



## **Disabilities and Coping During COVID-19 Pandemic**

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### **Introduction**

The COVID-19 pandemic, with its associated social distancing and other movement restrictions, poses serious mental health concerns for vulnerable groups identified by the Canadian Institutes of Health Research (CIHR). Individuals living with disabilities are part of this vulnerable demographic (CIHR, 2020). Adults living with multiple disabilities associated with 22q11.2DS, a microdeletion of the 22<sup>nd</sup> chromosome, are the focus of this investigation, which expands the current line of inquiry into disabilities and stress from viewing the disability itself as the stressor (on the family of the disabled) to understanding how those living with a disability are coping with social distancing and other stress-generating restrictions during the COVID-19 pandemic. This research also explores and identifies factors and interventions that may be useful in treating and/or mediating adverse impacts of the pandemic on those living with 22q11.2DS.

### **Research Questions**

The major research questions posed in this research include:

- How are adults with physical and intellectual disabilities associated with 22q11 Deletion Syndrome coping during the COVID-19 pandemic?
- How has the pandemic been affecting the mental health and wellness of adults with disabilities?
- What factors may be contributing to coping effectiveness of adults with disabilities?
- What types of current or prior physical and/or cognitive treatments may be contributing to coping effectiveness of adults with disabilities?
- What type of coping supports during the pandemic could assist the mental health and wellness of adults with disabilities?

### **Methods**

This study applied qualitative research methods to gather and document relevant data. Over a period of 11 weeks (May 12, 2020 to July 20, 2020), 11 in-depth virtual interviews (using Zoom-Pro) were conducted



with participants recruited via online notices, and targeted recruitment from community clinics, research networks, and established family networks of those living with 22q11DS in Canada and the United States. Seven of those interviewed were adults with 22q11DS, while four were parents speaking about their adult child with 22q11DS. As a supplement to the qualitative data collected from the interviews, the research team engaged organizations, research groups and other resources, including the Canadian Organization for Rare Disorders (CORD), Genes to Mental Health (G2MH) Consortium and the CONVERGE Working Groups for Disability and COVID-19, in order to inform future in-depth analysis. The interviews were transcribed by a professional transcriber and an initial analysis was done to identify themes.

### **Preliminary Findings**

The data obtained revealed both positive and negative experiences expressed by participants, although the positive outweighed the negative. Participants faced anxiety when hearing repetitive news stories about the pandemic. The COVID-19 restrictions also placed added stress on participants whose immune related deficiencies prevented them from getting out in public. The lack of a driver's license, due to the interruption in driving school sessions, led to an unwanted dependency on others and an inability to seek out coping activities such as driving to the countryside to fish or to another city to visit friends. Participants reported that one of their coping strategies involved stopping or reducing their news watching and for those who possessed a driver's license, it provided a means through which to participate in coping activities.

While the aforementioned negative experiences were shared, the vast majority of respondents (10) indicated that they were doing fairly well and that they had previously faced other more challenging situations than those posed by COVID-19. Other challenging situations mentioned include having family raise their child, recovering from an alcohol dependency, inability to manage finances effectively, difficulty dealing with palate and tastes, the inability to comprehend what's happening around them, dealing with abandonment by a mother, fears, and grieving the death of a grandmother. However, many participants were able to cope well due to a number of reasons: they had their support system close by; they were able to continue their treatment during the pandemic; and, receiving faith-based support, interacting with pets, and, participating in musical activities brought comfort.

### **Conclusion**

The COVID-19 pandemic poses a threat to the normal functioning of those living with multiple disabilities associated with 22q11.2DS and in some instances, these individuals face some difficulties over and above those not living with disabilities. However, findings also suggest that social distancing did not pose difficulties over and above those faced by the general population, for the majority of research participants. The following preliminary conclusions can be drawn i. participants' active treatment before the pandemic may have played a role in their coping; ii. Some non-traditional interventions may improve coping. The research team will conduct a more detailed analysis of the transcribed interviews using NVivo. Future research will allow for testing the impact of such variables as age, age at diagnosis, age at which interventions were provided, and early versus later diagnoses and commencement of supportive interventions, on coping ability.