

Carleton University COVID-19 Rapid Response Research Grant

“Change isn’t exactly easy”:
The effects of COVID-19 on
autistic university students’ experiences

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Effects of pandemic-related changes on general population

- Similar changes and measures during previous pandemics (e.g., SARS, Ebola) (Brooks et al., 2020; Jalloh et al., 2018) significantly affected general population (e.g., stress, depression, anxiety, PTSD)
- Unprecedented changes in daily routines
- Rapid changes in academic instructional delivery and social interactions

At Carleton University, survey of students (43% responded)

- Majority of students were either “very satisfied” or “satisfied” with overall quality of online courses (64.2%)
- Most students liked blended format i.e. synchronous and asynchronous delivery (44.9%)
- Majority of students reported an increased workload (64.4%)
 - Undergrads (66.8%)
 - Grads (45.2%)
- Many students reported mental health challenges
 - “depressed or hopeless” (58.5%)
 - “nervous, anxious, and overwhelmed” (74.2%)

Effects of pandemic-related changes on autistic population

- “Some of these issues may apply to everybody during this pandemic, but they are especially heightened for autistic adults” (Cassidy, et al., 2020, p.116)
- “Hidden inequalities” affecting the autistic community (Pellicano, 2020)
- School closures and isolation may have positive consequences for autistic individuals (den Houting, 2020)
- Online learning and social interactions may be preferred by autistic students (Sinclair, 2010).

COVID-19 Research challenge

Within a limited timeframe:

- Working with autistic students, identify and investigate the effects of the COVID-19 pandemic-related changes in academic instructional delivery formats and social interaction on the autistic university students
- Develop academic supports **with** autistic university students to increase autistic student success and retention

Neurodiversity



joint echolalia unashamed
best practices Universal Design following my IEP
knowing my rights real jobs for real pay stimming together natural
self acceptance still a cause that needs attention a basic human right communication
listening to behavior working with my headphones on talking to me and not my aide integrated classrooms
getting the help I need listening to me when I am hard to understand not telling people to look at you
helping my child use his AAC device for everybody paying my autistic employees a real wage
respecting my rights welcoming the world love inclusion
knowing joy autism acceptance is allowing my child to stim
providing sensory-free rooms proud loud hands unconditional presuming competence
allowing people to stim treating Autistic people as people
the radical notion that autistics are people listening understanding what will allow my child to flourish
respect unapologetic diversity where normal is self-defined
working on the floor scripting respecting all forms of communication
a community affair stimming in public without shame
open mindedness

Double Empathy Problem (Milton, 2012)

- Communication difficulties from mismatch in neurotype or ways of communicating
- Implications for learning and socializing between minority autistic university students and majority nonautistic professors, instructors and peers.

Engaged, participatory research

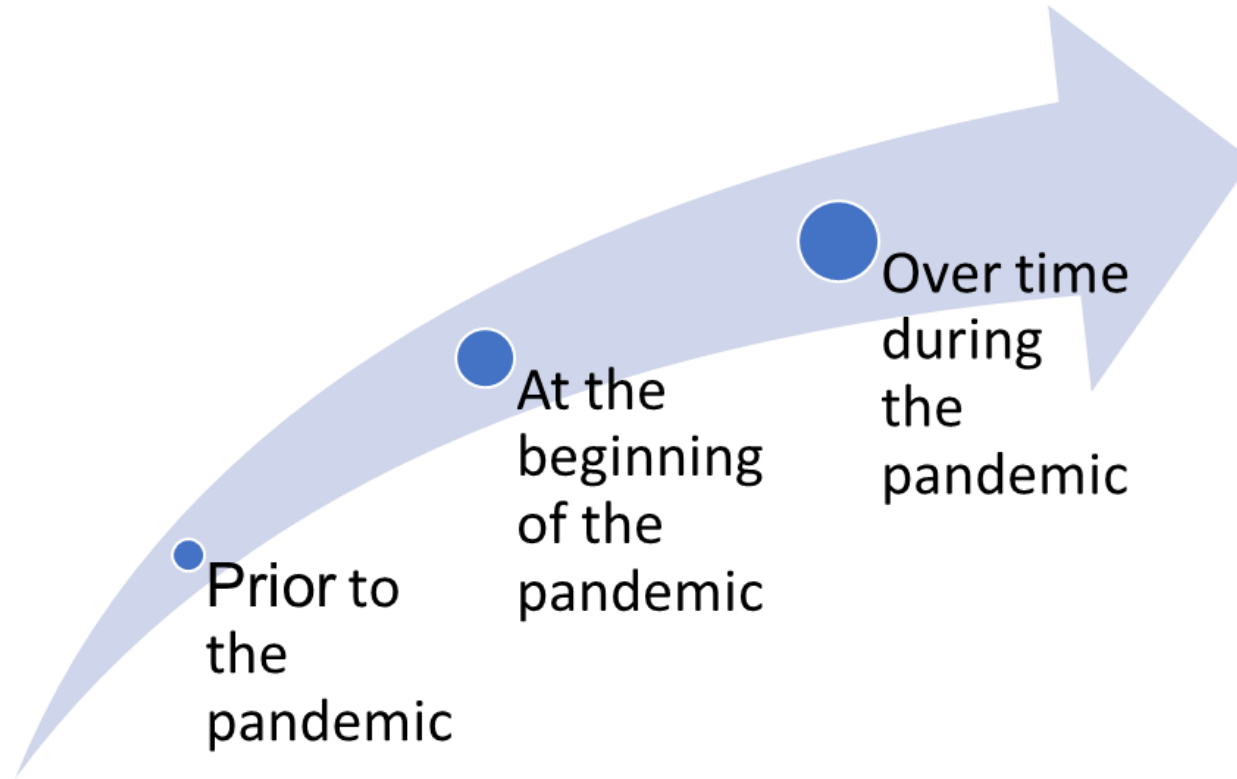
- “Nothing about us, without us” (ASAN, AASPIRE, 2021)
- All research must include the lived-experiences of autistic people at all stages of the research process
- Only then can the research be trustworthy, useful and relevant to the autistic community.

Research methodology

Emergent mixed methods study with a two-phase exploratory sequential design (Creswell, 2015)

- Ideal for understudied or not well understood research topics and PAR
- Phase One (qualitative)—current:
 - Two 45 to 90 minutes semi-structured interviews with 8 autistic university student; coded to identify emerging themes
- Phase Two (quantitative):
 - Development and administration of a large-scale survey informed by Phase One findings

Themes



General experiences prior to pandemic: Voices of autistic students

Feeling high levels of anxiety

- “I was so anxious, it's like I just, I was in constant panic mode; I couldn't process anything, and I took a long time to dig out; I was afraid I broke my brain.”

Struggling with sensory experiences

- “From waking up to going to sleep, no matter how positive a day you have, you are still going to be contending with the fact that these everyday stimuli that other people don't even notice are affecting you deeply. And like I said, it's the constant nature of that. It's the every-moment-of-every-day, for your entire life. And that's emotionally and mentally draining.”
- “I feel like, I feel so burnt out after school.”

General experiences prior to pandemic (2)

Struggling with attention and organizational skills

- “I ended up abandoning that course because I couldn't coordinate it.”
- “Managing time is always tricky for me.”

Feeling a need to mask or camouflage*

- “I can't be myself because that would be too weird. So, there's expectations of how you have to act and say and look as well.”

Enjoying intense interests

- “I love information; I've been called the walking encyclopedia.”

Avoiding “small talk”

- “I'm not sure what the words are [in “small talk”]. If it's a genuine thing; genuine exchange, if I am humaning with someone, that's fine, it's invigorating...”

*Camouflaging/masking refers to strategies which autistic people may use to hide their autistic traits in social situations.

At the beginning: Voices of autistic students

- Being relieved to stay at home
 - “By far and away, the best thing about it so far has been the relieving of the expectation and the obligations of actually going out and interacting in personal spaces.”
 - “But at the beginning it was...it was great! You weren't even allowed near people.”
- Struggling with uncertainty
 - “It was a little bit unnerving; change isn't exactly easy.”
 - “Pretty harrowing.”
 - “Some issues...It was a new routine so that didn't make it any easier.”

Experiences over time during COVID: Voices of autistic students

- Experiencing range of feelings
 - “It's kind of a 50-50, ‘cause it took away frustration at first. Though it was a "pick your battles" kind of situation.”
- Having increasingly negative experiences
 - Feeling lonely
 - “The worst thing about COVID as it dragged on, was that after a while, not being able to see many of my friends, I started to feel a lot lonely.”
 - Becoming overwhelmed
 - “Um, but now, [sigh] the interactive element has been completely injected into the technology and I mean, I'm having panic attacks in my house, because I have to have my ringer on.”
- Undergrads enjoying online learning (if have good executive function skills)
 - “I'm pretty okay not going back to campus until graduation.”
 - “The learning itself becomes a lot more self-directed and...the organizational tasks fall more heavily on the student then.

Experiences over time during COVID (2)

Grads wanting to get back to in-person learning

- “[I] didn't like it when they had, let's say there's, you know, some kind of a Zoom meeting and there's uh . . .20 or 40 faces on the screen. It can be overwhelming.”
- “I've said ‘invaded’ and I think I've described it like my house isn't mine, it's like it's being held by an occupying force” [because of seeing so many faces on the screen]
- “Even if, you know, on campus I mostly work on my own, just knowing that . . . I could go to the department and find some people to talk to there for a little bit, it was kind of encouraging.”
- “Just being in a place which wasn't so freeform, an actual academic environment, I'm not sure why it helped solidify the knowledge more, but it did.”

Undergraduates versus Graduates

Undergraduates

- Preferring online learning experiences
 - Needing strong organizational/time management skills
 - Avoiding stresses of going to and being on campus
 - Learning from safe space of home
 - Feeling happy to never go back to campus
- Over time, becoming lonely
 - Missing friends
 - Becoming bored

Graduates

- Missing being on campus
 - Wanting face to face interactions with profs, classmates and friends (in small groups)
 - Liking the academic working space (library; small classrooms; meeting in person with profs)
 - Struggling with large and complex projects
- Disliking social intrusion of being online
 - Feeling invaded
 - Feeling people have too much easy access to them

Other findings: Voices of autistic students

- Closed captioning/transcripts enhancing learning
 - “When they give the transcript, I'm drrrrrrrrrrrrrrrrrrrr, done! I retain it; I understand it.”
 - “I love closed captions, I have them on my TV all the time, it gives me something, I can break it into streams of input.”
- Experiencing email anxiety
 - “And it's hard to express the fact that, just how anxiety-inducing I find checking an email inbox. . . it's not rational.”
- Valuing neurodivergent mentors
 - “One of the mentors, I'm not 100% sure, but I'm 99.8% sure, and I just found that to be incredibly helpful because, I mean, who's better to help you than people . . . who have more understanding of what you go through.”
- Valuing one-to-one interactions with empathic instructors
 - “Working with her personally was really positive, she was really understanding, she made huge efforts to accommodate and try and understand the experience and like she was excellent.”

Conclusions

- Diverse experiences to the pandemic amongst autistic students
- Similar to nonautistic experiences, but more intense
- Underlying factors like sensory experiences, social challenges, executive functions are often more challenging for autistic students
- Meeting the needs of autistic students will be beneficial for all students
- Undergraduates and graduates report differences (in autistic and nonautistic students)
- Possible factors:
 - Familiarity?
 - Class size?
 - Complexity of material?
 - Executive function abilities?

Implications and Directions

- Given risk factors (retention, depression, suicide), it is critical to understand and appreciate the experiences of this group of students
- Participatory research, working with autistic community at all stages of research process, is the only way to
 - Understand their experiences
 - Develop effective supports
- “Build it back better”
 - Universal Design*
 - Hard copy of course content
 - Multimodal presentations
 - Flexible pedagogical and assessment processes

*Universal Design for Learning are guidelines for teachers to optimize learning for all students, regardless of their particular learning style.

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