The Relationship between Canadian Autistic Adults and Communication Barriers Before and Since COVID-19

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Introduction

Autism Spectrum Disorder (ASD) is a developmental disability primarily impacting social skills and sensory input. Other diagnoses such as Asperger's Syndrome and Pervasive Developmental Disorder (PDD) are referred to medically and academically as Autism in the DSM-5, released in 2013. Research in the Autism community converses primarily around children, and little is known about Autistic teenagers and adults. Since the COVID-19 pandemic and the multiple phases since 2020 there have been research papers and academic conversations around the aftermath of the pandemic in areas such as socialization impacts among Allistic (non-Autistic) individuals.

From January to April 2024, I compiled research articles from 2014 onwards to determine the common topics of discussion and how to breakaway the barriers being faced by Canadians ages 15 and up on the Autism Spectrum. Finding research that met the requirements was difficult since Autism research is dominated by the United States, United Kingdom, and Europe, and some research Canada participated in had less than 50% Canadian contributions. I also wanted to look into topics of discussion both before and since the COVID-19 pandemic to note any common features and any repeat conversations. It is vital that we compare and contrast research topics due to changes including a transfer to hybrid and remote environments.

Methodology:

Methodology in Autism research involves a combination of qualitative and quantitative research, as mixed-methods research is more holistic than the two separately. While the literature being reviewed does involve numbers, the research I will be working towards will primarily be qualitative. I will also be doing secondary exploratory research. Because of the time limit the research will be surrounding online, literature and case study research. The reason for this is to identify possible improvements in increasing Autism research based in Canada. There were three methodologies used in this research, all vitally important to encompass as much of the Autism community at large as possible.

Critical Theory

Critical theory is a common methodology used in the humanities and any conversation around topics concerning marginalized voices to critique current structures in our society. Critical theory allows us to think more about ASD and the relationship with the everyday.

Constructivism

Most common in education, constructivism discusses how our experiences and values are constructed and built further with knowledge we gain, thus can create tensions because of different interpretations on knowledge based on personal bias.

Post-Positivism

Telling the truth is at the epicentre of our lives the moment we comprehend morals and words, leading to philosophical connections. Lying involves consequences, but also telling the truth may be too blunt or controversial. Ultimately, according to post-positivism, the truth is important, as long as a person can see the truth is imperfect because of the experiences, values, beliefs and morals that shaped us and our worldview.

Theoretical Framework[1]:

The framework being used for this research was the Social Information Processing Theory (SIP) implemented by Crick and Dodge. The SIP theory was often used for social interactions with young Autistic children to demonstrate differences in processing situations. When it comes to teaching children about social skills, there are five steps to achieve understanding of how to react to future encounters.

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[1] Ziv, Y. et al (2013) *Social Information Processing in Preschool Children Diagnosed with Autism Spectrum Disorder,* Springer Science+Business Media, New York

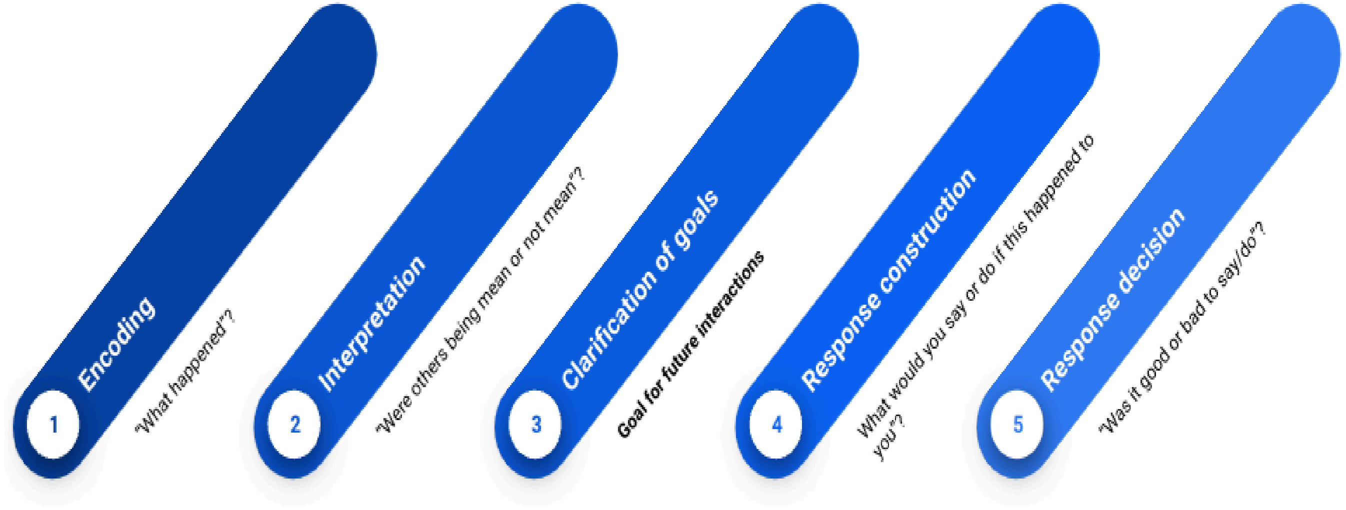

Figure 1: SIP Theory Steps to Process Social Interactions

1. *Encoding*
2. *Interpretation*
3. *Clarification of Goals*
4. *Response Construction*
5. *Response Decision*

Limitations

Many of the participants in the research articles are predominantly female and white. It should be acknowledged that race, gender, and sexuality in autism research is lacking. I recognize that most of the research I have observed is of Western and European origin. Because the research I will conduct is through secondary analysis, the sample size may be small and will be restricted to works after 2013 to recognize the change of ASD according to the DSM-5. There is also significant gaps in Autism research in Canada causing a small sample size of research articles

Ethical Considerations

The research will look at research papers which discuss Autism and the COVID-19 pandemic and will touch on how the two are connected when it comes to communication and socialization skills for adults on the Autism spectrum.

This process of secondary data analysis will take three months with a presentation and written report at the end of March or the beginning of April of this year. I will be referring to the names of the researchers, moderators, and other names that may be in the papers, but otherwise will follow confidentiality and anonymity. All references will be cited and sourced in APA.

Literature Review

Berrigan, P. et. al (2020). *Employment, Education, and Income for Canadians with Developmental Disability: Analysis from the 2017 Survey on Disability.* Journal of Autism and Developmental Disorders, 53:580-592

Patrick Berrigan, Craig Scott and Jennifer Zwicker did a quantitative study based on information in the 2017 Canadian Survey on Disability using descriptive statistics to show the continued disparities faced by people with developmental disabilities (DD) like ASD. Currently, people with Autism have poor employment outcomes, poorer situations for housing and are less likely to receive high education. Depending on where someone is in Canada will also determine the amount of support in place to ensure a successful and well-rounded life for people with DD.

This shines a spotlight on how far we still have to go to give people with disabilities what they need to live a successful life. The acknowledgement of limitations is of utmost importance as the study potentially missed a large number of people with disabilities (the homeless and people on First Nation reserves for instance), but that is not to place blame on the study. Based on personal experience, depending on the 'severity' of someone's Autism it can lead to little to no support from the Canadian federal government.

Cascio, M. et al (2020). *Person-oriented ethics for autism research: Creating best practices through engagement with autism and autistic communities.* Sage Journals, Vol.24 (7) 1676-1690

Defined by Cascio et al, "research ethics means issues that concern the welfare and wellbeing of people who take part in research". There is a difference in Autistic and Allistic (not Autistic) research since Autistic people need a more person-oriented ethical approach to research (to prevent meltdowns or shutdowns for example). Five methods to use include individualization, acknowledgement of the lived world, empowerment to make choices, and a significant increase in collaboration between participant and researcher.

This is a very important topic to discuss. Often Autistic individuals are not accommodated for and have to adapt to whatever situation they are in. So seeing something like this implemented in both research and in the world around us would make a vast improvement of quality of life.

Cassidy, S. & Nicolaidis, C. (2020). *An Expert Discussion on Autism in the COVID-19 Pandemic*. Autism in adulthood : challenges and management, 2(2), 106–117.

Sarah A. Cassidy along with co-moderator Christina Nicoladis did a roundtable interview with 8 individuals knowledgeable about the Autism community. From doctors and professors to parents of Autistic children and Autistic individuals, there was an even divide between professionals and everyday advocates. The main topic of discussion was how Autistic adults were impacted in the COVID-19 pandemic and conversations around accommodations and overall well being of Autistic adults were other important conversations discussed in this interview. Ultimately it was stressed that accommodations being requested (hybrid workplaces for example) and were being implemented because of the pandemic should remain a long term solution for building a more inclusive society, and how barriers around housing, social and financial burdens be lessened.

This was a great start to research discussing Autism and COVID-19 that involved multiple voices (including a Black woman; Autism research regarding non-Caucasian Autistics is severely lacking), however for the sake of the research question I am mainly critical of the one and only Canadian voice in the interview - the majority were from the United States and the United Kingdom where the majority of Autism research is based.

Courchesne, V. et al (2022). *Autism Voices: A novel method to access first-person perspectives of autistic youth.* Sage Journals, Vol. 26(5), 1123-1136

This qualitative study focused on the inclusion of information given by 33 Autistic youth aged 11 to 18 who are minimally verbal and/or had lower cognitive abilities to promote an increase of inclusion in research surrounding Autism. Using a pre-interview survey and conducting semi-structured interviews, what was discovered was no matter how it was communicated, there was a rich amount of information given and demonstrates how communication goes beyond verbal speech.

We often see and obtain information around Autism through verbal communication and neglect the perspectives of those who use other methods to communicate, such as communication cards or tablets with language apps. People process information differently so it is intriguing that there is little information from those who use different techniques to converse with people in their daily life. Advocating for voices that are usually excluded from discussions around Autism is vital.

Ghanouni, P. et al (2021). *Independent living in adults with autism spectrum disorder: Stakeholders' perspectives and experiences.* Research in Developmental Disabilities 119 (2021) 104085

Living independently is challenging, especially if there are barriers stopping us from thriving. This study focused on highlighting barriers faced by Autistic individuals trying to adjust to independent living. By conversing with 19 Autistic adults and parents of Autistic adults in semi-structured interviews it was found that there were three major factors into why adults with ASD struggle with living on their own. One was psychological stability due to a need for routine and thus any changes made could lead to emotional distress. Second was financial management - primarily the barrier of receiving an income in the first place due to high unemployment rates among people with ASD. Lastly, the overall adjustment to independent living is challenging due to a change in environment, plus a community with high amounts of smokers or busy streets can cause sensory overload leading to more emotional distress.

Canada in 2024 is currently having a housing crisis where people can barely, if at all, afford rent and the total cost of living, making those who are unemployed or need to prioritize finding housing to suit their needs can be extremely challenging. The low number of interviewees makes this research article a little less reliable and potentially misses a significant population of people since this was only for adults aged 25 and older. It would be beneficial to do a revision including more people and a different age range (maybe 22 and older) to see if there are any important findings.

Harmuth, E. et al (2018). *Barriers and Facilitators to Employment for Adults with Autism: A Scoping Review.* Annals of International Occupational Therapy, Vol. 1, No. 1, 2018, p. 31-40

This scoping literature review observed and gathered information from 161 articles around needs for Autistic adults in personal, environmental, and work-specific aspects of life. Key themes included issues around executive function, social difficulties, lack of long-term workplace support, stigma, and unclear expectations and boundaries. All these factors and more should be viewed as a whole of a problem needing resolving rather than tackling each problem individually, thus creating a more sustainable and coordinated approach to employment support and training.

While I fully agree that all these key themes need to be observed all together rather than separately, we also need to look further into job positions and employers themselves. Sometimes people with ASD have access and successfully completed job training and have lots of support but still do not get hired due to stigma that may be implemented without even being aware. Rather than only focusing on supporting Autists we also need to improve overall awareness and acceptance.

Lindsay, S. et al (2021). *Disclosure and workplace accommodations for people with autism: a systematic review,* Disability and Rehabilitation, 43:5, 597-610, DOI: 10.1080/09638288.2019.163658

This study looked at seven different countries including Canada. In total there were 77006 participants (13-75 years of age) across 26 studies looking at the varied results of disclosure and workplace accommodations. Out of 26 studies, Canada partook in 5 which had varying results. Some studies showed that disclosure resulted in Autistic individuals not being hired for a job or were denied workplace accommodations due to a lack of supportive employees/employers. Ultimately there is a conflict of consistency when it comes to having individuals with ASD disclose their situation due to valid concerns of possible discrimination.

McNeil, K. et al (2018). *Circles of care for people with intellectual and developmental disabilities; communication, collaboration, and coordination,* Canadian Family Physician, Vol. 64: April 2018

A clinical review on health information exchange (HIE) processes, the focus is to have improvements in communication, collaboration and coordination when talking to individuals with developmental disabilities (DD). It is important for physicians to speak slowly and clearly, use other delivery methods (drawings and pictures), avoiding jargon (words that may not be known across the general population), and ultimately adjusting the way the physician is communicating in a way that can be understood by a person with a DD thus making a patient-centered care plan.

We often get fixed into a routine, so much that we often have more difficulty when breaking that routine. When we're used to communicating a certain way it can be tricky to adjust for a select number that does not communicate the same way. Some physicians have been around for decades and can often stick to a way of talking to their patients with little to no changes when interacting with people on the Autism spectrum and other disabilities. This was mainly a critique of the current ways in healthcare, but it was important nonetheless to include in this literature review.

Salerno, A. and Schuller, R.A. (2019), *A mixed-methods study of police experiences of adults with autism spectrum disorder in Canada,* International Journal of Law and Psychiatry 64 (2019) 18-25

Salerno and Schuller gathered and analyzed data from an in-depth survey given to 35 Autistic Canadians to determine the amount and quality of police interactions. 53% have had more than 4 interactions and more than three-quarters have had at least one police interaction. With 58% a victim of a crime and 37% having a mental health crisis, themes when interacting with police officers included being met with aggression (20%), accusation (16%), and the Autistic was in distress (8%). There was a variety of responses, which qualitative data shows, including distrust, trauma, and overall fear of law enforcement, showing police should receive more education and training revolving around how to interact with Autistic individuals.

Without awareness there can be no improvements made. Depending on where someone is in Canada there may be a lot of knowledge of ASD or barely any at all. It is safe to say because of the different population sizes there may be some people who never interact with someone on the Autism spectrum. Having something simple as a handbook in case an interaction is a rare occurrence would be enough to bring awareness and improve situations that can lead to fear, anxiety and trauma if done poorly. Ultimately everyone needs to be treated with respect and improvements can be made by not automatically assuming something based on the way someone acts.

Vogan, V. et al (2016), *Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction,* Disability and Health Journal 10 (2017) 264-270

Examining health services through the eyes of 40 Autistic individuals (aged 18-61) over the span of 12-18 months via bimonthly surveys, people who struggled with the health care services were those searching for mental health and complex medical resolutions. The most sought-out services outside a family doctor included a dentist, counseling and psychiatry. Some barriers included not looking where to look, overwhelming amount of steps, difficulty describing issues, fears and anxiety around stigma around ASD, and past negative experiences.

Accessibility is an ongoing issue for invisible disabilities especially when it comes to finding resources. As someone that has had some negative experiences, it can be very draining to constantly self-advocate and accommodate to what people want, may it be verbal communication and a lack of visuals, or a lack of clarification due to the fast paced nature of doctor’s offices. It would be interesting to see how Autistics handle certain procedures like pap smears and other more stressful specialist visits.

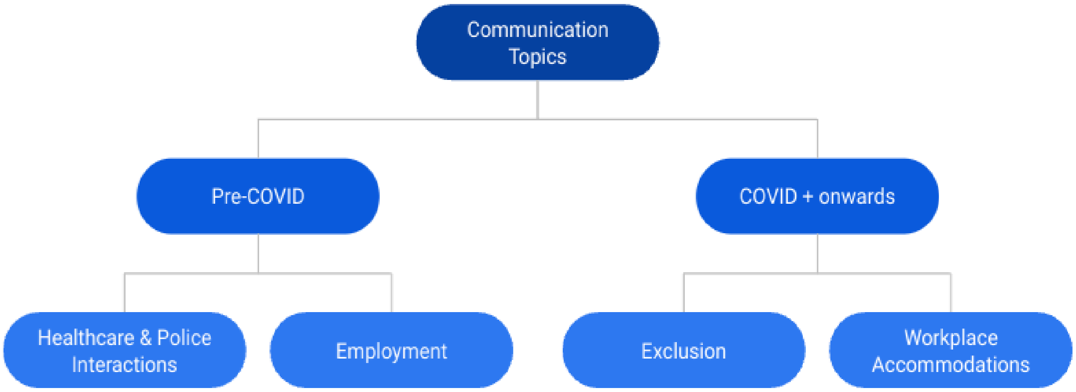

Figure 2: Topic Trends in Canadian Autism Research

Recommendations

There has been a consistent conversation about workplace accommodations for people with ASD. Employment opportunities for Autistic people have not changed from pre-COVID, although with inclusion of hybrid and remote work environments this should not be the case. Ultimately, we can see that Autists have constantly adapted to situations not ideal for them because of societal stress surrounding socializing. There needs to be accountability that not only there are improvements to be made in work-related topics, there needs to be vast improvements on all aspects of life, all coming down to basic understanding of different communication techniques and non-traditional ways to execute non-verbal communication.

In my personal experience as an Autist I was always criticized for not maintaining eye contact, something that myself and others find uncomfortable. The reason eye contact is engrained in the idea of success is because of information around eye contact being the number one technique to secure a job interview - because you appear interested and invested. The society we have built is essentially an all-or-nothing course of thinking because if we do not do what others tell us then we are looked down upon. It is a harsh way of putting it but breaking down assumptions and removing ableist lines of thought would be the first step, or at least being aware of unconscious bias and working to improve one's mindset.

As much as I want to give a straight answer to what needs to be done, there is no perfect way to improve on what has been ingrained in our minds for generations, however I can offer recommendations on how to bring about Autism awareness and to lessen communication barriers we have put on our Autistic population.

1. *The Government Level*

There are three different forms of government in Canada: municipal, provincial, and federal. Depending on where you are in Canada will depend on how much or how little Autism awareness there is. Municipal governments (city councils) should focus on figuring out if a. they have a population of Autistic people (via surveys) and b. if the city has businesses and tourist attractions that are sensory friendly, especially if the city wants to implement accessible tourism. The provincial government (government that oversees the different areas of their province) would be in charge of improving support for Autists within education, healthcare and housing, especially for Autists 12 and older, and improving transitions for Autists turning 18. The federal government needs to review their definition of Autism and the definition of who needs support. Being denied funding because of what transpired years ago should not happen, due in large part to Autism having a variety of support needs throughout their lifetime.

2. *The Workplace Level*

When the COVID-19 pandemic began, so did remote and hybrid job prospects and non-traditional interview setups. This was something Autists have been asking for for so long and yet there is still a large percentage of Autists that are unemployed or under-employed. Some Autists need the extra support for training, but what if some Autists have undergone training and still get rejected after the job interview? Traditional and non-traditional (online, group) interviews need to remove certain assumptions around non-verbal and verbal communication. Not speaking to a receptionist when you first walk in is sometimes not a sign of disrespect - it could be preparation for the interview. No eye contact does not mean disinterest, but could mean looking in eyes can be uncomfortable or even painful. Until we are at a point where everyone can be comfortable with disclosing a disability and not be in fear of being rejected, all we can do is not assume. But how to improve approaching disclosure?

a. Email templates “please let me know if you have questions, concerns, or wish to disclose any information to us”.
b. If something is disclosed, ask the interviewee if they are comfortable sharing the supports they need to succeed
c. Whether accepted or rejected, provide feedback on what can be improved at the next interview - we do not know what to change without feedback
d. Take courses in neurodiversity

3. *The Personal Level*

Being self-aware of bias and upbringing is the first step to supporting Autistic people. Autism is often a disability only aware from people who are or know someone who has ASD. Just like with everything we hear about for the first time we want to research, so research and learn about Autism. The best resources are the following:

a. People with Autism are always the best place to start (books, podcasts, TedTalks)
b. Academic and research journals (be aware of content published before 2014 due to language changes)
c. Classes surrounding neurodiversity

If there is interest in learning about neurodiversity (Autism specifically), these free courses can help:

Supporting Autistic Mental Health in the Workplace (Canucks Autism Network)

Autism and Neurodiversity in the Workplace (The University of British Columbia)

Conclusion

Canada has come far in supporting Autistic adults, but we still have a long way to go. Ultimately there needs to be collaboration and conversations between Autists and Allistics in order to improve the lives of people living with ASD in all aspects of living.