Examining the Impacts of the COVID-19 Pandemic on Service Providers Working with Children and Youth with Neuro-developmental Disabilities and their Families: Results of a Focus Group Study

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Abstract
The COVID-19 pandemic has imposed unprecedented service interruptions in many sectors including services for children and youth with neuro-developmental disabilities (NDD). We examined the experiences of service providers as they supported this population during the pandemic. Five focus groups were convened with 24 service providers offering support to children/youth with NDD and their families. Results highlight substantial service changes and challenges, as observed by service providers. Service closures and program delivery modification resulted in the rapid adoption of virtual services and reduced program delivery. Service providers have faced heightened workloads, personal weariness and 'burn out', and new levels of conflict at work, yet with little opportunity and support for self-care. Beyond challenges, new learning and growth have emerged, with heightened collaboration amongst organizations. Strains in service delivery during the pandemic have exposed programming and systems gaps, for which proactive capacity building is warranted and recommended.

Keywords
Neuro-developmental disabilities, pandemic, children, families, service providers

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Introduction

As COVID-19 began to take hold globally, it became evident that world regions had not sufficiently prepared and were forced to take a swift and reactionary approach to managing the pandemic. Initially without a vaccine, the prevention of COVID-19 spread relied on non-pharmaceutical interventions; not vastly different from those enforced during the 1918 Spanish influenza: quarantine and isolation, public gathering restrictions, and school closures (Tomes, 2010). These changes resulted in service access restrictions for children, youth and adults with neurodevelopmental disabilities (NDD), which include those with autism spectrum disorder (ASD), intellectual disabilities, fetal alcohol spectrum disorder and cerebral palsy, among other conditions. In this paper, we examine the impacts of the pandemic specifically on those who provide services primarily to children and youth. This complements a corresponding analysis, as part of a larger study, on the impacts of the pandemic on youth with NDD and their families (Nicholas et al., 2022).

Background

With the first reported cases of the novel coronavirus (COVID-19) in Wuhan China in December 2019, the virus rapidly spread around the world (World Health Organization, 2020). The first reported case of COVID-19 was seen in Canada in late January 2020 (Silverstein et al., 2020). By mid-March 2020, the country went into lockdown which has periodically recurred, with various levels of extensiveness, until the time of writing (April 2022). Societal institutions variably have implemented drastic measures to confine the spread of the virus. As of April 1, 2022, over 486.5 million people worldwide have been confirmed to have had COVID-19, with over 6.1 million people having died (World Health Organization, 2022). In Canada (where this study is located), over 3.4 million people are reported to have contracted COVID-19, with over 37,500 reported deaths to date (World Health Organization, 2022, accessed April 4, 2022).

Individuals with intellectual disability have seen higher rates of morbidity, as well as higher rates of mortality (particularly in ages up to 74 years) associated with COVID-19 (Turk et al., 2020). Though the exact reasons for this disproportionate impact have not yet been ascertained, potential causes may include higher rates of co-morbid issues in this population, as well as other social and socioeconomic factors (Turk et al., 2020; Boyle et al., 2020). These elements further may be exacerbated by inequities in pandemic aid and support (Petit & Tedds, 2020; Zwicker, 2020). COVID-19 in adults has presented as an acute respiratory condition, resulting for many in complications in multiple organs, including the heart. In contrast to adults, most children and adolescents present with mild COVID-19 symptoms that do not require medical intervention. While children to date have constituted a relatively small proportion of confirmed cases of COVID-19 with minimal pediatric deaths, the pandemic has imposed risks of deleterious social, health, developmental and educational impacts on children/youth with NDD and their families.

Impacts of Health Outbreaks on Children/Youth with Chronic Health and/or Disability Issues

In the SARS health outbreak of 2003, infection spread was also concerning although more localized, with Toronto, Canada being the hardest hit region outside of Asia (National Advisory Committee on SARS and Public Health, 2003). Reflecting on that experience and the outcomes of SARS, researchers reported significant secondary stresses from the pandemic on children/youth in families impacted by SARS, and on their parents as well as healthcare providers who supported them.
Pandemic infection control measures (e.g., isolation, quarantine, etc.) were shown to lead to significant and ongoing struggles such as post-traumatic stress disorder and related symptoms in a significant proportion of affected children/youth, parents and health care providers (Koller et al., 2006, 2010; Sprang and Silman, 2013).

Currently, many families with children/youth with NDD are reported to have had a wide variety of unmet support needs during the COVID-19 pandemic and lockdowns (Nicholas et al., 2020). Parents have reported that supports for these young people have been inconsistent and uncoordinated. However, effort has been exerted to nurture routines and target mental health support (Asbury et al., 2020; Toseeb et al., 2020).

Despite these efforts, much is yet unknown about the impact of the COVID-19 pandemic on services for children/youth with NDD and their families. Better understanding of service disruptions and their impacts is needed for ascertaining gaps and in turn offering mitigative and optimal services even under these difficult circumstances. To that end, the aims of this project, as part of a larger national study, were to determine the impact of the COVID-19 pandemic on service provision primarily to children/youth with NDD and their families. In this paper, we focus on the perspectives of service providers in addressing the following research questions:

1. How has service delivery been impacted by the COVID-19 pandemic?
2. What are the experiences of service providers?

**Methods**

Interpretive Description (ID) (Thorne, 2016) was utilized as a guiding qualitative research approach to address the research questions and enable analysis. Based on qualitative inquiry methods, ID is ideal in ascertaining experiences and perspectives as well as offering practical implications for programmatic policy and practice guidelines. A focus group guide was developed and pre-tested, for subsequent use in eliciting information from participants within each focus group. The focus group guide comprised open-ended questions that invited service providers to address overall research questions regarding services to this population in the pandemic, including how service providers and their organizations adapted work environments and processes to support individuals with NDD and their families.

Five focus groups were convened, consisting of a mean of 5 participants per group (range of 3 to 8 participants per group). They were facilitated through Zoom videoconferencing technology (Zoom Video Communications Inc, 2016). The focus group discussion was digitally recorded, then transcribed verbatim, and finally analyzed with the support of NVivo 11 qualitative data management and analysis software (QSR International, 2018). Data was coded and analyzed using an inductive thematic review approach, supported by an ID orientation. Accordingly, codes emerging from the transcripts were categorized and subsequently grouped into themes (Patton, 2014). As proposed by Thorne (2014, 2016), ID analysis is agile in integrating data collection and analysis, along with field notes, with a focus on contextualizing and integrating the data with participants’ perspectives. The ID approach identified broad issues in tandem with the granularity of participant experience and perspectives from the reviewed dataset, thus determining a holistic and practical understanding of the substantive area being examined.

Recruitment of service providers emerged from NDD service organizations in three large Canadian regions (Alberta, British Columbia and the Yukon). These organizations distributed information about the study to service providers in their organization. Prior to subsequent involvement, information about the aims and processes of the study were shared with potential
participants. They were informed that participant identities would not be shared by the research team, and identifying information would be removed from transcripts. Informed consent was provided prior to study engagement, and the study was reviewed and approved by the [REDACTED] Research Ethics Board.

The Sample

Twenty-four participants from the Yukon (n = 13), British Columbia (n = 5) and Alberta (n = 6) engaged in focus groups held between June and October, 2020. Organizations in which participants were employed, offered services primarily to children and youth with NDD and families, with some workers’ experience extending beyond childhood. Services included diagnostic assessments, developmental supports, service navigation, counselling and mental health supports.

Study participants had various roles/positions in their organization. Roles comprised front-line service provision (e.g., support worker, community worker, psychologist, psychologist, social worker, physician) and organizational and community leadership (program manager, executive director, family support coordinator, program coordinator, evaluation/research, Elder). Participants were female, with the exception of one male. Average experience working with children/youth with NDD and their families, was 16 years (range of 2.5 to 45 years). Four of the participants had offspring with NDD.

Results

Participating service providers described a range of organizational and program changes that have resulted from the COVID-19 pandemic, including: service closure or reduction, use of virtual programming, and shifts due to changing pandemic conditions. Professional and personal impacts of these changes consisted of busier workloads, extensive effort to address the heightened emotional needs of clients due to the pandemic, and worker fatigue and conflict. These impacts were described as intensely challenging, yet attention to service provider well-being and self-care was reported to be under-addressed in agencies. Amidst pandemic strain and adversity, participants also conveyed personal and professional learning for improved service provision under pandemic circumstances, opportunity for collaboration amongst service providers, and heightened exposure to, and consideration of, broader service and system gaps. Each of these thematic areas is described below.

Dilemmas of Service Closure or Modification

When the pandemic began, service providers described intense anxiety and fear in providing services to individuals with NDD and their families. A service provider noted, “those first 6 weeks [of the pandemic]… [brought] fear, not only as a parent, but also supporting the people we serve. They didn’t know what was going on, we didn’t know what was going on. Is this 2 weeks, 2 months, 2 years… what is it? And so we had to make some big adjustments.” Uncertainty was commonly identified as service providers lacked information related to plans for moving forward as an organization or more broadly, the NDD service sector. Service providers reported anxiety in regards to employment security and workplace safety, and in some cases, programs were completely put on hold, with employment cut or hours substantially reduced.

Whether by choice or in compliance with government directives, many agencies temporarily ceased and/or modified services. Illustrative of multiple closures, agencies which offer diagnostic assessments and/or intervention for children/youth with NDD-related symptoms, immediately
ceased conducting assessments and in some cases, intervention stopped or was moved to virtual delivery. Services that closed at the beginning of the pandemic have since reopened, but generally in a limited or modified way. Many service providers commented that they appreciated, or were looking forward to, returning to their work sites largely due to the social aspect of once again engaging with colleagues in-person.

On the other hand, several participants in varying settings and jurisdictions reported that their organization was mandated to remain open and continue offering in-person services during the pandemic largely because the resource was deemed to be an essential service. For instance, one agency remained open because it was, “reaching out to a very vulnerable population that didn’t have a lot of resources or [was unable] to access what resources were available to them at the time.” Agencies that remained open tended to serve vulnerable populations that struggle with basic needs such as food and shelter, and lack access to the Internet. Another organization was reported to offer mental health services, although many similar services were moved online.

**Sense of Jeopardized Safety.** Organizations that continued offering in-person services throughout the pandemic generally made accommodations to support the safety of their staff and service users, including the application of markings on the floor or walls and/or other measures that encouraged physical distancing, donning of personal protective equipment (PPE) among staff and service users, cleaning protocols for staff and service users as well as in occupied spaces (after facility use), standard administration of screening questions and temperature checking prior to facility entry, and a decrease in the number of staff and clients on site at a given time. Rotating staff groups were largely implemented to limit exposure such that if one individual or team was to become unwell, the entire staff would not be rendered unable to work.

An administrator of a small not-for-profit organization noted that the financial cost of in-person safety precautions, including training staff, continual cleaning/sanitation, and PPE, was prohibitive. Of further strain, PPE was difficult to obtain because demand exceeded supply particularly early in the pandemic.

**Worker Anxiety and Needed Support.** Being deeply aware of risk for acquiring and possibly spreading COVID-19, a participant noted heightened anxiety among staff which was exacerbated by continual changes in safety precautions over time. Another service provider described her fear when coming to work during the pandemic, stating: “I just wanted to not come to work because I’ve got too many family members and friends that are older and may be compromised. It scared me in the beginning. I think a lot of what I was doing was just like coming to work, [but having] minimal contact with people.” One participant acknowledged with gratitude that her organization’s executive director had quickly offered necessary direction and supplies that allowed staff to continue working in relative safety. Such leadership was deemed critical to supporting staff, yet was not always viewed to be offered which, in such cases, left staff feeling more vulnerable, stressed, uncertain and demoralized. A participant reflected on her sense of anxiety: “I’ve seen an increase of anxiety because… I’ve been totally isolated either at home or [work]. That’s it. Never been to the grocery store, never been anywhere, and then coming back and seeing all these changes and then seeing the clients’ [stress] being heightened because of all these changes and like yeah, there’s some anxiety.”

**Implementation yet Concern with Virtual Programming**

Many in-person services were pivoted to online platforms, and staff connected with clients through Facebook, email or telephone. Personnel from one agency described creative ways in which staff
were communicating with vulnerable youth in a peer mentorship program. In this instance, pro-
gramming was pre-recorded so that service users could access it at their convenience, while other
supports were offered online in real time.

The availability of programs to a wider range of ages and geographic locales was cited as a
realized advantage over localized and often age- or population-limited in-person programming
offered prior to the pandemic. In adapting services, providers worked to address technological
challenges such as adding closed captioning in online sessions and offering trouble shooting
support. They expressed concern that virtual supports were not accessible to all due to language
barriers, lack of access to WiFi or technology, and challenges for people with hearing impairment
and for autistic individuals. Yet they appreciated organizational effort to increase accessibility, as
illustrated by the following participant: “a few [clients]… did not have access to internet or to a
computer so we were able to provide… cellphones, computers and iPads so that… people could
connect and be supported.”

Within the delivery of online services, challenges were noted; for instance, participants raised
concerns about confidentiality of group programming, participant and staff online weariness, and
limits to assessment and risk appraisal. A service provider noted, “Because of privacy and liability,
it’s not very feasible for us to do a group mentorship class in the virtual world, in case things get out.
For confidentiality and liability (reasons), we haven’t been able to do that.”

Working virtually was described to require significant personal/professional adjustment, par-
ticularly when service providers lacked a ‘work space’ at work or home, appropriate technology
(hardware or software), and/or knowledge about technology use and its application in service
provision. Many service providers swiftly navigated a steep learning curve and quickly adopted
online skills. Particular challenges included the need to rapidly learn and apply online technology
for therapeutic ends, offer support programming, and navigate periodic changes relative to available
resources. Upon gaining information, service providers were tasked with immediately applying that
information in a therapeutic way despite not necessarily feeling adept or comfortable with the
technology, let alone applying it in a way that was hoped to offer therapeutic benefit to clients. As an
example, a service provider described strain as a result of, “the number of families that rely on
having me available to them,” but this was described as especially problematic, “during that time
[as] I was trying to learn all this stuff. I was not able to meet my learning [needs in terms of
technology application and use], but also meet their (client, family) needs. So it was very stressful.”

There was a wide range of proficiency and experience with technology use among service
providers. While some struggled, others pivoted to online service delivery easily, with many feeling
fortunate to be able to continue working despite substantial service interruptions and threats of work
stoppage during the pandemic.

Multiple participants noted that continually interacting online is more draining “cognitively and
just physically” than in-person engagement. Several described often transitioning from one online
session to another without breaks that typically would be built into an in-person appointment
schedule, including travel to clients’ homes or scheduled breaks between office appointments.
Others described personal struggle in working while also caring for children at home or others in
their family, and not having a clear differentiation between ‘working’ and ‘not working’ which
tended to lead to a sense of unending labour and fatigue. One participant described the struggle of
work-life balance: “[At the organization I work at], all of our staff have family members with special
needs…. So you’re managing all these situations at home while you’re still trying to get in your
eight hours a day, and something’s going to give, right? So it’s either the work or it’s the family, and
for me personally, it was a struggle because so many families were reaching out to [me and my
organization] in even worse situations than mine, and.. you cannot help them.”
**Shifts and Demands to Adjust**

Given substantial program and resource shifts during the pandemic, service providers described the need to devote significant amounts of time to keep up with changing resources and policies to share with individuals and families. This required a significant expenditure of time to update information about programs and services, including review of emails, web-based information, grey literature and policy documents because, as a participant noted, “what the pandemic has taught us is what we know today is not the case tomorrow.” Another participant stated that resource information available on the Internet can be difficult for families to understand, and often is not directly applicable to individuals with NDD. Service providers described assuming a larger role than before the pandemic in supporting families’ navigation of services via helping people find what they need, relaying pandemic-related financial benefits and other resources, and ensuring that information is available in “plain language.”

Multiple workers described fulfilling additional roles due to pandemic service gaps and closures. This periodically went beyond conventional practice as they identified emergent needs of individuals and families on their caseload (e.g., food access, service navigation, transportation). Some service providers described new programs that had been rapidly developed during the pandemic to address pressing and unmet needs (e.g., heightened food insecurity in a region). One organization took action after noticing an increase in substance overdose in their community: “Everybody… in their own little bubbles was saying this is a problem,… but nobody took the next step to say what are we going to do about it. So we initiated and got overdose prevention coordinators,… did some community education around harm reduction, and worked with the other agencies to try and increase naloxone kit availability in the community.”

Given the unsettling and rapidly changing nature of the pandemic, service providers continuously addressed unmet needs amidst a context of uncertainty related to the virus and continual and in some cases, amplified need – all while personally struggling themselves with some of the same worries their clients were experiencing. With these daily tensions and strains, workers described intense levels of stress and fatigue, yet attending to these issues was described as often missed in the aim of attending to the needs of others. A service provider stated, “all of a sudden, you’re falling apart and you don’t really realize why it is. You’re not coping the way you used to cope, you feel like you’re disconnected, you feel like you’re not as organized or you’re missing things that you never would have missed before… Mental health is so important, supporting people to have a break when they need it.”

To move forward in as constructive a way as possible given pressing challenges, participants described an imperative of strong communication at all levels. They appreciated as much clarity about the pandemic and care requirements related to the pandemic as possible, with regular communication from organizational leadership, as well as regional and federal governments. As an example, a service provider stated, “When you listen to [a pandemic/public health spokesperson] say, ‘This is airborne’ and you know, all of her messaging, it was so clear and she was so patient,… You get a lot of comfort in that… She was visible, clear and gave specific instructions which was very helpful.”

Participants further noted that coordinated networking, including shared planning amongst service agencies, was helpful. One service provider felt that their region had responded fairly quickly to service gaps which supported agencies in coming together to coordinate care. Another was critical that their agency was slow to adjust to COVID-19 care-related shifts. While the responsiveness of regional/jurisdictional leaders and organizations was valued, many service providers did not feel that needed information and coordination were sufficiently demonstrated.
Irrespective of the extent to which this was or was not thought to have been provided in an organization and/or region, all participants agreed about the importance of effective information diffusion, strong communication to staff and families, and collaboration amongst service providers and organizations during the pandemic. One participant emphasized, “communication is definitely key.” Of this communication, a participant noted that it precludes, “duplicating… work… and really ensure[s] that people take the learnings that they already have, and it gets disseminated to so many more families… I know in my work, a lot of the social workers were emailing out a lot of resources or saying, ‘Hey, let’s get together to talk about what you guys have found for COVID; these are the financial resources we found’.”

Impact on Service Providers

Participants described a range of impacts. These impacts fell into two broad categories: first, professional impacts which entailed heightened workload and required assistance to clients in meeting their informational and emotional support needs; and second, personal impacts which included personal/professional weariness, malaise and frustration as well as periodic conflict with administrators due to imposed rules in organizations and regions. Amidst this personal toll, service providers generally felt that insufficient attention was paid to self-care. A participant lamented on her long work hours, noting, “I’m sending emails at 8 or 9 in the evening… [I’m] not taking an evening off.”

Heightened Workload and Urgency to Address Information and Emotional Needs. Service providers reported variably feeling discouraged and demoralized at times during the pandemic, and felt overwhelmed and uncertain about the longer-term impacts of pandemic-related strain. A participant stated, “if nobody does it, it’s not going to happen. Or if we don’t do it, it’s just not going to happen. It’s not that people don’t want it to happen, it’s just that there’s no energy. People are tired. What I’ve found is like you can’t ask anything of anybody right now.”

In addition to day-to-day stresses, some service providers managed larger and/or more intense workloads as needs were heightened and many typical referral targets were closed. Several of participants’ agencies further had instigated new systems to check-in with clients via supportive telephone calls—outreach typically not offered prior to the pandemic. Service providers described diminished community capacity and a personal sense of responsibility, yet frustration due to the impossibility of achieving the aim of substantially easing strain for individuals and families, all amidst personal feelings of stress, exhaustion and malaise: “It’s not easy. You’re not putting out your best work because… you have standards that you have for yourself in your profession, and it’s been hard to meet them during these times. So that’s been something that produces anxiety.”

As illustrated above, personal/professional challenges experienced by service providers included troubling feelings that they were failing to adequately address needs and as such, were letting others down. Several described a daunting and pervasive sense of inability to help others as they normally could, would and felt that they should. As such, they described perpetually feeling stretched yet limited in affecting change as desired, which was illustrated by a service provider who stated: “As much as you try, you let somebody down. You’re letting your family down, you’re letting your spouse down, you’re letting somebody down. And yeah, that pressure of not being able to perform in your work life, your volunteer life, your school life, your parenting and even you know your paid support with your specialized services team – knowing you’re not performing how you’re supposed to be, is what weighs on one’s mind.”
Exhaustion, Yet a Lack of Self-Care. Service providers described weariness and deep personal strain due to continuously facing stressful issues, upholding safety protocols, and remaining hypervigilant: “There’s heightened anxiety, but there’s also exhaustion. Like it’s work to remember to sanitize your hands every time you open a door, go here, go there, just the work of doing the social distancing stuff… There’s just so much energy [that] goes into being COVID aware. When you add the energy that it takes to do the crisis support work that we do, there is not much room there for anything else to happen.”

Service providers described instances of being confronted with anger by clients who themselves were struggling with service restrictions and other pandemic-related frustrations: “We’ve definitely seen an increase of people that use our service being more aggressive towards us… There’s been some… tension and stress for a lot of people.” In response to these workplace challenges, participants conveyed the importance of self-care, yet this was seldom attended to due to unending work and perpetual worry. One participant stated, “you can’t be shutting things down because people’s… mental health doesn’t go on a hold because we’re in a pandemic. In fact, it goes up and so I think that an important lesson out of this is around supporting staff… We’re all in this together, we need to support each other and appreciate each other.”

From a managerial and supervisory perspective, finding ways to monitor wellness and offer support was made more difficult as virtual service delivery limited typical office engagement. Some staff needed more support and supervision during this time, but managers described difficulty gauging how much support was needed, and how to optimally offer that support in a virtual manner, as illustrated by the following program manager: “[It has been] definitely more difficult to support and supervise from afar, so it took some adjustments.” Another participant stated, “the lead outreach or myself checked in with everybody else as well individually throughout the week, so you can tell by people’s stress which way they needed to go. Some people say, ‘well why are you calling me today? I just talked to you yesterday’. The next person would be very thankful that you called again, right, so you just kind of work that out as the time develops.”

From Strain to Resilience and Learning

Amidst the struggles of providing supports in the pandemic, service providers also described examples of working together well, which reportedly was spawned by the needs of individuals with NDD and their families as well as service providers. Illustrating these silver linings amidst much struggle, service providers described collaboration that emerged during the pandemic, as well as instances in which the pandemic exposed system and service delivery gaps.

Collaboration and Partnership. Multiple service providers described agencies becoming more creative, flexible, and collaborative in providing services. A service provider noted, “I was surprised… how flexible people can be and how quickly people can organize when there’s something that’s quite urgent and unites us together. [It’s been positive] to see people trying to help each other or navigate different systems or answer questions or compile resources. It was kind of… a heartening thing to see this, even though it was such a challenge navigating the process.”

Some participants stated that the emergence of pressing risk and deep ruptures in the service system have generated a mobilizing sense of urgency for action as evidenced by collaboration and “out-of-the-box” problem-solving in response to common concerns. Participants generally described that this adversity created connection in ways that likely would not have happened without the imposing pressure of pandemic urgency to reach for solutions.
One participant, for instance, described concrete ways in which service providers had overtly connected with clients in new ways to support coping. This was particularly noted in smaller communities in which relationships were already strong, and this relational strength was leveraged by working together across organizations to address pressing needs (e.g. collectively ensuring food security). Participants described how members worked together to deliver food to those in need while the food bank and soup kitchen were closed: “Firefighters, … mental wellness [workers], youth workers, … even private individuals, our [government official] … and so many people said ‘I’ve been sitting at home feeling useless, and now I have a feeling that I can give to my community’ – I mean even people that you would never have dreamed of reaching out to offer support in whatever small way that they could.”

Exposing System Gaps. Participants stated that challenges emerging in the pandemic had identified and/or amplified gaps in services and broader systems of care, such as in the health and mental health systems, education system and disability services system. As an example, a participant noted, “[The pandemic has] really identified a lot of gaps that exist that were potentially hard to see before, and opened their eyes for not just folks that rely on these services or work within these services, but the community as a whole and society as a whole…. Programs can spend years trying to come up with this amazing awareness…, and well, this pandemic has done that.”

As illustrated above, participants viewed the pandemic as an opportunity to more deeply and critically reflect on what is and is not working in serving individuals with NDD and their families, with resulting opportunity to better address service needs during and after the pandemic. As such, the pandemic was recast, in this instance, as a generative opportunity to expose, scrutinize and inform problematic gaps in care for this population.

Discussion

These findings highlight substantial challenges associated with the COVID-19 pandemic related to services for children and youth with NDD and their families, as viewed by service providers. Impacts on individuals and families as well as service providers have been monumental – including for service providers, heightened workload and personal strain. Program and system gaps have been amplified such as an ongoing lack of services relative to need, and insufficient self-care/human resource supports to service providers. Amidst this pervasive struggle, new learning has emerged as service providers have sought ways to better meet the needs of clients in adverse pandemic circumstances.

These findings corroborate the limited literature addressing these issues in their identification of challenges among service providers in pandemics (Nicholas et al., 2008). Reflecting on service provider impacts in the 2003 SARS pandemic, (Nicholas et al., 2008) noted the need for improved orchestration of services and information flow, an effective mitigation strategy, and strong leadership in policy, program and practice planning. Such efforts continue to be of urgent need, perhaps heightened by the magnitude of the COVID-19 pandemic across communities worldwide. In this pandemic, services have been discriminantly classified as “essential” versus “non-essential”, with resulting consequences of service availability or unavailability for individuals with NDD and their families. Social care in NDD seemingly has fallen into a gray area, thus causing confusion for both service providers and recipients in terms of the urgency and access of services in the pandemic. Service access has been inconsistent across regions and insufficient relative to population need, with negative impacts on many with complex disability-related and other needs who require services in daily life.
To address pandemic-related resource gaps (as presented in this paper), person-centered and ethics-based action planning is warranted. From an ethical lens, resource and policy decisions related to infection risk mitigation, have longstanding implications that can be deeply consequential to the health and well-being of the NDD population and service providers. Critically considering these issues and their implications, monitoring and improving service adequacy, and ensuring workplace wellness among service recipients and providers, are priorities emerging from these findings.

**Attending to Professional Issues and Struggles**

This study echoes findings that emerged in the 2003 SARS outbreak in Canada, in which Gearing et al. (2007) amplified professional and personal difficulties amongst service providers in pandemic conditions. In the current study, a conundrum emerged in that service providers extended support in adverse conditions amidst personally living through related pandemic-related struggles daily. Service providers reported the conundrum of their commitment to optimal care, yet felt unable to provide care to that level, given prevailing service gaps and system issues. We are concerned about long-standing personal and workplace impacts among service providers (e.g., risk of individual burnout, premature staff resignation) both during and after the pandemic. Such concerns invite supportive human resource policy and sufficiently-funded resources to attend to current and future workforce needs. At the time of writing, finding employees has been especially competitive in Canada (https://www150.statcan.gc.ca/n1/daily-quotidien/220311/dq220311a-eng.htm?HPA=1). We are concerned about the risk for skilled workers potentially moving to other disciplines/fields that offer fewer occupational demands or pressures, and/or greater remuneration or human resource supports. Current and anticipated post-pandemic labor shortages heighten the urgency of this issue. Critically reflecting on proactive means of offering generative support to individuals with NDD and their families and ensuring the retention and professional growth of service providers, are pressing priorities.

Finally, the pandemic has amplified severe ruptures in societal structures that affect care to marginalized groups in our society and those who support them. Such challenges raise the need and urgency for sufficiently-resourced care systems and adequately-supported workers which requires proactive planning and human resource strategies such as employment assistance/counselling, opportunity for service provider self-care, professional development, and greater remuneration. We agree with Gearing et al. (2007) who suggested that care and wellness in a pandemic must be upheld not only for service recipients, but also for those who confer needed supports and services.

**Study Limitations**

This study involved a convenience sample of service providers in western Canada. We acknowledge geographic limitations and restrictions potentially imposed by service providers’ non-participation due to feeling too busy or stressed to engage in the study due to pandemic-related or other demands. Accordingly, this sample may under-estimate struggles of service providers in the NDD sector during the pandemic. Of further limitation, no study participants worked directly in residential care. These care recipients and workers may experience even greater vulnerability relative to infection risk during the pandemic due to a variety of factors such as congregant spaces, staff shortage, and among residents, variable understanding of risk and pandemic protocol (Government of Canada, 2020).
An important methodologic challenge reflects this study’s inclusion of only service providers rather than also eliciting the perspectives of service recipients. Research is needed to also amplify the experiences and impacts on individuals with NDD and their families both during and after the pandemic. Further, understanding immediate and longer-term impacts is critically important for determining and developing proactive strategies in the event of a pandemic or other large-scale environmental disaster.

Conclusion
Overall, this study conveys NDD service provider ingenuity and commitment, yet deep strain due to the COVID-19 pandemic; this includes anxiety, concerns over safety, heightened workloads, limited support systems, and rapidly shifting policies, expectations, and demands. Systemic issues have also been amplified during this period. Technology-based services have been advanced, but concerns remain over access and privacy. Connection amongst service providers, including those from different organizations, has been highlighted as a key path toward solutions and improved practices. These findings offer critical reflection and invite action to ensure proactive pandemic planning and response in seeking the well-being of service recipients and providers.

Declaration of Conflicting Interests
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Ethical Approval
This study was reviewed and approved by the University of Calgary’s Conjoint Health Research Ethics Board, REB20-0367.

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