

Impacts of the COVID-19 Pandemic: Pan-Canadian Perspectives From Parents and Caregivers of Youth With Neurodevelopmental Disabilities

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Introduction: The COVID-19 pandemic brought unprecedented challenges for youth with neurodevelopmental disabilities (NDD) and their families. Although health measures were implemented to contain the COVID-19 virus, they disrupted public service, profoundly impacting youth and their families' access to services. This study sought to better understand the perspectives and experiences of parents and caregivers of youth with NDD across Canada in

accessing services and their mental health needs during the pandemic.

Method: The study used a qualitative research design in which we interviewed 40 parents and caregivers across Canada.

Results: The results enabled us to understand the impact of service disruptions in significant areas of life, including health, education, employment, and risk mitigation.

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Discussion: Policymakers must consider a disability-inclusive lens during public health emergency planning and response to reduce the disproportionate impacts faced by youth with NDD and their families. *J Pediatr Health Care.* (2022) XX, 1–11

KEY WORDS

Public health emergencies, youth with neurodevelopmental disabilities, mental health, health policy, COVID-19 pandemic recovery

INTRODUCTION

The COVID-19 pandemic brought unprecedented challenges to society, with unique challenges for children, youth, and young adults (here onward referred to as youth) with neurodevelopmental disabilities (NDD) and their families (Inter-Agency Standing Committee, 2020; World Health Organization [WHO], 2020). Youth with NDD account for 7% to 14% of all youth in high-income countries. Youth with NDD have higher rates of existing comorbidities and chronic health conditions (Lunsky et al., 2013), which often result in poor physical and mental health outcomes (Lunsky et al., 2018). As a result, they are at a heightened risk of contracting infectious diseases such as COVID-19 and more adverse outcomes from infectious diseases than the general population (Inter-Agency Standing Committee, 2020; Lunsky et al., 2021). Persons with developmental delays are five times more likely to be infected and four times more likely to die from COVID-19 than the general population (Hakim, 2020; McQuigge, 2020). Caregivers may become infected with COVID-19 resulting in an increased risk of transmission to youth or children requiring care (Giménez Duran et al., 2010). Many adults and youth with NDD also live in congregate settings near others, making them prone to contracting COVID-19 infection (Courtenay & Perera, 2020).

Youth with NDD and their families also experienced unintended negative consequences of public health measures during the pandemic (United Nations [UN], 2020). Canadian public health institutions introduced several measures to contain the COVID-19 virus in Canada, including lockdowns, physical distancing, mask-wearing, self-isolation, restrictions on gatherings, nonessential workplace closure, and visitors' restrictions in health care settings and long-term care (McCoy et al., 2020). Although these measures were implemented to mitigate the impacts of COVID-19 and “flatten the curve,” they also resulted in several public service disruptions (WHO, 2019). Those providing long-term care and therapies, such as physiotherapy, speech therapy, and mental health counseling to youth with NDD, experienced operational service disruptions (UN, 2020). Service disruptions could be through therapies requiring in-person attention from the therapists that family members or others might not effectively execute (Triki et al., 2022).

These disruptions have been associated with negative impacts on youths' mental health and the well-being of their families. This led to more isolation, higher anxiety levels, increased behavior challenges among youth, and added caregiving responsibilities for families (Courtenay & Perera,

2020; Mutluer et al., 2020). For example, delays in accessing health care services negatively impacted youth's mental and behavioral health (Zhang et al., 2020). The disruptions also had unintended consequences on the physical health of youth with NDD. For example, reduced opportunities to participate in physical activities because of the closure of community-based services was perceived as deteriorating youths' physical health (Aishworiya & Kang, 2021). The disruptions in the educational environment have also impacted young students with NDD while compromising their unique learning needs (Majnemer et al., 2021). The transition from in-person to remote learning also affected the academic development of youth with NDD because of the loss of school-based services and a structured learning environment (Masonbrink & Hurley, 2020). Family members living with youth with NDD also faced negative impacts because of the pandemic. For example, families of youth with NDD faced added financial challenges because of loss of employment, increased day-to-day expenses, and youths' caregiving needs (Government of Canada, 2019). With the withdrawal of school-based services, recreational services, and respite care, parents and caregivers also faced the strain of balancing their caregiving abilities, home learning, and daily life demands, resulting in the deterioration of their well-being and mental health (Courtenay & Perera, 2020; BC Centre for Disease Control, 2020; Majnemer et al., 2021).

In light of the consequences illustrated above, a disability-inclusive policy response can contribute to providing the necessary resources and supports for individuals with NDD during emergencies (UN, 2020). A comprehensive policy response requires that governments engage persons with disabilities, assess their needs to match policy guidelines, and action and enhance their capacity to cope with emergencies (Kailes & Enders, 2007; Subramaniam & Villeneuve, 2019). Through the United Nations Convention on the Rights of Persons with Disabilities, signatory countries, including Canada, have committed to “take. . . all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk” (UN 2007, Article 11). The Sendai Framework for Disaster Risk Reduction requires governments to implement inclusive guidelines and local actions for vulnerable populations to increase their resilience in public health emergencies (United Nations Office for Disaster Risk Reduction [UNDRR], 2015). The social determinants of the health framework support the understanding that contextual factors such as policies, sociocultural environment, and care systems are essential influencers of health inequities (Alegria et al., 2018).

Unfortunately, there is a lack of inclusivity in approaches taken across Canada and insufficient emergency preparedness, planning, and response for people with disabilities, especially youth with NDD (Krahn et al., 2015). It is critical to understand the experiences of parents and caregivers of youth with NDD on how the pandemic, Canadian Government policies (Federal, Provincial, and Territorial), and associated public health measures affected their day-to-day lives. It can give insight into developing policies and programs that

will be more responsive to the needs of this population in the recovery process and future public health emergencies.

This research study thus aims to better understand the experiences and perspectives of parents and caregivers of youth with NDD across Canada in accessing services and their mental health needs during the COVID-19 pandemic. The study explicitly focused on the COVID-19 policy responses' impacts on parents, caregivers, and youth with NDD and identified recommendations for disability-inclusive policy planning and development.

METHODS

Study Design

This study used a qualitative research design and interviews to better understand the experiences and perspectives of parents and caregivers of youth with NDD and their families during the COVID-19 pandemic. The study used an interpretive description methodology to analyze the data to help gain insights into individuals' perspectives and experiences during the pandemic (Burdine et al., 2021; Hunt, 2009; Thorne, 2016). To address research objectives, this approach helped to gain knowledge of each participant's words, viewpoints, and lived experiences during COVID-19.

Participant Selection

We recruited parents and caregivers from a participant pool established during the previous study, which investigated disability service use among parents and caregivers of youth with disabilities across Canada. The pool had 81 participants across Canadian provinces and territories who consented to be contacted for follow-up interviews during the initial study. The participants were parents and caregivers of youth with NDD aged 0 months–30 years who lived in Canada and spoke English or French. We used maximum variation sampling to ensure participants varied for sociodemographic factors, including the gender of the parent/caregiver and their child, income, province or territory of residence, disability diagnosis, community size, and Indigenous self-identification. The sampling enabled an understanding of the diversity of experiences related to the study objective and events across population contexts (Patton, 1990).

We aimed to include a significant representation across Canadian provinces and territories. Hence, we separated the participants from the pool into their residence provinces. For provinces with three or more participants, we had a secondary goal of having participants vary as much as possible for other demographics. We continued interviewing until all participants from the pool had been contacted. For the underrepresented provinces and territories, we undertook recruitment support from our multidisciplinary research team to have sufficient representation.

Qualitative Methods

Methods for developing the interview guide

The interview guide was developed by reviewing the literature on the intersectionality of mental health and

neurodevelopmental disability during COVID-19 and other health emergencies. The guide was developed in English and French. Feedback on the appropriateness and comprehensiveness of the interview questions was solicited from the multidisciplinary research team and advisory council. The multidisciplinary research team and advisory council included persons with lived experience, knowledge users, community partners and experts in public policy, disability rights experts, mental health, disaster risk readiness, health care delivery, governance, ethics, global health, and pandemic response analysis including the Canadian experience of the severe acute respiratory syndrome pandemic and COVID-19 mental health knowledge synthesis. The interview guide was pilot tested with one parent partner, and modifications were made to improve its quality. The interview questions focused on access to services, education, employment, precautionary health measures, and mental health needs during the pandemic.

Data collection

Three researchers conducted semistructured interviews in English and French from February to August 2021, corresponding to the third wave of the COVID-19 pandemic. Interviews were conducted by phone or Zoom according to the participant's preference and audio-recorded. The average length of the interviews was 60 min. Participants were provided with a \$25 e-gift card after the interview completion.

Data analysis

Interviews were transcribed *verbatim*. English interviews were transcribed with Rev Software, which provides speech-to-text services to help convert audio or video transcripts into texts, whereas French interviews were transcribed by a French transcriptionist and then translated into English for analysis. A French-speaking researcher validated French transcripts to ensure translation accuracy. Validation was done by listening to a short clip of the French audio for one interview while reading the English transcript. The transcribed documents were imported into NVivo version 12.0 software—an application used to organize and analyze qualitative data.

An interpretive description methodology guided the data analysis. An interpretive description is a qualitative methodology applied within the context of health science that seeks to answer experiential questions yielding relevant output for practical and directly impactful use. In addition, a thematic analysis was used to analyze the interview data. The research analysts performed inductive coding of three interview transcripts and created an initial codebook to help guide the analysis. The analysts then coded three additional interviews to test and assess if they needed to adjust the codebook (Lincoln & Guba, 1985). The final codebook consisted of labeled codes, the definition of codes, and exclusions, but we remained open to additional codes emerging from the analysis. Codes were categorized and emerged in coalesced themes and subthemes inductively. Rigor was supported by evaluating and validating codes, themes, and subthemes with the principal investigator, coders, and independent analysts. Once the codes were established and a coding template

(Burdine et al., 2021) was developed, team members extracted and developed key messages from the categorized codes vis-à-vis associated experiences of the participants while looking for variations and similarities in participants' experiences.

To establish trust in the findings, peer debriefing was used by validating codes and themes with the project team members (Lincoln & Guba, 1985; Nowell et al., 2017). Furthermore, the analysts created interview synopses to strengthen the data analysis and amplify participants' voices. Synopses provided a comprehensive summary of the transcribed interviews relative to the study objectives. The synopses included an overview of the participant's background, key topics discussed, issues raised, and experiences during the interview. To support the validity of synopses, we shared them with the research team and advisory council members for feedback. It ensured that the analysis accurately captured the perspectives of those not coding the interviews. The synopses allowed us to summarize interview data related to the study objectives, observe and gather insights into the data, discern the commonality and distinction in participants' experiences, and modify the interview guide (Burdine et al., 2021).

RESULTS

Characteristics of Sample

Overall, 40 parents and caregivers were interviewed for the study. The sociodemographic and disability characteristics of the participants are described in Tables 1 and 2.

Findings of Qualitative Interviews

Findings from our interviews enhanced our understanding of the pandemic's impact on youth with NDD and their families in their day-to-day lives. We separated findings into four categories, as represented in the Figure 1, representing areas of life that speak to the impact of the COVID-19 pandemic.

Area of Life: Health

Access-related changes to health and wellness services, such as access to physicians, therapies, mental health services, and physical activities, negatively impacted families and their children. It also compromised parents' need for respite and overall well-being.

Many participants mentioned that they experienced delays accessing general practitioners and getting physician referrals for medical services. Consequently, it led to unnecessary emergency room visits, which posed challenges for youth and their families because of noninclusive hospital visitation policies restricting visitors. Participants mentioned that restrictions in hospital visits were sources of anxiety. Participant 17 shared,

She had three surgeries since the pandemic began and follow-up appointments were impossible to get. The only advice clinic staff could tell me was, 'Go to ER if you have a question.' I wasn't about to sit in the ER for 12 to 18 hours with a child who just had surgery.

Participants highlighted that several therapeutic services were canceled, resulting in developmental and social regression and worsening behavioral challenges among children compared with prepandemic levels. Participant 39 said, "She goes to sensory-based occupational therapy. She had that service since she's been five. She is 12 and was going weekly, and they had to shut down. So she went backwards, hard and fast."

In addition, participants mentioned that the canceled services placed additional stress on parents as the onus was on them to find new services while dealing with daily life obligations and desperately looking for respite care.

Shifting health services to virtual mode negatively affected their young children's outcomes. Many participants said that the virtual therapies were not as helpful as in-person services because parents believed that children's developmental outcomes improved with service providers one-on-one and in-person. Participant 6 mentioned, "We found that in-person therapy is much more beneficial for him. It has been worse than usual because his supervisor is now supervising virtually, and he is not adequately supervised. We're hoping that we can resume in person."

The study also found that challenges in accessing wellness services profoundly impacted youth's mental health and physical well-being. Participants said that inadequate mental health services and longer wait times led to worsening mental health issues, including anxiety, depression, and behavior challenges among their children.

Some participants also reported that the closure of community-based recreational activities during lockdowns, such as libraries, physical activity programs, and after-school programs, disturbed the daily routine and regressed the physical development of their children. As a result, children faced more isolation and frustration at home and displayed aggressive behaviors. Participant 38 said, "For my child, routine is important. She needs to be able to go to school and exert physical energy through play. Without her being able to do that, she had increased frustration."

Area of Life: Education

Most participants provided their perspectives regarding K-12 education. Many parents expressed concern about their children's academic development because of online learning because it lacked in-person learning experience and associated resources and support. Participant 39 shared, "School came home and there was no help offered. This year they finally tested her in math. She's in grade Seven and wasn't even close. I think that kids with disabilities were significantly forgotten about."

As the schools transitioned from virtual to in-person, many parents shared that there were limited services and support for their children with NDD. The services and supports included therapies, counseling, and educational assistants.

Some parents also reported that returning to school caused anxiety in their children. Participant 22 said,

TABLE 1. Sociodemographic characteristics of study participants (n = 40)

Characteristics	No. of participants	%
Language of interview		
English	34	85.0
French	6	15.0
Gender identity of participants		
Man	2	5.0
Woman	38	95.0
Gender identity of participants' children with NDD		
Man	28	70.0
Woman	12	30.0
Age of participant, years		
18–29	1	2.5
30–49	25	62.5
≥ 50	13	32.5
Age of youth with NDD, years		
0–5	3	7.5
6–15	21	52.5
16–25	12	30.0
26–30	2	5.0
Relationship of the participant to youth with NDD		
Biological parent	29	72.5
Adoptive parent	9	22.5
Other relation	2	5.0
Indigenous self-identification		
First nations status	1	2.5
Métis	4	10.0
Nonindigenous	33	82.5
Educational Characteristics of participant		
High-school graduation	1	2.5
Some college or technical training	5	12.5
College or technical training graduation	13	32.5
Some university	4	10.0
University graduation	16	40.0
Gross household income in 2018		
< \$40,000	4	10.0
\$40,000–\$79,999	15	37.5
≥ \$80,000	17	42.5
Community type		
Large Urban Population Centre (≥ 100,000)	18	45.0
Medium Population Centre (30,000–99,999)	9	22.5
Small Population Centre (1,000–29,999)	11	27.5
Rural Area (< 1,000)	2	5.0
Province/territory of residence		
Alberta	5	12.5
British Columbia	4	10.0
Manitoba	7	17.5
New Brunswick	2	5.0
Newfoundland and Labrador	1	2.5
Nova Scotia	2	5.0
Ontario	4	10.0
Quebec	7	17.5
Saskatchewan	7	17.5
Yukon	1	2.5

Note. NDD, neurodevelopmental disabilities. Participant responses for various sociodemographic characteristics were excluded from Table 1 if the participant did not respond to the question or if they selected “prefer not to answer” or “do not know” as a response option. Therefore, the number of responses reported for various sociodemographic characteristics may not equal the total number of participants, and percentages may not add up to 100 %.

“He’s got a little bit of anxiety today because he knows he’s going back tomorrow. His ticks have elevated a little bit. A lot of it is from thinking about going back to school.”

In addition, a few parents expressed concern about restrictions on activities that comforted students before the pandemic. Restricted activities, such as taking breaks from the classroom or bringing toys to school, resulted

TABLE 2. Disability characteristics of youth with neurodevelopmental disabilities (NDD; n = 40)

Characteristics	No. of participants	%
Primary NDD diagnosis		
Autism spectrum disorder	16	40.0
Fetal alcohol spectrum disorder	8	20.0
Cerebral palsy	4	10.0
Tourette's syndrome	4	10.0
Angelman's syndrome	3	7.5
Global developmental delay	1	2.5
Rett's syndrome	1	2.5
No. of NDD diagnoses reported		
> 1	19	52.5
1	21	47.5
Difficulty with daily activities		
A little difficulty	3	7.5
Moderate difficulty	17	42.5
A lot of difficulty	15	37.5
Cannot do most activities	4	10.0
History of diagnosis of emotional, psychological or mental health conditions		
Yes	18	45.0
No	22	55.0

Note. Participant responses for disability characteristics were excluded from Table 2 if the participant did not respond to the question or if they selected "prefer not to answer" or "do not know" as a response option. Therefore, the number of participants reported for various disability characteristics may not equal the total number of participants, and percentages may not add up to 100 %.

in anxiety and anger among students returning to school. Participant 15 mentioned, "If she ever felt overwhelmed, she would get anxious or angry. She could leave the classroom voluntarily. Even if it meant just taking ten

minutes and jumping on the trampoline. That is completely gone now with the school."

FIGURE 1. Areas of life impacted by the COVID-19 pandemic.

Areas of Life	
	Health
	Education
	Employment
	Risk Mitigation

Area of Life: Employment

Many parents and caregivers said that because of the pandemic and increased caregiving responsibilities, they experienced employment changes regarding job losses, reduced work hours, intermittent periods of employment, and inadequate work opportunities resulting in increased financial burdens.

Employed parents found it challenging to manage work-from-home and caregiving responsibilities with little respite. Consequently, many parents reported feeling less productive, exhausted and overwhelmed in their family lives.

Participant 26 shared,

There was no defined time. It was work when I wasn't dealing with the kids. I was burning the candle at both ends. You didn't wanna stop at 4:30 or 6. Then I'm gonna be seen as less productive because I'm at home dealing with kids.

Some participants working as essential workers in health care and retail sectors mentioned that they faced competing work demands because of increased employment hours resulting in higher burnout and stress. In addition, they constantly experience feelings of fear of catching and spreading the infection to their loved ones. Participant 19 said, "There's much more stress working in the hospital, thinking that you're gonna bring it home. I was more worried about bringing it to my son."

A participant whose child with NDD was employed as an essential worker presented another perspective. The participant opined that having accommodations at the workplace

could help meet the unique needs of employees with NDD. Participant 4 mentioned:

She got a lot of support from her employer during the pandemic because, at one point, she was very anxious. They told her to take a week off and rest. She is satisfied that they could accommodate her mental health needs.

Area of Life: Risk Mitigation

Many participants said that public health measures did not consider the needs of youth with NDD and their families and compromised their quality of life and participation in public spaces. Many participants mentioned that activity limitations prevented their children from using personal protective equipment, such as wearing masks or hand sanitizers. For example, participants shared that children with sensory disorders were sensitive to the touch and smell of masks and hand sanitizers. As a result, wearing masks caused anxiety for parents and their children when in public spaces. Participant 9 said, “Procedure masks are very hard. They have a smell that we do not smell, but he smells it. It nauseates him. Going into places where masks are mandatory generates too much anxiety.”

A common expectation among some participants was the need for tolerance in society concerning unique circumstances preventing youth from complying with some measures. Participant 307 said,

Certain people do not have a problem telling my child to do something, like putting your mask over your nose. It’s not pleasant when you’re out and people are staring more than they normally are. Government officials could have done a better job of looking at people with disabilities.

Several participants opined that a high volume of COVID-19 information, frequently changing guidelines, and difficulty understanding the policies caused an information overload, confusion, and frustration. Participant 33 said,

I don’t think it’s clear enough for people that do not understand the information easily. I think accommodations must be made so people of all functioning levels could have understood what was going on and what they should be doing.

Many participants also highlighted that youth with NDD, their parents and caregivers should have been prioritized during vaccine distribution for their safe entry into society. Participants’ main reasons were because of the youth’s compromised immunity and frequent contact of youth and their families with their caregivers and service providers. Participant 23 shared, “Because it’s shown that people with disabilities are at higher risk. So we need to protect them. Their life’s value is just as important as anyone else.”

DISCUSSION

The findings from our study invite careful consideration and implications for policy advancement in the identified areas of life during emergencies, as described below.

Health Policy

The study found that families and children with NDD faced challenges accessing health services, such as medical, therapeutic services, and respite care, impacting their well-being. In addition, virtual delivery of health services often did not meet the unique needs of youth with NDD because of difficulty assessing their developmental outcomes. Many youths with NDD have greater functional and behavioral challenges, resulting in a higher rate of service access use, including general physicians, specialists, and hospitals (Majnemer et al., 2021). The youth also require a continuum of therapeutic interventions, such as speech therapies and occupational therapy support, to ensure full participation in society (UN, 2007). Service disruptions reduce youth’s health capacity and compromise their caregivers’ quality of life (Vasilopoulou & Nisbet, 2016). In postpandemic recovery planning, special considerations and stakeholder collaborations are needed to include the unique access-related needs of youth with NDD and their families to improve this population group’s health capacity (WHO, 2020). Some countries have adapted service accessibility guidelines or health services to accommodate the unique situations of youth with NDD. For example, in India, round-the-clock medical services for psychiatric and neurological emergencies were made available during the COVID-19 pandemic and its epidemic stages for individuals with NDD. Similarly, a WhatsApp-based service in Argentina was developed to support individuals with disabilities during medical emergencies (Bhan & Julka, 2021). Such accessibility guidelines and proactive interventions could guide decision-makers regarding future emergency preparedness and planning.

During the pandemic, steps were taken to support Canadians’ increasing mental health needs. They included enhanced digital access to mental health services and financial investments to invest in mental health distress centers (Government of Canada 2020). However, not enough was done to address families and youth with NDD’s unique mental health needs (Majnemer et al., 2021). The one-size-fits-all approach to addressing growing mental health needs does not suffice, and population-specific adaptations are needed in the health policy response (Inter-Agency Standing Committee, 2020). Research has suggested that health policy considerations prioritize youth with NDD and their families in providing a continuum of health-based services, community support, and recreation opportunities during emergencies and postpandemic recovery (Inter-Agency Standing Committee, 2020; UN, 2020; Zhang et al., 2020). Government at all levels could consider Sendai Framework’s guiding principle to strengthen access to psychological support, mental health services, and community support for persons with disabilities in emergency preparedness planning and postpandemic recovery (UNDRR, 2015) Enhancing disaster preparedness...rehabilitation and reconstruction (Sendai Framework, Priority 4). Access to health services and participation in recreational opportunities is a right and a social determinant of health that helps improve quality of life (Shikako-Thomas et al., 2012). Addressing this determinant is

essential to reducing health inequities exacerbated by emergencies (WHO, 2022).

Policy recommendations

1. Provide patient-centric accommodations and a continuum of care for youth with NDD and their families accessing services during the pandemic and recovery period.
2. Include modifications to the design and delivery of health care services centered on functioning and unique health-oriented needs of youth with NDD.
3. Provide uninterrupted and adapted access to affordable mental health care, professionals, and community support to address youth with NDD and their families' unique mental health needs during emergencies.

Education Policy

The study found that restrictions limiting access to school and the entire systems of care attached to the school, such as rehabilitation, special education staff, and tools, resulted in families of youth with NDD experiencing significant challenges in different areas of their development. Adequate support and accommodations were also unavailable when students transitioned back to in-person schooling, contributing to a prolonged experience of delayed academic and developmental achievements. There is growing evidence that online learning for youth with NDD is less efficient as they thrive on in-person teaching strategies, structured learning environments, and in-person resources such as specialized instructors, educational assistants, and therapies (Majnemer et al., 2021). International studies in some Balkan countries have highlighted the limitations of virtual teaching methods in the academic development of youth with NDD (OHCHR, 2021).

Individualized education support and accommodations are needed to facilitate inclusive and uninterrupted access to quality education for youth with NDD, regardless of the education delivery model. The United Nations Convention on the Rights of Persons with Disabilities Article 24 suggests structures and processes that must be implemented to guide the creation of inclusive, accessible, and continuous learning for persons with disabilities (UN, 2007). Particular considerations for continuing all services, including educational services, in risk and humanitarian emergencies, are also planned in Article 24.

Structured monitoring and data collection of consequences of policy responses, such as school closures, reopening strategies, and virtual delivery models, is essential to evaluate the impact of educational measures used during the pandemic on youth's learning outcomes (BC Centre for Disease Control, 2020).

Policy recommendations

1. Invest in allocating individual planning and provide rapid adaptations in access to educational services and support for online and in-person schooling.

2. Ensure that youth with NDD have access to inclusive learning resources during and postpandemic, irrespective of the mode of education delivery.
3. Monitor and evaluate the impact of the pandemic and resulting policy response on the academic outcomes of youth with NDD both in the short-term and long-term.

Employment Policy

We found that many families caring for youth with NDD faced changes in their employment status. Changes included loss of employment, reduced working hours, and challenges of maintaining regular work activities resulting in increased caregiving demands. With limited options for respite and restrictions on informal and formal supports, families had to incur higher expenses and juggle caregiving and work.

In addition, we found that participants who worked as essential workers, such as health care and retail sector workers and paraprofessionals, experienced increased work hours and a higher risk of contracting COVID-19 infection, resulting in high burnout levels.

International and Canadian research studies have highlighted that families having youth with NDD experience reduced labor-market participation rates and increased caregiving expenses than other families (Government of Canada, 2021; Institute for Research on Public Policy, 2016; OHCHR, 2021).

Unprecedented changes in employment and associated work-life conditions are social determinants that impact income and contribute to health inequities (UN, 2007). Public health emergencies like the COVID-19 pandemic further aggravate inequities for vulnerable populations. Response policies must incorporate a disability inclusion lens to overcome the barriers to continuing labor-market participation during and postpandemic (Government of Canada, 2021). Employers should consider inclusive workplace policies, and such response policies must incorporate a disability inclusion lens to overcome the barriers to continuing labor-market participation during and postpandemic (Government of Canada, 2021). Furthermore, special consideration must be given to parents and caregivers working as essential workers (UN, 2020) as they are required to report to work every day despite emergencies and are at higher risk of contracting and passing COVID-19 infection (Canadian Public Health Association, 2021). Reasonable workplace accommodations and a fair emergency remuneration system are some approaches to support essential workers (Kinder, 2020).

To reduce COVID-19's impact, many high-income countries created job protection policies, access to employment protection, and topped-up emergency benefits for low-income households and vulnerable populations (Organization for Economic Co-operation and Development, 2020). Systems of care, including governments and employers, could consider intersectional aspects to reduce the pandemic's short-term and long-term economic impact on families and essential workers caring for youth with NDD (Government of Canada, 2021).

Policy recommendations

1. Introduce and adapt job protection policies for employees (parents and caregivers) caring for youth with NDD to mitigate the financial effects of emergencies.
2. Ensure employers consider the unique needs of employees, essential and nonessential, caring for youth with NDD by adapting workplace policies and implementing inclusive accommodations.
3. Track changes in the employment status of employees caring for youth using a collaborative stakeholder approach, including employers in essential and nonessential work sectors and governments at all levels.

Risk Mitigation Policy

The results highlighted that youth with NDD had difficulty complying with public health measures, including wearing masks and physical and social isolation because of their underlying conditions. They also faced discrimination and challenging societal attitudes because of difficulty following the measures. Adhering to the measures is not always possible for youth with NDD. For example, persons with sensory issues have difficulty complying with mask bylaws because of medical barriers, and this could result in increased isolation and prevent safe societal participation (Kohék et al., 2020).

Participants also believed that COVID-19 information and public health guidelines were overwhelming and difficult to understand. How information about emergencies is communicated can significantly impact a person's quality of life (Seth et al., 2022). Research has shown that during crises such as Hurricane Katrina, challenges in understanding emergency information and guidelines deteriorated the well-being of individuals with disabilities and increased mental health symptoms (Gillespie et al., 2016; National Council on Disability, 2005). Inclusion and prioritization of stakeholders such as families, parents, and caregivers of youth in designing public health measures could contribute to creating more inclusive responses and consideration upholding their right to full participation in society during emergencies and improving health outcomes (Kuper et al., 2020). For example, information in easy-to-understand formats, such as plain language, could ensure equitable and optimal information uptake and facilitate informed decision-making (Seth et al., 2022). The Sendai Framework proposes strategic approaches to collaborate with stakeholders, like families and their representative organizations, in developing emergency information in the early stages of the pandemic. It could be helpful for decision-makers to learn and be prepared to use these measures when necessary (UNDRR, 2015).

Participants also mentioned that youth with NDD and their families were not prioritized during the ongoing vaccine planning and distribution. Prioritizing youth with NDD and their families in the early stages of vaccine distribution establishes a safety net for them and the people they interact with daily (Campanella et al., 2021). A task force was set up in New Zealand to prioritize individuals with disabilities and their families in the COVID-19 vaccination program. The program

established a dedicated health line number and provided vaccine information in plain language (Government of New Zealand, 2021). Allocating priority status during vaccine rollout ensures that youth with NDD and their families continue to live safely and participate equally in society (Hotez et al., 2021, pp. 1–2).

Policy recommendations

1. Ensure that public health guidelines are inclusive and flexible and address the barriers that prevent the full participation of youth with NDD and their families.
2. Collaborate with the families of youth and their representative organizations to co-create public health measures and pandemic information.
3. Create clear-cut criteria for prioritizing youth with NDD and their families in national vaccination programs.
4. Ensure that exemptions to public health measures for youth with NDD and their families are clear and well-understood through educational campaigns.

LIMITATIONS

This study used maximum variation sampling for participant recruitment. Despite decent sample size representation from many provinces, we experienced limited representation from Atlantic Provinces and Territories. We also had limited participation from Francophone families. Furthermore, parents and caregivers were mainly women than men. When contacted for the study, many families deferred to the mothers as the primary caregivers. Diversity in sample size could have led to a richer representation of perspectives and experiences. The study has not focused on intersectional issues, for example, exploring the pandemic's impact on youth with NDD and their families with Indigenous status. Examining intersectional issues is an exploratory area of research.

CONCLUSIONS

This study conducted qualitative interviews, analyzed using interpretive description methodology, and revealed the experiences of youth with NDD and their families during the COVID-19 pandemic. We saw that the pandemic, associated health measures, and resulting disruptions increased barriers for youth and their families in significant areas of life, including health, education, employment, and risk mitigation. Inclusive approaches centered on the unique needs of youth with NDD and their families must be considered during health emergency planning to mitigate its adverse impacts on families and children. Decision-makers must put the inclusive and family youth-centered approaches at the center of recovery and future policy development to reduce participation barriers during public health emergencies.

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