

# Promoting improved social interaction to people with autism spectrum disorder: Reimagining representations in television and social media

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I have worked in the non-profit sector of the Office of People with Developmental Disabilities (OPWDD) for adults and children with developmental disabilities for the last six years. Within that time frame I have worked as a direct support professional (DSP) working one-on-one with individuals residing in group homes. I have been an assistant director and assistant residential supervisor managing the day-to-day functions of several group homes. I advocated for individuals with developmental disabilities as their Medicaid service coordinator working with their other service providers and families to improve the quality of their lives. I have been a community habilitation coordinator training and establishing community based services for individuals and their specific one on one staff. And currently, I am a behaviour specialist; I create and implement behaviour plans and counsel individuals who have behavioural issues within five group homes in the New York metropolitan area. Throughout my career, I have worked with over 300 individuals served in Rockland County, NY with a variety of developmental and intellectual disabilities. I have learned that disabilities are not cookie cutter and what works for one person may not work for another who has the same diagnosis; people are all different. Of all of the lessons I continue to learn from working one on one with such amazing people, my biggest take away is people in the community have no idea who is living next door. I have been out in the community with several of my individuals and we as a group have received scowls, frowns, disdain, and fear. Some people will attempt to be kind and shoot a quick smile before quickly scurry away from us.

Five years ago I took six individuals to Party City (a party supply store) to purchase their Halloween costumes. The six individuals I was with were a variety of ages from their 30s to late 50s; all with a variety of functioning levels and diagnoses (moderate intellectual disability, autism, intermittent explosive disorder, etc.) This particular weekend was just prior Halloween. The store was packed with families and their little ones looking for superhero costumes and princess crowns. My individuals love Halloween just as much as anyone else and required the perfect costumes. In the midst of all the typical chaos you would find in this situation, my individuals were dealing with their own struggles. Jack is stemming and making clicking noises as he paces the aisle. Georgia is upset because they don't have the costume in her size. Patrick is yelling and shaking his fist because I was helping Georgia before him. Daniel is jumping up and down saying: 'Daniel light the match, burn the building down.' Granted managing all these people and their varying needs is not easy, but within a few minutes everyone

calmed down as I helped to fulfil all of their needs. An older gentleman came up to me and told me I was doing 'god's work'. I nodded and smiled at his kind gesture. But in all honesty, he was wrong. I am not doing god's work. I am working with people, people who have their own needs and are frustrated – Probably were no more frustrated than the other families who were also in the same store. The willingness to want to learn or better understand individuals with disabilities is instead the real work of god.

'Heyy you guyssss!' A familiar film quote for most of us people born before the 1990s. The quote is from the film *The Goonies*. This is a film in which a horribly disfigured family member was forced to live in solitude away from society. If you are not familiar with this film how about *Pet Cemetery*? In this film, a woman's sister, who is also horribly disfigured, was shunned by her family and spent her days hidden in a room in the back of the house.

Let's take a quick look at how literature is provided in US school systems. *Of Mice and Men* by John Steinbeck is a novel following Lenny. Lenny is developmentally disabled and cannot control his strength or anger. In doing so, other characters in the book suffer horrific consequences, or the 1831 classic novel, *The Hunchback of Notre Dame* by Victor Hugo. One of the story's main characters is Quasimodo, a half blind half deaf man with a physical disability that was abandoned by his family and shunned by his community, banished to the Cathedrals of Paris where he lives in solitude.

There is no question that media throughout the years have depicted individuals with intellectual or developmental disabilities as hideous, dangerous, and unpredictable (Renwick, 2016). Some of the older 'vicious monsters' have spent many years locked away from society in asylums and mental hospitals. Then, in 1972, the taboo treatment of these disabilities gets exposed in the media.

In doing so, Rivera's (1972) exposé opened society's eyes to the conditions that individuals with intellectual disabilities, developmental disabilities, and psychiatric conditions suffer from while residing in asylums like Willowbrook, NY. The images and reports of these conditions were enough to turn even the strongest of stomachs. Luckily, news of these conditions spread like wildfire throughout the US and a majority of these asylums were shut down.

### Media exposure: Community inclusion and debunking stereotypes

As time unfolded, and the general public was exposed to various disabilities, a shift in representation of people with intellectual disabilities began to occur. We see more films like *Forest Gump*, *What's Eating Gilbert Grape*, *Rain Man*, and *I am Sam*. These films that showcase a more personified image of individuals with disabilities were only made within the last 30 or so years, almost 50 years after Rivera's exposé. Although we are moving in the right direction with breaking down these faulty beliefs about disabled individuals (Reajo & Pilao, 2018), we really need to prepare ourselves for a new wave of exposure like we have never seen before in the media. At the moment, roughly 1 out of 40 children are diagnosed with autism spectrum disorder (ASD).

### Diagnostic shift: Terminology and diagnosis

Years ago, people with ASD were considered 'retarded' or 'socially awkward'. Fortunately, the use of the word 'retarded' is no longer used in current terminology; and these people who would be lost diagnostically are given the supports and services they need. However, what we can do as a society is become more educated to what it means to be autistic and work on reducing the stigma of developmental diagnoses. A firm grasp on what it means to be diagnosed with ASD will enhance the probability of positive social interactions.

The fifth edition of the *Diagnostic and Statistical Manual* (American Psychiatric Association, 2013) defines autism spectrum disorder as: 'persistent deficits in social communication and social interaction across multiple contexts, as manifested by deficits in social-emotional reciprocity, non-verbal communication, developing, maintaining and understanding relationships.' Another category for diagnostic criteria includes 'restricted, repetitive patterns of behaviour interests or activities including two of the following: repetitive motor movements/objects/speech, insistence on sameness, inflexible routines/patterns, highly fixated interests, hypo or hyperactivity to sensory input.'

Autism spectrum disorder is categorised as a spectrum because the criteria of ASD includes a variety of symptoms for both high functioning individuals to severe/profound deficits in functioning. Individuals with ASD have one of the largest differences in IQ status. Some individuals may have an IQ lower than 70 which is the standard for someone having an intellectual disability or may have an IQ well over the average of 100. (100 IQ is the average for 'normal cognitive individuals'). In ASD, individuals who are non-verbal also sometimes present as lower functioning.

IQ tests are adaptive for non-verbal individuals (Bölte & Poustka, 2002). Someone may be non-verbal but obtain an IQ score well over 100. From my personal experience working with individuals with ASD I worked with a young man under the age of 10 who was non-verbal but had an IQ of over 145, which is equivalent to Albert Einstein's IQ!

Individuals with ASD are predominantly male (Murphy et al., 2009); averaging about 3 in 4 individuals with ASD (Herman et al., 2007). Individuals with ASD can be verbal or non-verbal. Non-verbal individuals may be able to communicate by using PEC cards or picture cards, assistive technology on iPads, or by gestures and vocalisations. Individuals with ASD exhibit repetitive or ritualistic behaviours, some of these common behaviours include hand flapping, pacing, inflexible routines, preoccupation with specific items/hobbies, humming, vocalising, repetition of words or actions (Seltzer et al., 2003). The emotional behaviours we see with ASD include poor eye contact, social withdrawal, emotion regulation deficits, low levels of emotional intelligence and social-reciprocity (Leach & LaRocque, 2011).

In the end, regardless of an individual's culture or background, all human beings communicate by non-verbal communication. So, given that we cannot solely depend on our verbal communication to connect with others, understanding nonverbal communication in greater depth becomes increasingly important. Whether someone is mute or blind, people generally do not refuse to participate in social interaction with these individuals. Interacting with people with ASD should be no different. The bottom line is we must all adapt our understanding of others and how we communicate with them to meet the needs of the other individual.

### Understanding ASD in real terms

Societally, across all intersections, we truly need to develop a basic understanding of what ASD is, and is not. In doing so, we can really evaluate how ASD affects individuals in more real terms. This begins with understanding how to facilitate social interaction in the real world. This can be achieved through a two-pronged approach: (1) Encouraging the media to depict more positive representations of individuals with ASD; and, (2) Promoting increased interaction with people with ASD through psychoeducation in the media and film.

People have a propensity to witness in the media, what will in turn, inadvertently inform us about certain groups of people. What I just described was how the media has the power to create social constructs. People then subconsciously internalise these constructions and use them to better relate with society and the world around us. People will trust the information provided with less scepticism when it is in the media. So, living in a community where there is not a lot of exposure to individuals with

intellectual or developmental disabilities and your only basis of understanding comes from the previously mentioned films and novels, you may be afraid and standoffish during your encounters with these individuals. What you think you know about a certain group will affect how you interact with them. This is the concept of prejudices and discrimination. Prejudices are the thoughts that we have about a certain group; discrimination is the act that is played out because of our prejudices. The media producing prejudices have been around for as long as social media has existed. The media has such a strong influence on people's thought processes that it can alter and control your biases (Entman, 2007).

A common term from the media teaching us to develop prejudices are propaganda films, which, like the notorious Nazi propaganda film *Triumph of Will*, is a testament to how media can distort reality and convince you that what you are witnessing is an absolute truth. An entire nation believed that all Jewish people were subservient, and that Hitler and the Nazi party were truly looking out for the best interest of the German people. Thousands of men and women learned to believe this based on what they were taught. It must be mentioned that I am not comparing current media and films to Nazi propaganda, however it is important to understand the power that these entities can possess. In current day media, there is so much access to what is being produced that it would be ignorant to believe that we are filtering out incorrect representations that we witness on a daily basis. So, the circle of misunderstanding has the potential to solidify, which is why it is so crucial that the media begins to provide accurate information, such as the violence portrayed of individuals with disabilities.

Individuals with any type of psychological diagnoses like autism, schizophrenia, depression, PTSD, etc. are not inherently violent, but victims of abuse and criminal behaviour. People tend to associate mental illness with violence when they are rarely the perpetrators. Films showcase a dark and twisted past that insinuates that this is why they are violent now and as a society it is just accepted. Most commonly now is the association of mental illness and school shootings; people hear violent behaviour and immediately assume mental illness. Autism is no stranger to being represented as dangerous and violent. Can individuals with Autism have aggressive-like behaviour? Yes, it's possible, but the reason for the aggression is able to be pinpointed to a specific cause, not just to be violent. Individuals with Autism are not sadists or masochists who enjoy hitting themselves or others; they are often frustrated or overwhelmed and unable to communicate what is bothering them. Once we have a better understanding that individuals with autism or any other disability are more likely to be victims we can reduce the stigma or being afraid of them, and thus promote more interaction. The media needs to move away from glorifying mental illness (Kumar et al., 2019) as this dark, dangerous malevolent affliction.

### Establishing a more humane mental health culture for people with ASD

The media must soften its stereotypical image of ASD as well as other mental illnesses. By softening the image, we will no doubt see a significant increase in tolerance and acceptance by others as well as people within the ASD community. This can be accomplished when the media not only focuses solely on someone's shortcomings but their strengths as well. For instance, if someone with ASD engages in self-harm by hitting themselves when they are frustrated, the viewer cannot leave with that as the takeaway about the individual – there should be some context clue about why the individual is frustrated or one of the other areas in their lives where they do thrive-memorisation, artistic skills, maths, etc.

This issue has been a controversial issue over the past decade or so, but it is important that it continues to be addressed and addressed until this theory is left in the dust. There are many opinions and arguments all over social media and news outlets that state that Autism is caused by vaccines. This theory has been disproven by many scientific researchers and the person who originally made this claim reported that he had falsified documentation and lost his medical licence. This theory is dangerous and cause for concern in the autism community because it insinuates that there is something to blame, someone is at fault or that who they are is a mistake. By labelling people with ASD of being the

result of a choice that the family made can be detrimental to their sense of self and how others view them. Regardless of the science behind what causes autism, we as a community need to focus on how we can be supportive now. Social media can play an intricate role in this topic as a majority of people seek out the opinions and recommendations from others dealing with similar situations (Sanghera, 2018). This topic is not addressed to imply that you should or should not vaccinate, but to rule out autism as a result. The prognostic factors associated with Autism indicate that genetic mutations and environmental factors regarding age of conception and course of pregnancy are what increase the likelihood of developing autism. Social media can help stop the divide when it comes to the discussion of vaccines in relation to autism.

To understand individuals with autism you need to have a basic comprehension of what someone with autism will experience on a day to day basis. As a precursor, each person with Autism may experience different symptoms and may come with a variety of intellectual abilities etc. Each person can be drastically different, which made diagnoses so difficult at first and we see such vast scale of people who fit under an ASD diagnosis. Have you ever been driving in a car and the sun setting is too bright in your eyes? Or been to a concert and the music is just way too loud you can hear your heartbeat in your ears? Ever bought a new shirt and the tag is unbelievably itchy on your neck? Imagine experiencing these sensations on a daily basis.

Individuals with autism can have heightened sensory experiences and we call it 'sensory overload' (Crane et al., 2002). There is so many things happening in their environment that it over floods their processing circuits in their brain and makes it difficult to concentrate or focus on the simplest of tasks. The light shining through the window may be blinding to them and they can't see their surroundings, someone tapping their foot as they take a test may make it impossible for someone with autism to hear their own thoughts. These daily hurdles may be difficult to ignore and can cause frustration and irritability to occur. Remember when I mentioned that individuals with ASD may have aggressive tendencies? Usually when they are overstimulated you may see more behavioural outbursts that occur. Any behaviour like hitting, punching, breaking things etc. all serve a function. Every behaviour is to fill a certain need-disability or no disability. Behaviors of any kind tend to fit within one of the following categories known as MEATS: medical, escape, attention seeking, tangible, or sensory. Individuals with ASD may hit themselves because they are frustrated because they are non-verbal and not receiving the attention they need, or because they have a medical issue they don't know how to communicate. Imagine having everything you want to say stuck in your head but unable to express yourself to others? Simply frustrating.

Being able to get to know someone with ASD you will be able to figure out what bothers them and most importantly what soothes them and they find enjoyable. People with ASD may need adjustments to their environment to accommodate their sensory stimulation. So people with ASD may avoid going to the mall to avoid large crowds, or may require specific brands of clothing that are comfortable to their touch. When it comes to accommodations for individuals with ASD it can be difficult to find a place that can support their needs. However, some businesses are beginning to get on the bandwagon and offering services that would be comfortable for those is ASD. Some companies are including sensory options into their businesses which offer less visual and sensory stimuli so individuals with ASD can avoid becoming overwhelmed. More and more businesses and places are becoming more sensitive to ASD needs but there is always was to improve so we do not exclude others from participating in social interactions. This concept may be difficult to portray in television or media but it is important to address the notion that every behaviour serves a purpose, if we see more situations of cause and effect in relation to ASD typical symptoms, we may encourage society to look for alternative measures to take instead of avoiding the problem. Another possibility is integrating more first person experiences in film that can appropriately demonstrate what it may feel like to have Autism. If we really took a look into

what it would be like to be in someone else's shoes we can become more empathetic to how we relate to others.

People with ASD tend to avoid social interaction with others. This typically occurs because the person with ASD has difficulty reading social cues, so to avoid embarrassment and humiliation they may avoid interaction to protect themselves. People with ASD have difficulty reading facial expressions, non-verbal gestures and filtering out what they say. Imagine buying an outfit that you think is very flattering and you feel great. If you ask someone with ASD their opinion, they may tell you flat out that it makes you look like your grandmother's couch, and to add insult to injury they may ask "why are you crying?" That person was not trying to be hurtful but shared their opinion not knowing that it may be upsetting to hear. They are honest and they are genuine with their responses. In addition to having difficulty filtering their thought processes they have difficulty understanding relationships. Have you ever had difficulty understanding your significant other or friend and wish they would just tell you what is bothering them? Of course! It is a constant guessing game for people with ASD to gather as much information from their surroundings as possible but still sometimes miss the mark on the social cues.

### IMPLICATIONS

ASD individuals wish they knew what others were thinking or feeling but are unable to identify what you may be experiencing. This makes it difficult for individuals with ASD to maintain their friendships or even make one to begin with, which can lead to a very isolated social life. Another issue in regards to social interaction with people with ASD is that typically people with ASD have a hobby or interest that they enjoy wholeheartedly. So one person may like trains and cars and will know everything you need to know about vehicles; because this is their main interest they may only want to talk about this subject even if you have no idea what they are talking about. It's not that they do not care about your interest, but they have difficulty seeing that someone else may not want to talk about trains for three hours straight. So to improve social interaction with people with ASD, you may need to be the one to initiate conversation. They may want to say hello but cannot bring themselves to physically do so. And when you are engaged in a conversation, you may need to be more verbal with sharing if something they said was offensive or hurtful; not to make them feel bad or put them down but to help them develop better social skills. This is where promoting social interaction with individuals with ASD can flourish in television and social media.

Out of all of the big blockbuster films that were previously listed, the best depiction of a high functioning young man with autism is from the Netflix series *Atypical*. This show does a fantastic job of depicting someone living with Autism and the struggles they go through with making friends, dealing with family issues and beginning to date. Not only does it depict an individual with Autism flawlessly, it does not focus on Autism being this person's world, it is a piece of his world. He is a teenager with teenager issues and drama, and he also is diagnosed with ASD. This person is not defined by his diagnosis, but it is something that he deals with every day. I think this television show truly captures how we need to prompt positive perceptions of ASD, normalise it. This show normalises and identifies the life of a family, with all of its graces and flaws. Life is messy, unpredictable and sometimes unfair. Film, whether it's hitting the big screen, being broadcasted on national television or binged from a streaming service should show all that it means to human, just for as it is, not extra dramatizing or shock value imagery. If we can have popular shows like *Friends*, *Seinfeld*, or *This is Us*, why can't we incorporate more characters with diagnoses like Autism where their diagnosis isn't the niche or punchline of why they are on screen.

Another common issue to avoid in media is the notion that individuals with ASD need to be 'fixed'. Media overdramatises that people's lives would be better if the issue they were struggling with just went away miraculously. This fairy tale type of idea is very dangerous not only for ASD but for everyone. Sometimes, the situations we deal with are lifelong or unavoidable. You wouldn't tell someone with

spastic quadriplegia that if only they could walk they would be so much better; so why treat someone with ASD that way? What should be emphasised more is the impact of how growth and developing skills to adapt to the cards we were given can improve the quality of life. Autism should not be portrayed that if only he was verbal, or if he suddenly got better than he could get a job. Being optimistic is important but its damaging being delusional, for the individual and their family. Some people with ASD may never speak, may never get a job or be fully independent, and that is acceptable. Individuals with ASD have a developmental diagnosis, but that does not mean that they do not have the potential to learn. Maybe someone's goal is to maintain eye contact for five minutes, or to refrain from hand flapping while out in the community; these goals can be mountains to people with autism and should be treated as such.

## CONCLUSION

Promoting improved social interaction with individuals with ASD through more positive and accurate representations in television and social media should have started a long time ago. A quote which I think is applicable to multiple facets of life but particularly when it comes to the portrayal of any diagnosis is: 'it is not your fault but it is your responsibility'. We may have not written the book on stigmas and stereotypes but it is our responsibility to make the required changes. So whether you are a screenwriter, director, actor, social media influencer or a person, If you come across someone who is non-verbal, learn how they communicate; sign language, iPad texting, writing things down etc. If the person is non-verbal and lower functioning observe their behavior and join in on activities that interest them. The old debate of the chicken or the egg: will we promote better social interaction by witnessing it through media, or will our interactions influence what is portrayed in media? Regardless, effort does not go unnoticed. Ultimately, the quality of someone's life can be changed by your actions.

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