

## AUTISTIC VOICES PROJECT – NARRATIVE SUMMARY

### What's the Autistic Voices Project?

Led by the Canadian Autism Spectrum Disorder Alliance (CASDA), the Autistic Voices Project (AVP) was prompted by the need to better understand the impact of COVID-19 on employment experiences amongst Autistic Canadians, specifically, unique challenges faced and opportunities that have emerged. The purpose of the AVP is to bring the experiences of Autistic Canadians to the forefront and highlight the criticality of their employment-related experiences during COVID-19. Employment experiences constitute those who are currently working, either remotely or in-person, those who have been laid off due to the pandemic, and/or those who are actively job-searching.

The experiences of Autistic Canadians are presented to you in the format of lived experience testimonial videos, that we hope you find to be impactful and thought-provoking.

### What did we do?

From December 2020 to February 2021, informal interviews were conducted with 30 Autistic Canadians, using Zoom online software. Canadians on the autism spectrum were invited to partake in this project via targeted emails, social media postings, and general dissemination via CASDA member channels and other autism-specific community organizations across Canada. Interviews ranged from 20-minutes to 1-hour-and-30-minutes and questions inquired about experiences working, job searching, and/or being unemployed during the pandemic, related to challenges, benefits (when applicable), supports received, and impact on mental health and overall wellbeing.

### What did we find?

Participating Canadians on the autism spectrum provided diverse experiences from across Canada, including Ontario, British Columbia, Alberta, Nova Scotia, Manitoba, Quebec, and New Brunswick. Autistic Canadians ranged in age from 18 to 48 with some working remotely or in-person, others actively looking for work, and some who were unemployed and were either laid off or chose to take a break for work due to personal, COVID-related reasons.

Results from these interviews were grouped to highlight key learnings across the 30 interviews. Interview excerpts were pulled and clipped into 10-second-to-one-minute videos to be used in the final lived experience testimonial videos. The following lived experience testimonial videos were developed and edited, in collaboration with and co-led by a person on the autism spectrum: 1) Introduction, 2) job role changes, 3) challenges, 4) benefits/opportunities, 5) supports, 6) mental health, and 7) closing remarks/advice.

#### *1. Introduction*

This video compilation includes background information about our diverse range of participants, including educational backgrounds, province of residence, and examples of past job roles. For

example, one individual spoke to her extensive educational background, such as obtaining a PhD in English Literature from the University of Edinburgh. Another spoke to his past job experiences as a flight attendant and gas station attendant handling customer service duties.

## 2. Job Role Changes

This video showcases changes to job roles and tasks experienced by employees on the autism spectrum due to the COVID-19 pandemic. For example, one woman spoke to how there are now less tasks for her to perform in her role as a café attendant at a coffee shop: *“With no seating, there’s no tables to wipe, there’s no condiment stand – there hasn’t been a condiment stand for a long time I think because of everything going on”*. Additionally, she spoke to a reduction in her work hours saying, *“I used to do six hours – two, three-hour shifts – now I’m doing one, four-hour shift”*.

## 3. Challenges

This video highlights the challenges and barriers faced by Autistic Canadians related to job searching, remote work, in-person work, and/or being unemployed during the COVID-19 pandemic. One woman spoke to challenges related to remote work, for example, the inability to seek in-person clarification or ask questions related to job tasks. She said, *“It’s harder to do in an email, and it’s harder to, you know, like I would get these sort of directions and sort of like, I’m not really sure what it is you’re asking me to do”*.

Another woman discussed challenges related to video calls saying, *“People expect you to turn on your video and it’s really hard for me as an Autistic person because there’s uh a lot of social masking you have to do, but not only that, you also have to be able to decipher what the other person is saying just by looking at their face”*.

Regarding in-person work, one man spoke to the difficulties of wearing a mask while doing manual labour tasks, and that it was difficult to breathe while lifting heavy objects. For another man who is actively looking for work, he discussed heightened challenges and greater competitiveness due to reduction in available jobs with more people applying for the same roles.

Additionally, and notably, some participants explained employment gaps that have surfaced and/or worsened for people on the spectrum during the pandemic. For example, one man spoke to the pandemic making it harder for people on the autism spectrum to find a job: *“Now it’s making it harder for neurotypicals as well, so that’s automatically going to make it even harder than it was before for us”*.

## 4. Benefits/Opportunities

In this video, you will hear from participants who describe some of the benefits they have experienced, and emerging opportunities related to working during the pandemic, both in-person and remotely. Regarding remote work, one woman spoke to the benefits of being able to control her sensory environment: *“I don’t have like people coming by and just wanting to socialize... I love working from home”*. One man spoke to the newfound benefit of online interviews, and that

having his job interviews conducted through Zoom have helped ease stress, saying, “I’ve had uh, I’ve had a much easier time speaking.” Another man, who is still working in-person said, “It’s still good to get to talk to people...we do have regular customers and with your coworkers as well, um yeah, a lot of the social interaction that you wouldn’t get otherwise... that’s definitely one of the benefits of still working in-person”.

One woman spoke to the support that has arose ubiquitously related to mental health, wellbeing, and supporting those who are unemployed:

*“This is the first time I’ve seen a lot of public support for just the, the stressful um experience that is COVID and particularly for the people looking for work or struggling to work to the same level of productivity that they had before the pandemic... And it’s been really helpful to see that, because it’s helped me give myself permission when I need to, to kind of take time and step back”.*

## 5. Supports

Participants discuss the variety of supports they’ve received throughout the pandemic, such as from family, friends, employment support agencies, external professionals (e.g., therapists), and their work supervisors, managers, and colleagues. For example, one woman spoke to how her manager has been exceptionally supportive throughout the pandemic: “My manager has been talking to me every week, he really like makes time even if we don’t do Zoom, he eats lunch with me on his lunch break once-a-week... And he really explains things to me when I have any questions”. Other participants spoke to support from family throughout the pandemic while working or looking for work, for example one man said, “There’s my mother who helps me with like reviewing resumes, preparing for interviews, etc.” Another man discussed supports from an employment support agency, and how they help him prepare for interviews and how to write a resume and cover letter.

## 6. Mental health

In this video, participants share their experiences related to mental health during the pandemic. Mental health experiences relate to those who are employed and struggling to find work, those currently employed, and those expressing fears and worries related to COVID-19 in general. We found mental health experiences to be both negative and positive. For example, one man stated, “I’m usually happy uh staying at home during this difficult time because I feel safe, but sometimes, yeah the worry about the uncertainty of the future kind of gets to you.” Another man, who is currently unemployed, commented on the repetitiveness and mundane nature of his days: “It’s just a lot of uh kind of like repetitive, monotonous uh days. Keeping up with the pandemic is very emotionally draining”. One woman, who was laid off, stated, “I miss things like a routine at work, I miss earning a living, and being with people at work as well.”

One woman, who is working remotely, highlighted how working from home has impacted her mental health positively: “This is the absolute best work arrangement I’ve ever had.”

## 7. Closing remarks/advice

Participants share their closing thoughts and advice for other people on autism spectrum and employers; they share key takeaways and pertinent points related to employment for people on the autism spectrum during the COVID-19 pandemic and beyond. One woman said:

*“I would love to see employers take COVID as an opportunity to be more compassionate workplaces, to be more accessible workplaces for employees with autism. Because I think, all of what everyone’s experiencing now, working from home and sort of going ‘wow this is really difficult and I don’t work well this way, and I prefer this’, those are things that I think autistic folks and neurodiverse folks, just in general, spend a lot of time dealing with that, just generally, in your everyday work environment. So, you know, I would just like to encourage employers to recognize that, you know, that stress that you’re feeling, that anxiety, the feelings of helplessness or you know, that you’re not doing enough, you’re not doing good enough, that’s what a lot of your employees might be feeling all the time, in what you consider normal work circumstances. So maybe instead of going back to normal, going back to something that’s a little bit better for everyone”.*

### **Why is this important?**

We hope that these lived experience testimonial videos will be shared and disseminated amongst employers, employment support agencies and relevant workers, and individuals on the autism spectrum and their families.

We encourage everyone to reflect on these thought-provoking experiences provided by Autistic Canadians, and that these videos increase knowledge and awareness about the challenges faced and leverage some notable benefits and key practices moving forward. The COVID-19 pandemic has altered drastically life for everyone; however, we hope that these lived experience video testimonials shed light upon the intensified difficulties faced by Autistic Canadians, and what we can do moving forward, to create autism-confident workplaces in a world beyond COVID-19.

*This project 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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