human resources professionals who regularly interact and have an understanding of those with ASD believe that many of the roadblocks faced regarding job interviews can be overcome with pre-interview preparation. These hiring experts recommend that interview skills need to be role played. Candidates need to be taught how to position their bodies, actively listen, and how to become comfortable asking and being asked open-ended questions in an interview.

Once my oldest began to apply for part-time jobs I can vouch that interview preparation is time well spent. When my child applied for his first job in high school as a cashier at a local drug store, the upcoming interview was clearly concerning him. I asked him if he wanted to go through what he might expect as a potential interviewee. He was thrilled and we spent a couple of hours going through everything from how to enter the room, shake hands, to maintain eye contact, what to wear and how to listen for clues from the interviewer as to what they were looking for in an employee. We also prepared questions that he would ask the human resources person at the end of the interview, so he would appear interested in the job and would know about things like wages, hours of work and job responsibilities that were all unknown and potential stressors.

My son was successful in obtaining that position, and I am proud to say also successful in getting every other job he has applied for since. Athletes often say they are successful on game day because they “put in the work” beforehand. Parenting a child with ASD is very similar. Why will they think work is important if you don't model that? Why will they take on regular responsibilities if they have never been asked to do something as simple as chores? How do you

expect success in a job interview if you don't prepare them for it?

Dress code does exist

If your child with ASD is anything like mine, and many that I taught, they are not well known for their sartorial splendour. It is one of the many things that neurotypical individuals prioritise before they go out in public, but many with ASD often see it as an afterthought. We have worked very hard with our son, with varying levels of success, to make him realise there are clothes appropriate for casual settings, school, church and the work world.

As parents, we had clothing checks before he left for school offering low-key fashion advice that would make sure he wasn't teased for what he was wearing, and his clothing would not single him out in a crowd.

Employers have come a very long way in dealing with potential applicants with ASD, but most potential employers will tell you to arrive looking like you have taken this interview seriously and want to make a good first impression.

I always remember Dad telling me he hired over two hundred people in a week-long hiring blitz for a new store opening based on ability, resumes and whether or not they shined their shoes. Dad associated the attention to detail that potential applicants took preparing themselves for their interview as an indication of how seriously they would take their work and interactions with customers.

There were times our fashion critiques led to conflict with our son, but we held firm and soon he began to realise he couldn't wear woolly work socks with short pants in the summer or his big green sweater to school for weeks on end. While it didn't stop him from wearing running shoes to his wedding, he did look wonderful in his suit and tie on his big day.

Individuals with ASD have told me they prefer when places of employment provide either a well-defined and unambiguous dress code upon hiring or provide the uniform eliminating any chances for fashion faux pas.

Until I entered the teaching profession, every job I had came with a uniform and I appreciated that source of worry being eliminated. My son, a long-time service industry employee while attending school, has had a similar experience at the three businesses he has worked for, simplifying the work preparation routine immeasurably. It hasn't stopped him from losing more name badges and swipe cards than you can imagine, but I can safely say he has never gone to work inappropriately dressed.

I, for one, will be intrigued how easily employees with ASD transition back to the office once all COVID restrictions are hopefully lifted sometime in 2022. I expect there will be some anxiety felt when individuals will no longer be able to work in pyjamas and bare feet.

How badly do you want your child to work?

How badly do you want your child to have a fulfilling and challenging career? How content are you to simply let the child collect a pension, stay home and play video games in their room? These are very important questions that we as parents need to answer and answer honestly.

Are you prepared to fight your child when they initially reject doing household chores or see a paper route as something they have no interest in doing? Are you ready to debate your brilliant neurodiverse son or daughter about the value of preparing for job interviews when they may pretend that they know everything? Are you in it for the long haul, working on proper attire for work with your child?

If you make the decision that a career is a possibility for your child you are all-in until they move out on their own, and even then, you are the first one they call when they have a conflict at work or an interaction at work causes them anxiety. My son has not lived at home for seven years, yet I would suggest that over half the texts my wife and I get from him even today relate to the frustrations and challenges of working in a neurotypical world.

An overwhelming majority of individuals I know who have ASD never achieve their driver's licences for many very good reasons. Most service jobs that are entry level employment for almost all Canadian teens have irregular hours and are open late. While our son enjoyed walking home after 11 pm because of the security he felt in the small town where we live, there are many other circumstances when a parental ride was necessary because of inclement weather. Are there nights you don't feel like getting off the couch to pick your child up from work? I can confess there were a few, but if the absence of a parental drive meant quitting that job, my wife and I were looking for our keys. We were part of his team and committed to ensuring our son was a success at any job he took on.

Do you disclose your condition at work?

There has been considerable debate regarding disclosure (about being on the spectrum) at work, and what impact that may have on employers and fellow employees.

One school of thought encourages sharing your disability in order for neurotypical people to understand the broad variety that makes up the spectrum. They need to see the "full smorgasbord of abilities and challenges that people dealing with the disability truly face."

Dr. Stephen Shore famously said, "If you have met one person with autism, you have only met one person with autism." (Lucas, 2019)

Another individual on the spectrum who did share at work posted her cautionary tale, "After I came out, some at work felt I could no longer do my job. Others wondered why I could talk, did not behave like a child and didn't rock constantly." (Dunne, 2015)

I was always forthcoming with my workmates and bosses about my diagnosis. I felt from day one that there was nothing in my condition that should be secret, and if it explained to the outside world why I behaved like I did I would much rather have that than people thinking I was just "different".

My oldest son has never had a problem telling employers what he needs from them, and because he is a good, honest, forthright employee, they have been good to accommodate him.

When working at a local automotive supply store, the manager wanted to train my son to cut keys. My son engaged his boss in conversation immediately, reminding her that one of the characteristics of his ASD was poor hand/eye coordination and that the key cutting machine looked like an accident waiting to happen. The manager agreed and his career as a key cutter ended before it began. I still see that former manager regularly when I am shopping and she never fails to ask about my son, so excited that one of her cashiers is likely going to be a university professor.

Self-advocacy is a hard thing for many with ASD, but it is so essential regarding employment. My affected son's wife also has ASD, and in preparing her for job interviews we have impressed upon her that in the section of the interview where you are allowed to ask questions, she should tell the employer any special accommodations she will need from them that will allow her to be a good employee. She was initially concerned that people would react poorly to her sharing, but I convinced her that any employer who wasn't willing to accommodate her needs wasn't someone she would want to work for in the first place. She was pleasantly surprised that

in an interview for post-doctoral research the interviewing professor was very complimentary regarding the information she shared and thanked her for making it clear what she needs from the get-go. relatable message, which can also help leaders better understand what it is that individuals with disabilities actually require.

The changing work world

The work world is slowly but surely changing for those with ASD. With commitment and preparation by both individuals and their support networks, meaningful and fulfilling work is more possible all the time.

Autism specific hiring initiatives are being pioneered in the United States by Walgreens, ZenithOptimedia, Microsoft, SAP, Hewlett-Packard, Ernst and Young and Home Depot, often with the support of multiple levels of government looking to assist people with disabilities like autism. (Rudy, 2021)

SAP Software calls this process “recognizing the skills of differently-abled people.” SAP has a 90% retention rate for its staff with ASD and makes it a priority “to value and support the diverse thinking and problem solving that their employees bring to work every day.” (Rudy, 2021)

Jobs like software testing, quality control, stockroom operations, production line assembly, data entry and accounting play to the recognized strengths of those with ASD, and the passions and fixations that are the hallmarks of many with autism can translate into valuable skills in the workforce. (Rudy, 2021)

I would be remiss not to state clearly that not all people with ASD are number oriented. The work these employers are doing to enable those who want to work in accounting and computer programming is wonderful, but what about those who are not interested in numbers? I studied history, as has my son. Others are interested in music or the trades. Some want to enter the workforce right out of high school. Much more needs to be done for those individuals. I also suggest that much of the professional and employment literature ignores one other area of work that many with ASD, me included, have excelled: teaching at all levels.

I only became aware of my own ASD diagnosis when my son was diagnosed, but now as I look back on it, my attraction to teaching makes perfect sense. I have been very fortunate to carve out a satisfying thirty-one-year career teaching high-school history in a large composite rural high school in Ontario. Few jobs have more predictable structure than teaching. There are only so many days in the school year and each period is the same length every day. As a classroom teacher, I was clearly in charge of my workspace, and I did not have to interact with other teachers to be successful in delivering my lessons. I was the captain of my own ship, and interaction with other teachers was often limited to a few minutes in the lunchroom each day. My time was spent in my office and classroom with students who valued me for my expertise rather than my friendship. The power dynamic was all one way, and there was little confusion for someone with ASD as to who was in charge. High school, college and university instruction also feeds a very narrow knowledge band that is so typical for many with ASD. My great love has always been history of all kinds and short of writing or researching, teaching has provided me a wonderful outlet to legitimately feed that appetite without appearing to be odd.

A family friend of ours whose child has ASD has been able to turn an encyclopaedic interest in dinosaurs into a high-profile academic career that takes him around the world as one of the leading experts on Tyrannosaurus Rex.

My son’s interest in military history has caused him to prepare and deliver a well received

Master's thesis and a widely praised PhD paper that will hopefully open doors to him teaching and writing.

It also didn't surprise me that my monthly poker friends, who all worked at my school, made up of teachers and support staff, were overwhelmingly on the spectrum whether they admitted it or not. We felt comfortable with each other's company and accepted each other's ticks and foibles with mostly grace and certainly an understanding of having walked many miles in those people's shoes.

It does not surprise me at all to see that the bulk of my son's friend group is made up of individuals from university and his job at a chain supermarket who are almost all challenged in one way or another. There are individuals dealing with mental health challenges, extreme health issues, and of course, autism. My son says he can spot a fellow traveller with ASD at a distance, and from my experience he is seldom wrong.

I am also very pleased to see him imparting to friends what he has learned about the work world, bosses, and dealing with annoying and ignorant customers. He has become one of the biggest advocates of the United Food and Commercial Workers Union who represent all the workers at his store. He has come to realise the importance of the union acting as an advocate with management who can often appear unsympathetic and unreasonable to the neurodiverse.

My son's ASD has at times benefitted him hugely as a service industry cashier. Once he learns the routine that differs from one employer to the next, he is comfortable with the job. He takes and enforces the store rules seriously and will not be bullied by customers because he knows he has authority on his side, all common characteristics of ASD. Bosses like having him working the late shifts when customers are often the most troublesome, and as a grocery store that sells liquor, his till is the one designated for alcohol sales. If the store policy is to ask for identification of everyone under 25, he will do it even if the line is long and customers are fussing. If the rule is you can't buy liquor for someone else or buy while you are intoxicated, it is enforced meticulously at my son's till much to the chagrin of some shoppers and to the delight of his bosses.

Repeated studies of ASD employees who are properly supported in a full-time job environment indicate that employees like my son bring to their work every day an intense attention to detail, commitment to quality and consistency, creative and out-of-the box thinking, ability to excel at repetitive tasks, have lower turnover rates and are recognized for their honesty and loyalty. (Dunne, 2015)

Companies who have reported success in retaining their ASD employees say clarity in the workplace is a key to building an autism-friendly jobsite. There must be clear directives and deadlines, instructions must be nuance-free, and managers must be quick to clear obstacles that prevent those directives from being met.

Some workplaces have gone as far as normalising the need to negotiate different workplace rules depending upon the needs of the ASD employees and the company. Accommodations will vary from employee to employee and may include the need to wear noise cancelling headphones, have access to a quiet room to work if the office is too chaotic, or ensuring that lights aren't flickering in the employee's workspace to best address the sensory symptoms of autism. In my son's case, insomnia is a serious issue, making early mornings very difficult for him. Employers, after being informed, have, for the most part, been very good to

avoid assigning him morning shifts.

Susan Dunne, author of *A Pony in the Bedroom*, a memoir of life with undiagnosed autism, wrote about finally finding work peace when she was hired by an autism charity in Great Britain, “It really didn’t take that much...just a willingness to allow some time out when I needed, a relaxation room for breaks and a recognition that not everyone wants to be part of coffee time and Secret Santa exchanges. I enjoy working with clear structure and set tasks...in an environment where no one thinks it’s strange if I stick my fingers in my ears at sudden noises. I appreciate when people at least try to give me a warning of changes ahead of time and I feel a great debt of loyalty to the manager who took a near meltdown in her stride and put it within an understandable autism context. I am happier at work and I spend a lot less time requesting sick notes for social overkill.” (Dunne, 2015)

Master’s thesis and a widely praised PhD paper that will hopefully open doors to him teaching and writing.

Is activism the answer?

What do people with ASD and their support networks need to do to further open up the workplace to those who are neurodivergent?

ASD advocates worldwide have reminded those with autism that they are consumers too, and that worldwide people with disabilities, including ASD, are a \$3 trillion dollar market for consumer goods and services. (Long and Kearon, 2018) Advocates in the ASD community have suggested that concerned individuals should actively support firms that provide meaningful employment for those on the spectrum while boycotting companies who do not.

I know as a parent of a child with ASD I make sure I shop at the businesses that employed my son and at the other stores in our community that are willing to employ the neurodivergent.

When I have had the opportunity to speak to people in the positions of responsibility at these businesses, I have complimented them on their hiring practices and reminded them that their decision to hire individuals who are neurodivergent has not gone unnoticed and has changed where I shop.

In the United States alone, a \$220 billion market is controlled by people with disabilities, including autism, their friends, families, and associates. (Long and Kearon, 2018) When polled, the neurodivergent and their allies indicate they prefer to patronise businesses that hire people with all disabilities including ASD.

Concluding thoughts

Too many people with ASD have found themselves marginalised in the adult workforce. While more companies are making a real effort to hire those with ASD, parents and caregivers need to take on a much larger role in helping their children be work ready. Success at work for those with ASD is not an accident. It takes careful planning and a commitment from both parents and the individual to enter a challenging environment that is all too often only understood by those who are neurotypical.

The ASD community must also use their considerable economic muscle to affect change and influence private industry to do a better job of hiring, training, and retaining those with autism, not because it is the socially acceptable thing to do but because it is the profitable thing to do.

References

- Dunne, S. (2015, September 16). Autism as an adult: 'on the many days I spend alone I forget how to talk'. The Guardian. Retrieved January 8, 2022, from <https://www.theguardian.com/social-care-network/social-life-blog/2015/sep/16/autism-as-an-adult-on-the-many-days-i-spend-alone-i-forget-how-to-talk>
- Long, L and D. Kearon. (2018, June 30). Changing the Spectrum: Autism in the Workplace. Retrieved January 9, 2022, from <https://www.autismspeaks.org/blog/changing-spectrum-autism-workplace>
- Lucas, S. (2019, June 25). Want tips for managing employees with autism in the workplace? The Balance Careers. Retrieved January 8, 2022, from <https://www.thebalancecareers.com/managing-employees-with-autism-4154667>
- National Autistic Society. (2021, February 19). Annual Report. Retrieved January 9, 2022, from https://s3.chorus-mk.thirdlight.com/file/8/MC9ENnuMIWGsg6MCcaTMK1lS1k/NAS_AnnualReport_2020_sp-website.pdf
- Psychology Today. (n.d.). Autism in the Workforce, Retrieved January 11, 2021, from <https://www.psychologytoday.com/us/basics/autism/autism-and-the-workforce#>
- Rudy, L. J. (2021, September 10). 10 facts you need to know about autism and employment. Verywell Health. Retrieved January 8, 2022, from <https://www.verywellhealth.com/things-you-need-to-know-about-autism-and-employment-4159850>
- Sparrow, M. (2018, February 26). Why is the autistic unemployment rate so high? Retrieved January 9, 2022, from <http://www.thinkingautismguide.com/2018/02/why-is-autistic-unemployment-rate-so.htm>
- Taylor S. and Ciccioppo A. (2018, November 9). Assisting adults with autism transition from post-secondary into the workplace. CERIC. Retrieved January 8, 2022, from <https://ceric.ca/2018/11/assisting-adults-with-autism-transition-from-post-secondary-into-the-workplace/>