

Autistic Voices Project Literature Review

Employment Challenges Pre-COVID-19

Autistic people constitute an untapped talent pool of potential employees who could help increase productivity and success in the workplace.(1-4) Employers have reported that Autistic employees show superb efficiency in work-related tasks, are trustworthy, honest, detail-oriented, and consistent in their work.(3,5,6) However, despite these benefits and many Autistic Canadians being able, willing, and eager to work, they face worse employment outcomes compared to their neurotypical peers and other disability populations and struggle to find and maintain employment.(7,8)

According to the 2017 Statistics Canada “*Persons with Disabilities and Employment*” survey, only 33% of Autistic Canadians, aged 20+, report being competitively employed compared to 79% without disabilities.(8) Furthermore, those who are employed are often underemployed, meaning they unwillingly work part-time hours, receive minimal pay, and/or underutilize their skills in roles that are below their intellectual potential.(5,8) In a 2020 survey of 171 Autistic Canadians, 88% reported being employed at some point in their life, with 56% indicating difficulty with maintaining that employment.(9) Reasons for not staying employed included challenges with social and communication skills, bullying and harassment, difficulties fitting in, mental health challenges (e.g., stress, anxiety, burn-out), and unsupportive workplace environments.(9)

In 2020, the Canadian Autism Spectrum Disorder Alliance (CASDA), undertook two projects, one with Ready, Willing, & Able to identify eligibility and delivery issues of current employment programs for Autistic Canadians,(10) and one with Kids Brain Health Network (KBHN), to develop policies to inform Canada’s upcoming National Autism Strategy.(11) From the latter, compellingly, the need for a focus on the development and enhancement of pre-employment programs and inclusive workplaces to support Autistic employees became evident. Currently, the needs of Autistic Canadians who are transitioning to employment outweigh the available supports and resources.(12) Additionally, we know that workplace/organizational factors such as culture, attitudes, supports, and policies tremendously impact, both positively and negatively, the employment opportunities and outcomes for Autistic people.(13,14) Corroborating and augmenting this, preliminary findings from the Autism Employment Scan from conversations with Canadian practitioners further highlight a lack of knowledge about workplace adjustments/accommodations, poor attitudes and awareness amongst employers, and that there are limited, funded employment supports available for Autistic employees.

COVID-19 and Employment

In late 2019, the COVID-19 pandemic began in China, rapidly and profusely spreading globally. (15) The first Canadian COVID-19 case was in January 2020, and by March, cases precipitously increased resulting in lockdown measures implemented across Canada. (16,17) Although COVID-19 is having variable, deleterious effects amongst all Canadians, disabled Canadians are being impacted at substantially greater levels in multiple facets of life, such as employment.(18) For example, out of approximately 13,000 Canadians with disabilities or long-term conditions who participated in a Statistics Canada online questionnaire, over one-third of participants reported experiencing temporary or permanent job loss and/or reduced work hours during the pandemic. Additionally, those with multiple health conditions were more likely to report job loss since March 2020 compared to those with only one health condition.(18)

At an international scale, we see similar patterns showing that people with disabilities are facing newfound, worsened employment rates.(19, 20) Although minimal research exists that showcases the direct impact of COVID-19 on employment for those on the autism spectrum, preliminary work highlights that COVID-19 is/may exacerbate pre-existing employment challenges and inequities faced by this population.(21-23) In Canada, the “*Pandemic Canadian Autism Needs Assessment Survey*” revealed that the pandemic has exposed and enhanced pitfalls and gaps related to employment for Autistic Canadians. For example, one participant noted, “*I have not been able to access the Canada Emergency Response Benefit because I did not earn enough income prior to COVID-19 due to facing barriers to employment related to my autism... I am still living below the poverty line, since housing takes up more than half of my living expenses, and COVID-19 has exposed the pitfalls of that reality*”. (24) However, despite this work, information and literature on the topic of employment and COVID-19 amongst Autistic Canadians to date has been scarce. Thus, we decided to speak to four organizational leaders and representatives of employment agencies and programs across Canada that support Autistic Canadians. Organizational leaders were identified as leaders in the field through prior engagement with the KBHN-CASDA Employment Policy Working Group and contacted via email by VT.(11)

From these conversations, we heard that despite novel barriers due to COVID-19, programs, services, and supports continue to run with adjustments and refinements made to accommodate an online format and delivery. Prior to COVID-19, programs were offered in-person, for example job sampling, peer mentors/buddy programs, employment skills training, and job coaching. However, organizations have been forced to come up with innovative alternatives to deliver high quality supports and services (Table 1). First, for job sampling, one organization is developing virtual job sampling scenarios to replicate a variety of job roles in multiple industries. Second, mentorship programs have shifted to an online format dovetailing audio-visual and text/direct messaging check-ins and supports. Third, for employment skills and other relevant training, organizations are utilizing different approaches. For example, online asynchronous

learning platforms are being used to support and accommodate people on the autism spectrum to access e-learning modules at times that are most convenient for them. This has increased accessibility for those who were unable to attend limited, restricted, in-person session times. Video communication platforms are also being utilized to shift content from in-person training to online, for example, with one program called Employment Retention Training and Assessment. Finally, leveraging technology seems especially useful for the purposes of job coaching. For example, one application called Brain-in-Hand, originally developed in the United Kingdom, is a solution-focused, person-centered application that can be accessed through a smartphone to provide individualized, tailored, job support (e.g., coping strategies, identifying and utilizing strengths, assessing workplace needs, etc.). (25) Applying technological advancements to provide job coaching services or on-the-job-supports is also seen and suggested in the literature.(19, 26) For example, leveraging virtual reality technological platforms to provide job coaching services.(27) For those without access to technology, or if technological options are too costly, organizations have provided alternatives to access important information and training resources, such as providing Chromebooks and data sticks. Additionally, organizations noted leveraging existing, less costly, assistive technologies and platforms available for purchase or that are already available to their team (e.g., tools embedded within Microsoft products, Zoom, etc.).

Regarding remote work, organizational leaders and representatives highlighted a myriad of advantages and disadvantages of remote work for Autistic employees (Table 2). For example, one organizational representative noted that working remotely has alleviated anxieties around in-person, workplace social demands and has allowed employees to take optimal, needed time when responding to workplace demands/tasks that they may have been expected to do immediately if in-office. However, some organizational leads and representatives made particular note of some disadvantages and challenges of remote work for this population. For example, one organizational leader noted that working from home may impact productivity, particularly, when employees struggle to seek help or clarification. Although scarce, additional, external sources have also highlight some of these points (28-30).

An additional remark, made by all organizational representatives, was that, unsurprisingly, mental health challenges have increased. There is a notable need for enhanced, more frequent mental health supports and check-ins for Autistic employees across Canada. This aligns with global reports and research findings that indicate mental health challenges have worsened throughout the pandemic amongst those on the autism spectrum.(21, 24, 31-34) Mental health challenges can include worries about contracting the virus or the safety of loved ones, abrupt changes to routine resulting in stress, and/or the deleterious effects of social isolation on overall wellbeing.(24, 34) In response to these heightened needs, one organization is providing online mental health training to employees to support recognition and response to signs of distress in employees.

Although there are preliminary data on the impact of COVID-19 on Autistic Canadians, and we have highlighted emerging practices utilized by Canadian employment support agencies, there is a paucity of work that highlights the voices and experiences of Autistic Canadians. To best understand future directives and what's needed to support Autistic Canadians regarding employment, their experiences must not only be considered, but highlighted and prioritized. Thus, the Autistic Voices Project addresses current gaps regarding the perspectives of Autistic Canadians related to COVID-19 and employment to bring their experiences to the forefront by developing and disseminating lived experience testimonial videos. Interviews and conversations were held with 30 Autistic Canadians from December 2020 to February 2021, using Zoom software. Through these impactful, novel video testimonials, Autistic Canadians highlight the current challenges faced that need to be addressed, and also areas of opportunity brought to light due to COVID-19. These videos are meant to change knowledge and awareness about the impact of COVID-19 on employment for Autistic Canadians amongst other Autistic Canadians and their families, employers, employment agencies, and all those who support people on the autism spectrum obtain and maintain employment.

Since the beginning of this pandemic, the world as we know it has shifted immensely. Although undoubtedly, there have been challenges faced, it is important to learn from these experiences and understand how we can use this information to engender change and improve the employment outcomes of Autistic Canadians. Importantly, we cannot go back to “business as usual” before the pandemic. One organizational representative highlighted that there is no standardized or singular approach that will benefit all Canadians on the autism spectrum. We can, however, speak with Canadians on the autism spectrum to learn and understand what strategies, practices, and policies will be best suited to target their unique needs. We must leverage learnings from remote work, technological advancements and utilization,(19) best-practices from employment support agencies, and the perspectives and experiences of Autistic Canadians to create more inclusive, autism-confident workplaces and improve employment outcomes for Canadians on the autism spectrum.

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Note: Based on the literature and the strong preference of the Autistic members of CASDA, CASDA recommends either using identity-first language, or more neutral terms such as "person on the autism spectrum." In order to respect the agency and diversity of voices within the community, CASDA will use such terms interchangeably, as recommended in our 2020 Language Guide.

This project, led by the Canadian Autism Spectrum Disorder Alliance (CASDA), was delivered in partnership with The Employment Recovery Project. The Employment Recovery Project is an initiative aimed at improving workplace inclusion for persons with an intellectual disability or Autism Spectrum Disorder (ASD) through addressing critical hiring and support needs that have emerged in response to COVID-19. The Employment Recovery Project is delivered by Inclusion Canada (formerly the Canadian Association for Community Living) and CASDA and works in collaboration with Ready, Willing and Able.

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Table 1. Supporting Autistic Canadians in a Virtual Environment: Emerging Practices from the COVID-19 Pandemic

Virtual Emerging Practices	Canadian Organization Examples
Job Sampling	<ul style="list-style-type: none"> ● Provide experiential learning through interactive and immersive job simulations in customer service, contact centre, data entry, etc. ● Creating virtual job previews for industries such as hospitality, retail, information technology, etc. ● Provide scenario-based learning vignettes to simulate learning experiences and situations that may arise on-the-job. ● Considers sensory and other challenges participants might face.
Peer Mentors and Buddy Programs	<ul style="list-style-type: none"> ● Virtually work with Autistic employees to support with and guide on a variety of tasks. ● Audio-visual connections and check-ins. ● Provide support with general workplace skills; assist with networking and connecting with others; support technical skills related to the job role. ● Create a virtual network and social culture of allies within the organization.
Employment Skills Training	<ul style="list-style-type: none"> ● LinkedIn Learning courses to help people on the autism spectrum develop micro credentials to augment skills and increase competitiveness in the labour market. ● Content and components from in-person employment retention training and assessment programs transferred online using Zoom software (e.g., didactic lectures, assignments, teamwork training, working through stress, etc.). ● Team-building online meetings to provide Autism-specific training (e.g., practicing presentation skills, social reactions/cues)
Job Coaching	<ul style="list-style-type: none"> ● Brain-in-Hand job-coaching technology.

	<ul style="list-style-type: none"> ○ If the employee requires a greater level of support, the application can connect virtually the employee with a real-life job coach or mentor. ● Virtual job-coaching meetings. ● Online soft skills support through job coaching. ● Virtual job coaching offered for employers and managers to support Autistic employees.
<p>Leveraging Current Technology and Assistive Devices</p>	<ul style="list-style-type: none"> ● Examples include JAWS ® Screen Reading Software, Microsoft Play my Emails, Digital Sticky Notes, Closed Captioning (on video conferencing platforms like Microsoft Teams, Zoom, etc.), MURAL, Text-based chat software, etc.

Table 2. Advantages and Disadvantages of Remote Work for Autistic Employees

Disadvantages	Advantages
<ul style="list-style-type: none"> ● Without in-person social interactions, remote work may make Autistic employees feel even more isolated and/or heighten anxieties. ● When working remotely, it is difficult for managers to check-in as frequently or become aware of distress in the employee. ● May impact employee productivity if the employee isn't comfortable seeking help or asking questions. ● Change in regular workplace routine may be difficult. ● Creating work-life balance; learning how to stop working and manage time at home. 	<ul style="list-style-type: none"> ● Mitigates issues with workplace “downtime” (e.g., when employees on the autism spectrum do not have job tasks or projects to work on in the office, they sometimes feel judged or under observation) ● Comfort of working in the home environment. Allows employees to feel safe working in a familiar space where they can manage and adapt the environment as needed. ● Reduces potential sensory difficulties. ● May improve employee productivity, with the employee being less distracted and more comfortable in their home setting. ● Reduces in-person social interactions for employees who have difficulties or anxieties surrounding socializing.

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