Special Olympics
British Columbia

Health

COVID-19 and People with Intellectual Disabilities in British Columbia

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Summary

Despite more than two years passing since the novel coronavirus first emerged, there remains a scarcity of peer-reviewed data concerning its effect on people with intellectual disabilities. However, it is clear that people with intellectual disabilities are at a heightened risk of serious illness and death, and face additional barriers to accessing effective testing and treatment compared to the general population.

Background

Purpose:

The lack of available information concerning the effects of pandemics on people with intellectual disabilities left service providers and regulatory agencies with scarce evidence on which to develop policies and practices during the Covid-19 pandemic, particularly so during the early stages of the outbreak. This document is intended to provide an overview of the experiences of people with intellectual disabilities in British Columbia, a summary of the research that has been conducted since the pandemic began, and suggestions for the successful management of future outbreaks.

Methodology:

A literature review was completed in December 2021 by accessing major academic databases, including PubMed, JSTOR and Wiley. Keyword searches included “Covid-19” or “pandemic” in conjunction with “intellectual disabilities” or “developmental disabilities.” This information was supplemented by extensive consultations with stakeholders including people with intellectual disabilities, service providers, community organizations, regulatory agencies, caregivers, and family members. In addition to individual and focus group discussions, three surveys were disseminated to identify information specific to British Columbia (1. Supporters and Family Members, 2. Service Providers, 3. Individuals with Intellectual Disabilities).

Prepared for Special Olympics British Columbia

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Introduction

In December 2019, Wuhan – the capital of Hubei province in China – became the centre of an outbreak of an unknown disease that produced pneumonia and additional respiratory symptoms in those affected (Zhou et al., 2020). Over the weeks that followed, scientists isolated a novel coronavirus from infected patients which the International Committee on Taxonomy of Viruses (ICTV) named 'severe acute respiratory syndrome coronavirus 2.' Shortly after, on February 11, 2020, the WHO stated that the disease caused by the new virus is to be referred to as 'Covid-19' (Zhou et al., 2020) (WHO, 2020 (B)). By March 11, 2020, cases had been identified in 114 countries, prompting the World Health Organization to declare that Covid-19 had reached pandemic status (WHO, 2020 (A)).

With little recent historical precedent on which to base public policy, governments scrambled to develop non-pharmacological interventions aimed at reducing the spread of disease and protecting their populations. In many countries, measures included restrictions on the movement of people and the closure of public spaces and businesses. By April 3, 2020, more than 3.9 billion people across 90 countries were subject to restrictive public health measures colloquially known as 'lockdowns', including 'stay at home' orders (Sanford, 2020). At the time of writing of this report, a majority of Canadians have lived at some point under a form of government-mandated 'lockdown,' though measures are largely less restrictive or non-existent now than the 'stay at home' orders implemented at the beginning of the pandemic (CTV News, 2022)(Province of British Columbia, 2022)(Ontario Newsroom, 2022).

For people with intellectual disabilities (ID) and their supporters, the global pandemic has been an exceptionally difficult time period, even when compared to the hardships experienced by the general population. Prior to the pandemic, up to half of all people with intellectual disabilities experienced chronic loneliness (Gilmore & Cuskelly, 2014). As the pandemic began and 'lockdowns' were implemented, the sources of community and socialization that had previously provided a sense of belonging were no longer available for many people with ID. For example, due to the nature of their roles, many people with ID were not able to transition to remote work (Oakley et al., 2021). Likewise, many community centers and programs that catered to people with ID were prevented from offering full services, particularly during periods with the strongest 'lockdown' measures (Oakley et al., 2021).

In addition to the disproportionate social consequences of the pandemic, it is clear that people with ID have an increased likelihood of serious illness or death from a Covid-19 diagnosis compared to the general population (Gleason et al., 2021). Notably, people with ID have a high prevalence of pre-existing conditions that are recognized as increasing the risk of mortality from Covid-19, including hypertension, heart disease, respiratory disease, and diabetes (Turk et al., 2020). Furthermore, people with ID often face needless barriers to service access that increase the risk of adverse outcomes. For example, social distancing requirements and current procedures make accessing testing facilities particularly difficult for individuals with sensory concerns or additional support needs (Oakley et al., 2021). Additional barriers are faced by people with ID during times of resource scarcity, with triage decision making processes often designed to exclude people with ID from receiving services, either directly or indirectly (Oakley et al., 2021).

While much remains uncertain as the world moves forward, it is clear that Covid-19 will eventually become endemic within the global population and that future outbreaks of novel diseases will inevitably occur. It is therefore critical that the public policy failures and successes of the last two years are identified, analyzed, and shared widely. This is particularly important for policies affecting marginalized population groups, including people with intellectual disabilities. Prior to Covid-19, information about the effects of pandemics on people with ID was almost non-existent. Without adequate attention, the same will be true next time. This document represents an attempt to amplify the voices of people with ID and their supporters, and to provide an overview of the existing research that has been conducted during the pandemic. If anything is clear after reading, it should be that more is needed!

Definitions

Intellectual Disability – Intellectual disabilities are one of the most common form of developmental disabilities, and are generally accepted to refer to significant cognitive limitations requiring an individual to rely on external support for daily needs and activities. For the purposes of this document, an individual is considered to have an intellectual disability if the following three criteria are met:

1. IQ is below 70-75
2. There are significant limitations in two or more adaptive areas (skills that are needed to live, work, and play in the community, such as communication or self-care)
3. The condition manifests itself before the age of 18

This definition follows WHO-Europe guidelines which include children with autism who have intellectual impairments as well as children who have been placed in institutions due to environmental factors such as perceived disabilities or family rejection who go on to develop an intellectual impairment (WHO-Europe, 2016)

Service Provider – Any individual or organization that provides a service or support to multiple individuals with intellectual disabilities. This category includes group home administrators, community organizations, charities, medical practitioners, government agencies, advocates and more.

Supporter – Any person who provides formal or informal assistance to an individual with an intellectual disability who is not a family member. This category includes friends, neighbors, home share providers and more.

Our Survey – Three surveys were disseminated by Special Olympics BC in Winter 2021/2022 to identify information specific to British Columbia (1. Supporters and Family Members, 2. Service Providers, 3. Individuals with Intellectual Disabilities). “Our survey of (insert respondent group)” is a reference to one of these three surveys.

The Pandemic – Unless otherwise specified, ‘the pandemic’ refers to the outbreak of Covid-19 from the first cases discovered in December 2019 until the drafting of this report in June 2022.

Lockdowns – Non-pharmaceutical interventions related to the Covid-19 pandemic including stay-at-home orders, curfews, quarantines and related measures.

Risk of Infection and Mortality

Due to a variety of factors including inadequate data collection, the introduction of new strains of Covid-19, and improvements in medical knowledge concerning effective treatment strategies, it can be difficult to accurately determine disparities in infection rates and mortality between individuals with ID and the general population. With that in mind, all studies identified during research for this report indicate that people with ID are both more likely to contract Covid-19 as well as to experience adverse outcomes and death as a result of infection. It is believed that factors such as a heightened prevalence of underlying health concerns (Turk et al., 2020), difficulties accessing services (Oakley et al., 2021), and the need for close contact during the provision of support are the cause of the disparities (Embregts et al., 2020). These factors are not unique to the Covid-19 pandemic as there is evidence from past outbreaks of disease, including the 2018 influenza epidemic, that point to increased mortality amongst this population (Cuypers et al., 2020).

While estimates vary, it is clear that individuals with ID are at a significantly heightened risk of contracting Covid-19 compared to the general population. In perhaps the most extensive study to explore the topic, US-based researchers' analyzed data from 547 health care organizations and found that people with ID were more than three times more likely to contract Covid-19 (3.1%) than those without ID (0.9%) (Gleason et al., 2021). Likewise, a study from Scotland identified a cohort of 17,173 individuals with ID and found that the rates of positive Covid-19 tests amongst people with ID were 2 times higher than the general population (Henderson et al., 2021). Interestingly, only 13.6% of respondents to our survey for people with ID had tested positive for Covid at some point during the pandemic, compared to almost 1/3 of the general Canadian population (Aziz, 2022). However, more research is needed to determine if this is a reflection of successful policy, or the result of disparities in access to testing or other factors.

It is believed that higher incidence rates are not due to any inherent medical or genetic aspect of intellectual disabilities. Rather, they are the result of lifestyle factors and barriers to successful preventative measures that are common for people with ID. For example, many individuals with ID require extensive support to help with daily activities which is often not possible to provide without close contact. This is particularly true for those living in congregate settings or other group living arrangements where it is common for multiple professional staff to be present (Campanella et al., 2021). Furthermore, many individuals with ID do not have a drivers' license or access to their own vehicle and are therefore reliant on shared or public transportation for their daily needs which can increase the risk of infection (Gleason et al., 2021). Lastly, many individuals with ID have sensory issues that can prevent the wearing of masks for long periods of time and leave them vulnerable to infection (Gleason et al., 2021). The presence of increased risk can be a key source of stress in the lives of those who support an individual with ID. In our survey of supporters and family members, 21.8% of respondents stated that their number one fear during the pandemic was the individual they support being at increased risk of serious illness and mortality due to their pre-existing conditions.

In addition to being more likely to being infected, individuals with ID are far more likely to experience adverse outcomes from Covid-19 than the general population. US-based researchers found that 14.5% of individuals with ID and a diagnosis of Covid-19 were admitted to ICU, with only 6.3% of those without ID requiring ICU admittance (Gleason et al., 2021). The same study found that having an intellectual disability was the strongest independent risk factor for mortality from Covid-19 after age. A second US-based study similarly found that intellectual disabilities followed only cancer and developmental disorders in terms of mortality rates (Makary, 2020). Once again, estimates vary greatly concerning the extent to which having an ID affects mortality rates. However, there appears to be a consensus that people with ID are at least twice as likely to die from Covid-19 as the general population. Researchers in the US found that 8.2% of people with ID who contracted Covid-19 died of the disease, compared to 3.8% of those without ID (Gleason et al., 2021). A similar study analyzing data from private health insurance claims found that mortality rates for people with ID were 2.75 times higher than the general population (Makary, 2020). Studies from the UK point to a wider mortality gap than observed in the US, with independent studies identifying mortality rates that were 4.1 (6.3 if accounting for expected under-reporting) (Glover, 2020) and 3.7 (Bosworth, 2021) times higher than those observed in people without ID. While more research is needed, it is believed that living in a congregate setting increases the risk of mortality from Covid-19 (Perera et al., 2020)(Landes et al., 2020).

The high rates of pre-existing conditions found in individuals with ID is a key factor in the increased risk of serious illness and mortality as a result of a Covid 19 diagnosis. In fact, many of the conditions identified in the general population as significant risk factors are far more prevalent amongst people with ID. For example, a study from the University of Maryland identified individuals with obesity, hypertension, and poorly managed diabetes as the most likely to die of Covid following hospital admission (Goodman et al., 2020). According to recent studies, people with ID are more likely to be obese and morbidly obese (Hsieh et al., 2013), and more likely to suffer from diabetes compared to the general population (Vancampfort et al., 2021). Perhaps most alarming given the respiratory nature of Covid 19 is the finding from the UK that even prior to the pandemic, respiratory disease was the number one cause of death for people with ID (O'Leary et al., 2017).

Individuals with Down syndrome are at an even greater risk of severe disease, with one study finding a four-fold increase in the need for hospitalization upon infection and a ten-fold increase in mortality (Clift et al., 2020). It is believed that the increased risk stems from the well-documented accelerated ageing processes in people with Down syndrome (Wisniewski & Pratico, 2016). It is recommended that people with Down syndrome be considered an at-risk group if they are over the age of 40, which is 20 years younger than the general population (Hüls et al., 2021). It is important to note that while it is particularly prevalent amongst people with Down syndrome, evidence shows that the risk of mortality from Covid-19 is higher at earlier ages for all people with ID. For example, one study in the UK found that mortality was 30 times higher than the general population at ages 18 to 34, 19.2 times at ages 35 to 44, 10 times at ages 45 and 64, and 6.7 times from age 65 and 74 (Glover, 2020).

Physical Health

Newly available research is beginning to help stakeholders understand the effects of Covid on mortality and hospitalization rates for people with ID, yet few studies have focused on how the pandemic has affected the overall physical health for this population. For example, no studies were identified during the drafting of this report that analyzed the effects of so-called ‘long-Covid’ on people with ID, even though an estimated one third of the general population experiences at least one symptom of long-Covid after infection (Taquet et al., 2021). Despite the lack of available research, it is believed that the pandemic has had a significant negative effect on the overall health of people with ID. 54.5% of respondents to our survey for supporters and family members believed that the pandemic had caused a significant deterioration in the physical health of the individual they support, while a further 12.7% believed there was a minor deterioration. In Ontario, a study of service providers reported that 33% of staff observed increased physical health concerns in their clients (Bobbette et al., 2020). Due to the effect on wellbeing, service delivery, and daily support needs, it is important that these knowledge gaps be closed as our society learns to live in a world where Covid is endemic. Enhanced knowledge about long-Covid is particularly critical given that many symptoms identified in the general population, such as fatigue, insomnia, and “brain fog” (NHS Choices, 2022), will have a considerable influence on the daily support needs of individuals with ID.

There is an increasing body of evidence emerging that indicates rates of physical activity were substantially impacted by the pandemic, particularly so during lockdowns. In the UK, 61% of parents of children with ID reported reduced rates of physical activity during lockdowns (Theis et al., 2021). Similarly, researchers in China found that in April 2020 (during a strict lockdown), children with ID engaged in only 10 minutes of moderate to vigorous physical activity per day (Yuan et al., 2021). For reference, a previous study conducted shortly before the pandemic found that the average child with ID engaged in 31.7 minutes of moderate to vigorous physical activity daily (Liu et al., 2020). Notably, the UK study also found that during lockdowns, rates of vigorous physical activity saw a greater decline than light and moderate physical activity (48% v. 38%)(Theis et al., 2021). Our survey for people with ID appears to confirm the results found elsewhere, as 67.8% of respondents stated that they had reduced their rate of physical activity during lockdowns, while 27.3% stopped being active almost entirely. Likewise, our survey for supporters and family members suggested that 69.1% of individuals with ID were less active than they were pre-pandemic.

Early in the pandemic, service providers correctly noted that many people with ID would lose access to their usual sources of physical activity during lockdowns, and were quickly able to adapt their services to promote physical activity at home and online during the pandemic. However, the results of our survey for people with ID have shown that online and home workout supports were ineffective for much of the population. For example, only 36.3% of respondents had participated in an online workout or exercise program during lockdown periods, with many individuals commenting that the workouts they were offered did not meet their personal support needs. Further research in this area is needed to shed light on the barriers faced by people with ID in accessing online or home based physical activity supports as well as potential methods of encouraging more moderate to vigorous physical activities in residential settings. It is also worth noting that the physical and mental health of caregivers and supporters can have a substantial effect on the capacity for an individual with ID to engage in physical activity. For example, one respondent to our survey for people with ID reported a significant reduction in their own physical health following the decline of the mental health of their home share provider. To increase effectiveness, future interventions designed to provide online and home-based supports for physical activity should actively consider the roles of supporters and caregivers in the process.

Sexual Health

People with ID of all ages have the same sexual desires as the general population, including the desire to enter romantic relationships and marriages (Healy, et al., 2009). Yet little is known about how the pandemic impacted people with ID in terms of their sexuality and desires to form relationships. Historically, studies have shown that due, in part, to conservative caregiver and parental attitudes towards sexuality (Tamas et al., 2019), people with ID are often required to develop their sexuality and form relationships within a restricted framework (Frawley & Wilson, 2016). Due to the isolation and limitations on movement that many people with ID experienced during lockdowns, it is expected that developing relationships and engaging in sexual activities became more difficult. However, more research is needed to confirm this hypothesis. In the one study to explore the area extensively, researchers in Spain found that sexual appetite increased in 38% of individuals with ID, possibly due to the lack of actual opportunities to carry out sexual practices (Gil-Llario et al., 2021). The same study found that many people with ID responded by increasing their frequency of online sexual activity, with 88% of sending nude images of themselves and 83.6% viewing pornography (Gil-Llario et al., 2021). As many individuals with ID haven’t received the necessary training and education to manage the risks of online sexual activity (Gómez-Puerta & Chiner, 2021), the risk of abuse or misuse is high. Sadly, results from the Spanish study show that the sexual victimization of people with ID is a trend that continued during lockdown. An alarming 6.7% of participants in the study reported being sexually forced, while 19.2% acknowledged having forced themselves on another person (Gil-Llario et al., 2021).

Mental Health

The Covid-19 pandemic has had a substantial impact on the mental health of Canadians of all backgrounds and abilities, the effects of which will likely not be fully understood for years to come. For people with ID, there is a particularly pressing need for research and evidence-based interventions given the alarming rates of mental health concerns and psychiatric disorders that were identified in the population prior to the pandemic and its associated restrictions (Morgan, et al., 2008)(Cooper, et al., 2015). Pre-pandemic studies had identified an increased prevalence of, inter alia, depression (Morin, et al., 2010)(Hermans et al., 2013), dementia (Strydom, et al., 2009)(Shooshtari, 2017), anxiety (Reid, et al., 2011)(Cooray & Bakala, 2005)(Hsieh et al., 2020) and aggressive behavior (Crocker, et al., 2014)(van den Bogaard et al., 2017) amongst the population. In one of the most extensive studies to explore the topic in Canada prior to the Covid-

19 pandemic, researchers in Ontario found that over a two-year period, 44% of adults with ID had a mental illness diagnosis (Lin, et al., 2016).

When asked about the lasting impact of the pandemic on people with ID, respondents to our survey for service providers frequently referenced social withdrawal and isolation. Several noted that, despite programs and services returning to pre-pandemic levels, participation rates were far lower than seen previously. Similar comments were left by family members and supporters, for example, one parent found that their son “became quite used to not doing anything and started saying no to invites to go out”. Likewise, many individuals with ID who responded to our survey reported struggles with isolation, particularly during the lockdown stages of the pandemic. “I survived, but I am getting to the stage where not getting hugged and kissed is really hard. Zoom’s great, but, one thing I realized is that I’m more extroverted than I thought I was” commented one young SOBC athlete. To date, few studies have explored in-depth the effects of the pandemic and associated restrictions on isolation and loneliness for people with ID (Lunsky et al., 2022)(Schormans et al., 2020). However, due to the loss of daily structure and routine that resulted from the pandemic (Scheffers et al., 2021), it is expected that pre-pandemic levels of isolation increased amongst the population. An analysis of five studies conducted in 2016 found an average prevalence of loneliness amongst people with ID of 44.74% (Alexandra et al., 2018), which compares to only 10.5% in the general population (Beutel et al., 2017). For many people with ID, social isolation begins at childhood, with studies finding that children with ID and ASD report fewer friends and a lower quality of friendships than their typically developing peers (Taheri et al., 2016).

There is considerably more evidence of the effects of the pandemic on anxiety and depression levels for people with ID. In Spain, 60% of people with ID reported feeling more afraid or more anxious (Amor et al., 2021). The same study found that the living context was closely associated with expressions of anxiety, with people living in organizational housing experiencing higher rates than those living independently or with family. In Poland, female students were found to be at a heightened risk of anxiety and depression during lockdown, with more than one third experiencing at least mild symptoms (Gacek & Krzywoszanski, 2021). Of their male counterparts, 20% met clinical criteria for depression, while 15% met criteria for anxiety. Studies indicate that a key source of anxiety during the pandemic was an inability to understand information about Covid-19 and the reasons for lockdowns (Amor et al., 2021)(Embregts et al., 2020), which highlights the importance of ensuring information is presented in plain language and in accessible formats. As one Special Olympics athlete noted, “the scariness of not knowing what was going on was very hard, (sic) hard to sort through misinformation.” Based on recent studies, it is highly likely that staff supporting people with ID utilized therapeutic untruths (deception perceived to be in the individuals’ best interest) to manage anxiety amongst people with ID, although more research is needed to determine the impact of the technique (McKenzie et al., 2020).

Overall, it appears that the pandemic has had an overwhelming negative effect on the mental health of people with ID in BC. Of respondents to our survey for people with ID, 63.6% reported their mental health to be ‘worse than normal’, with 13.6% reporting that it was ‘way worse than normal’. Similarly, 83.6% of respondents to our survey for family members and supporters indicated that the mental health of the individual they support deteriorated during lockdowns, with 21.8% noting a significant deterioration. This is consistent with research findings from the UK, where 90% of parents reported a negative impact on mental health of their child, with 42% rating the mental as “much worse” than prior to lockdowns (Theis et al., 2021).

While more research is needed to determine the effects of declining mental health on pharmacology in Canada, in the UK, doctors are seeing a rise in requests for psychotropic medications (Courtenay, 2020), with hypnotics and benzodiazepines being the most commonly prescribed (Naqvi et al., 2021). Notably, UK-based researchers have found a greater increase in the prescribing of psychotropic medications in urban settings compared to rural communities, suggesting that the intensity of pandemic restrictions may be a key contributor (Naqvi et al., 2021). The importance of analyzing the effects of the pandemic on rates of pharmacology in the Canadian context cannot be understated due to the high rates of prescriptions present prior to Covid-19. In 2013, researchers in Ontario found that 50% of individuals with ID were dispensed multiple medications concurrently, with 22% being dispensed five or more (Lunsky, et al., 2013).

The following quotes come from respondents to our survey for people with ID and participants of an informal dialogue session hosted by Special Olympics BC, and do not necessarily reflect the opinions of Special Olympics BC. With that in mind, they provide meaningful insight into the mindset and outlook of people with ID in BC during the pandemic:

"We're all in this together got old, real fast." (comment made in the context of discussions about dismissive attitudes towards the mental health of people with ID)

“I was also terrified, especially when taking the bus…..before I heard that if one person gets sick, the whole bus gets sick.”

“There has been lots of hatred in the world, so that kind of frightens people.”

“Once I was able to see my friends for the first time…..it was quite awesome, but overwhelming. I started crying…….When my support worker was able to come, that made a big difference.”

“When we met in person, we had to wear masks. It is hard to know when someone is sad or nervous or happy.”

“What I’ve learned throughout is to never take anything for granted, because we never know what we will miss until we don’t have it anymore.”

“I think there’s hope for the future, I’m more cautious than ever because Covid’s had a big effect on my life. My mom had Covid, and I unfortunately lost my partner to Covid as well.”

“I’m optimistic for the future, I think it’s been really encouraging to see how many Canadians have already got double-vaccinated and people who aren’t are on their way to doing that. I think people are a little more upbeat and encouraged by the progress we’ve made. It might be a new normal……but I think moving forward I definitely have a lot of hope and I think the future is gonna look promising for all of us.”

“I’m hearing about SOBC programs opening to some extent, it’s promising…but I have a hard time being optimistic all the time too, because I’m on social media a lot. I’ve been paying very close attention to what’s going on…….Every time I hear about hospitals being overwhelmed and moving patients around it makes me nervous. It makes me not want to visit hospitals.”

Barriers to Accessing Health Care

The mere presence of a healthcare service is insufficient to ensure that people with ID are able to achieve the intended benefits. Differences in support needs and communication styles (Doherty et al., 2020), as well as other factors such as negative attitudes towards the population (Hemm, et al., 2015)(Ali et al., 2013)(Pelleboer-Gunnink et al., 2017), and a lack of participation in decision making processes (Doherty et al., 2020)(Oakley et al., 2021) can produce additional access barriers for people with ID. These barriers are particularly pronounced for services that are considered mainstream, or designed primarily with the general population in mind, can result in negative experiences for people with ID (Taggart et al., 2007)(Donner et al., 2010)(Pelleboer-Gunnink et al., 2017). Throughout the pandemic, many of the specialized services on which people with ID depended were closed or restricted due to government-imposed regulations (Jeste et al., 2020)(SOBC, 2022). Furthermore, few of the services introduced to provide Covid testing, vaccination, and treatment included specialized pathways for people with ID (Province of BC, 2022)(SOBC, 2022). This left service providers, supporters, and people with ID to identify and advocate for reasonable adjustments to services to facilitate access and better health outcomes (Campanella et al., 2021)(Waddington & Robbins, 2021).

Healthcare service providers across Canada worked tirelessly to adapt to the ever-changing environment that arose from the pandemic. Respondents to our survey for service providers reported extensive efforts to ensure that the risk of infection was low enough to provide access for their clients with ID. Examples included increased cleaning/sanitation, measures to avoid congestion in common areas, limiting the number of caregivers allowed to attend, diverting patients to smaller clinics, and the use of videoconferencing to allow the participation of additional specialists. NGO's, community groups, and research institutions supplemented the work of service providers by creating resources aimed at educating practitioners about the needs of people with ID, and helping people with ID and their supporters feel more comfortable accessing services. For instance, the HCARDD program based in Ontario created blog posts highlighting the experiences of people with ID as they got vaccinated (H-CARDD, 2021). Blog posts included advice for people with ID who had not yet received their first dose as well as information to assist service providers to make reasonable adjustments to their practices. Another example is a social story created by Surrey Place, which included pictures and simple language descriptions guiding readers through the process of becoming vaccinated (Surrey Place, 2022). Based on the results of our survey for supporters and family members, these measures were generally effective for the majority of people with ID. When asked, 63.7% of respondents stated that reasonable adjustments to medical services were made most or all of the time, while a further 21.8% found them they were made sometimes.

Due to the lack of available research, the extent to which people with ID in BC lost access to medical services during the pandemic is unclear. However, anecdotal evidence from our survey for supporters and family members suggest that many did lose access and the results were highly detrimental. For example, one parent reported that her daughter with ID was unable to see her dietician for her seizure diet, and that the frequency of seizures and associated health issues increased as a result. Several other respondents noted how the pandemic highlighted the lack of available mental health services for people with ID in BC, however, many also expressed optimism that these services will be improved in the near future. A few international studies have explored the topic and found that individuals with ID lost access to medical services at alarming rates. For example, a US based study that was open to caregivers of people with ID globally found that 36% of respondents lost access to at least one service (Jeste et al., 2020). During the reporting period, 67% of respondents in the USA and 53% outside of the USA were able to meet with at least one provider through telemedicine, with the most commonly accessed providers through telemedicine being neurologists and general practitioners. The same study reported that many of the most common priorities of caregivers during restrictions concerned the provision of medication, including larger supplies, reminders to renew prescriptions, assistance and monitoring of new medications, in home medication administration, and home delivery services.

A critical component of service access during a health crisis is successful communication between all stakeholders involved. The effects of a failure to successfully communicate were visible in communities across the country, including in Saskatchewan where some individuals with ID were so confused by public health messaging that they decided to stay home entirely, in some cases forgoing daily necessities such as groceries (Vescera, 2020). Young people with ID in particular have been found to perceive greater difficulty in understanding information about Covid, with a Spanish study finding that 25% found it difficult to understand the reasons for lockdown (Amor, et al., 2021). Here in BC, only 4.5% of respondents to our survey for people with ID were unable to find information about Covid in plain language, which speaks to the dedication and attention to detail of service providers during the crisis. However, this did not necessarily translate into high rates of Covid health literacy as 56.5% of respondents reported difficulties understanding what information was fake or wrong. Notably, 43.5% of respondents primarily received their information on Covid from family and friends, while 21.7% got it from the news, 8.7% from service providers or supporters, and 4.3% from social media. This suggests that future interventions need to consider targeting the support networks of people with ID, particularly where literacy skills of the supported individual are limited (Courtenay & Perera, 2020).

Testing for Covid formed a large portion of many governments' strategies to contain outbreaks and allocate health care resources during the pandemic (NIH Leadership, 2020)(US Department of Health and Human Services, 2022). Here in BC, testing strategies primarily involved the establishment of temporary facilities offering PCR tests on-site (Buffam, 2021) until at-home rapid antigen tests became more widely available later in the pandemic (Ministry of Health, 2022). This strategy involved invasive nasal or throat swabs and often required people to travel to unfamiliar locations (BC Center for Disease Control, 2022). Given that many people with ID have sensory sensitivities and difficulties adapting to changes in routine (Tomchek & Dunn, 2007)(Uljarević et al., 2017), additional support and reasonable adjustments to practices were needed to ensure access. Evidence from elsewhere suggests that high-quality preparatory materials such as social stories and other plain language information are particularly effective in reducing access barriers to testing (Oakley et al., 2021). Of the 43.5% of respondents to our survey for people with ID who had to take a test for Covid during the pandemic, only 34.8% felt that the service provider was able to explain how it would work and the reasons for it. These results are comparable to those of Autism Europe, who found that 24.5% of those who accessed a test were unsure if they had received adequate information about test procedures, and only 38.6% were provided with condition-specific reasonable adjustments (Oakley et al., 2021).

Little is known about the rates of diagnostic overshadowing experienced by people with ID during the pandemic, however, it is likely that it forms a significant barrier to effective service access for the population (Brown, 2020). Diagnostic overshadowing occurs when a medical professional attributes an individual's symptoms or complaint to their intellectual disability or co-occurring mental health diagnosis without fully exploring the actual cause (Reiss, et al., 1982). For example, the deterioration of an individuals' mental health resulting from the effects of a Covid infection may be falsely attributed to a relapse of a previously-diagnosed mental health concern due to the associated restrictions that accompany a Covid diagnosis. It is important that practitioners are reminded that people with ID may present different symptoms from a Covid infection than those presented by members of the general population (Alexander et al., 2020). Supporters and family members can assist by creating a Covid care plan for the individual with ID in their care that includes information relevant to diagnostic overshadowing can help to ensure that an accurate diagnosis is made (Alexander et al., 2020).

Supporters and Family Members

"I missed my friends, my staff, and my sports… My caregiver (supporter) saved me." This quote from our survey for people with ID highlights the extent to which the Covid-19 pandemic increased or altered the role of supporters and family members of people with ID. Supports that were previously provided by service providers such as cleaning, cooking, recreation, and transportation were often not available or practical, thereby leaving supporters and family members to fill in the gaps (Rogers et al., 2021)(Redquest et al., 2020). Of respondents to our survey for supporters and family members, 87.3% needed to spend more time to meet the needs of the individual they supported during lockdowns, with 47.3% needing to spend significantly more time than they did prior to the pandemic. As one family member noted, "supports were typically only outside the home (cooking, cleaning, etc.) were not done by support but by me and at times it became overwhelming." Others found that the availability of supports could often change with little notice, leaving them to feel as if they were "on call all of the time".

For some households, supports were available but family members and supporters chose not to utilize them due to decisions on acceptable risk levels, not just for the individual with ID, but also for others in the household that may be immunocompromised or otherwise at an increased risk of serious illness or death. Of respondents, 70.9% lived with at least two other people, while 14.5% lived with four or more other people. This often led to the avoidance of supports such as public transit, thereby resulting in an increased reliance on family members or supporters for alternate supports. In perhaps the most extensive study to explore the topic, researchers in Spain found that 81.4% of families believed that their adaptation to increased support needs was either good or very good (Navas et al., 2021). However, there was a direct positive correlation between the perceived strength of their adaptation, and the intensity of their relative's support needs.

Many family members and supporters took extensive measures to help the supported individual through the hardships associated with lockdowns and pandemic restrictions. To keep the individual safe, the vast majority of respondents to our surveys indicated that they closely followed public health orders, including "getting vaccinated, limiting exposure and continuing to wear masks in public." To increase quality of life, many respondents focused on increasing the ability of the supported individual to engage in online programs and home entertainment, as well as trying to find outdoor activities. “We set up lots of online programs, bought her an iPad so she could watch preferred shows online, had her do one daily activity, gave her a weekly schedule to look forward to, called family more often, took her out for drive thru treat and participated in some light chores at home to help maintain her space.” For some, this involved making substantial sacrifices; “having to quit my job and be with him to fill in that gap and keep his mental health at a safe level was challenging. My job is to stay strong and support – so that is what I did.”

In addition to experiencing hardship associated with heightened support needs, many family members and supporters found themselves increasingly concerned for the wellbeing of the individual they support. The most common concerns for family members and supporters who responded to our survey included the mental health of the individual they support (29.1%), access to services on which the individual depend (21.8%), and pre-exiting conditions placing the individual at higher risk of serious illness or death (21.8%). Many respondents left additional comments indicating that the social isolation experienced by the individual they support was particularly worrying. These results are in line with international findings which have found similar concerns expressed by parents (Navas et al., 2021)(Neece et al., 2020)(Asbury et al., 2020)(Kim et al., 2021)(Cacioppo et al., 2021)(Greenway & Eaton-Thomas, 2020)(Paulauskaite et al., 2021), siblings (Redquest et al., 2020), and caregivers alike (Grumi et al., 2020)(Lightfoot et al., 2021).

Given the increased support needs, concern for the wellbeing of the supported individual and personal hardships stemming from the pandemic, it is not surprising that studies consistently point to worsening mental health outcomes for family members and supporters (Asbury et al., 2020)(Grumi et al., 2020)(Masi et al., 2021). For example, a study from the UK found that moderate to severe levels of anxiety were reported by 43% of parents of children with ID compared to only 8% in parents of children without ID (Willner et al., 2020). The same study found a prevalence of moderate to severe depression of 45% in parents of children with ID compared to only 11% of parents of children without ID. Likewise, a study in Spain found that 66.3% of family members experienced increased levels of stress and anxiety with rates rising to 73.9% for those whose child or relative had extensive support needs (Navas et al., 2021). Family members and supporters of individuals displaying a high frequency of challenging behaviours have been found to experience particularly high rates of mental health concerns (Chen et al., 2020), in part due to a decrease in social support stemming from the challenging behaviour itself (Willner et al., 2020). Notably, our survey for family members and supporters found that 60% of supported individuals exhibited more frequently challenging behaviour during lockdowns. In the words of one respondent, “the stress level in our home was overwhelming due to our person’s outbursts, mental health and overall unhappiness.”

Evidence from our surveys in BC appear to confirm international results pointing to increased stress and mental health concerns arising from the pandemic. Of respondents to our survey for family members and supporters, 56.4% said lockdowns caused minor deterioration in their mental health with a further 16.4% finding that it caused a significant deterioration. While international research highlights concerns for the supported individual’s wellbeing and increased support needs as key contributors to the decline in family member and support mental health, research is needed to determine the relationship between finance and mental health. An alarming 35.1% of respondents to our survey for family members and supporters indicated that they experienced financial strain as a result of the lockdowns which undoubtedly had an effect on overall wellbeing. Similarly, research is needed to further explore the effects of family member and supporter physical health on their overall wellbeing. Of respondents to our survey, 67.2% engaged in slightly less exercise during lockdowns while 61.8% noted a decline in their overall physical health.

Anecdotal evidence appears to show that the effects of lockdowns and pandemic restrictions on family cohesion appear to be determined, in large part, by the living situation of the supported individual. Many respondents to our survey for family members and supporters spoke of the positive benefits experienced by those living together. For example, several respondents left comments discussing the role lockdowns played in developing family relationships and support systems. In the words of one family member, "It brought me closer to the individual I supported. It gave me a clearer understanding of what can be improved on going forward". For another respondent, the lockdowns increased their perceived capacity to support their family member with ID; "I am stronger than I realize and that I have gained increased confidence in trusting what I know to be best for both of us." These comments were starkly different from those left by family members and supporters of individuals living in group homes and other communal living situations. In these situations, family members and supporters were often unable to visit the supported individual for extended periods of time due to restrictions on visitation. According to one respondent, "as my family member lives in home share in community. Due to lockdown I was not able to visit my family member for almost 10 months." While perhaps necessary to ensure the safety of those living in communal arrangements, such restrictions added to the stress and anxiety experienced by many family members and supporters.

Due to the critical role family members and supporters play in the lives of people with ID, it is important that they are supported by government, medical practitioners and community organizations, particularly during challenging times such as the Covid-19 pandemic. According to our survey, 41.8% of family members and supporters got sufficient support from government, 65.4% got sufficient support from medical practitioners, and 34.6% got sufficient support from community organizations. Although, it should be noted that government and medical supports were more likely than community organizations to be continuously available throughout the pandemic due to the nature of the restrictions in place. While more research is needed to identify gaps in the current support system in BC, researchers in Spain found that when increased support was requested by family, 49% of cases mentioned the need for reconciliation/respite support, 45.8% mentioned emotional support, 14.6% mentioned specific training to care for their relative, and 9.4% mentioned the need for financial support (Navas et al., 2021).

The following quotes come from respondents to our survey for family members and supporters, and do not necessarily reflect the opinions of Special Olympics BC. With that in mind, they provide meaningful insight into potential reforms and the perspectives of a key stakeholder group:

"The lockdowns allowed me to note the shortcomings of organizations and systems whose purpose it is to assist persons with intellectual disabilities. Notably, in three areas: 1. Lack of sufficient support in physical activity. 2. Lack of promoting healthy nutritional options for the intellectually or physically disabled within the organizations. 3. Lack of services promoting intellectual stimulation."

“It made me realize how unprepared we are for our children's future without us. I thought we were prepared. We need to have key people they can call on.”

“I think mentally affected adults in a home with only 2 people, should not be restricted as much as senior residential care homes with hundreds of patients. They got swept up into that category. There needs to be a separate category of information for smaller care situations. Allowing parents to be with their autistic kids is important.”

“Services could have been provided by a walk outdoors... that appeared never to be the answer... Our ID guy hated zoom calls..and he became easily frustrated.”

“Since we all had to isolate this is a difficult situation. I did think there could have been more attempt to send out craft projects for the individuals. Home projects like building a bird house or cooking projects.”

“Continued with flexibility in use of support funding. (The pandemic did not end September 30, 2021 despite what [service provider] thinks.)”

“Honestly, I can't think of anything else other than making Special Olympics, CAN and other like services that support adult with special needs to be considered essential.”

Service Providers

Many organizations that serve people with ID were placed in an immensely difficult position during the pandemic. With limited experience or best-practices to follow, organizations were forced to strike a balance between reducing the risk of infection for a medically vulnerable population (Gleason et al., 2021), and ensuring the ongoing provision of daily support and vocational needs to their clients. To compound matters, 83.6% of respondents to our survey for service providers found that the needs of individuals they support changed because of the pandemic. For example, one respondent noted that individuals they support required far more time and assistance due to mental health concerns. Another found that many of their clients were uncomfortable obtaining services at designated centers, while also hesitant about receiving services through home visits. Adapting services to meet these new requirements and needs required creativity, dedication, and effective communication between stakeholders. This was particularly true during early stages of the pandemic when inconsistent public health responses and messaging led many organizations to make their own decisions (Kavanagh et al., 2021).

Difficulties in service delivery were further magnified by the rapidly changing financial environment that resulted from the pandemic. Of respondents to our survey for service providers, only half qualified for new government financial supports related to the pandemic, while 27.6% saw a reduction in funding from non-governmental sources. The result was that 16.7% of organizations had programs that were affected by financial strain, and an additional 11.1% experienced financial strain but were able to limit its effect on programs. However, only one respondent organization observed a corresponding reduction in the amount of clients they needed to support. In fact, the vast majority (72.2%) saw little to no change, while 11.1% reported seeing a drastic increase in those seeking their services.

Additional complications for service providers came from government-imposed health restrictions which forced half of respondent organizations to substantially alter their services, while 33.3% needed to cease some or all services entirely at times. Yet, despite the difficulties, the results of our surveys highlight the remarkable efforts made by service providers to continue supporting their clients. Of respondent service providers, 72.2% implemented a new or modified service during the pandemic, many of which were web-based. Examples include increased availability of virtual mental health supports, the creation of online learning platforms, and efforts to establish social connections online to combat isolation and loneliness. It is generally agreed that this enhanced focus on virtual supports can be beneficial moving forward due to the increased capabilities, flexibility, and responsiveness that they provide, but also that such supports are unable to meet the needs of all individuals with ID and cannot be a replacement for in-person services (Zaagsma et al., 2020)(Scheffers et al., 2021)(Araten-Bergman & Shpigelman, 2021)(Embregts et al., 2021). As one respondent to our survey for service providers noted, reviews, meetings, and specialist appointments taking place only on zoom “left many gaps in the process”. Furthermore, there may be increased risks associated with online supports including difficulties determining the reliability of assessments, and ensuring confidentiality is maintained (Scheffers et al., 2021)(Courtenay & Perera, 2020). It is therefore critical that service providers increasingly offer staff training on the safe and effective use of online supports as the use of such supports will inevitably remain beyond the pandemic.

The importance of supporting service providers during a public health crisis such as the Covid-19 pandemic cannot be underestimated. Not only do they provide invaluable services that many people with ID depend on, but they are often key stakeholders on which government efforts depend. For example, a 2021 report by the U.S. Department of Health and Human Services found that the commonality between states with the most comprehensive data, infection response, and prevention strategies for people with ID was the cultivation of partnerships across all stakeholder groups (Plourde et al., 2021). In BC, respondents to our survey for service providers were largely positive when asked about the supports they were offered by government sources. Commonly accessed supports included various CLBC programs, federal financial supplements for wages, Health Authority and Ministry of Health guidelines and communications, and supports related to personal protective equipment and rapid testing. To further enhance government supports during future public health emergencies, many respondents suggested that it is necessary to enhance the role of people with ID in the policy-making process.

The need to improve supports for staff who work for organizations supporting people with ID became increasingly clear as the pandemic progressed. In addition to their existing roles and responsibilities, many staff supporting people with ID experienced exceptional pressure to serve in roles for which they may have had little to no training (Trip et al., 2022). For example, staff were often required to participate in the development and implementation of infection prevention strategies, despite an estimated 22% not having been trained to do so by June 2020 (Kavanagh et al., 2021). Given that many individuals with ID face difficulties following and understanding the importance of such strategies, many staff experienced significant hardship as a result (Lunsky et al., 2021). Likewise, additional burdens for staff arose through the expectations from family members that they be proactive in facilitating communication through online platforms even though 70% of family members had never used such platforms in this manner prior to the pandemic (Trip et al., 2022). Enhanced training in these areas will facilitate improved service delivery and reduce the burdens and associated stress experienced by staff supporting people with ID.

Research has long shown that staff who serve people with ID experience heightened levels of stress and burnout compared to the general population (Ryan et al., 2019)(Mitchell & Hastings, 2001)(Jenkins et al., 1997). During the pandemic, these disparities became even more pronounced: a study of mental health workers supporting Canadians with ID found that one in four reported moderate to severe levels of clinical distress, while 34% met requirements for anxiety and 22% for depression (Lunsky et al., 2021). Similarly, an Irish study found heightened levels of anxiety and depression across various sectors supporting people with ID, and that levels were highest for those who supported individuals displaying challenging behaviors (McMahon et al., 2020). Notably, 62% of staff serving people with ID in Ontario found that their clients were more aggressive during the pandemic which likely contributed to 69% of staff reporting more stress at work (Bobbette et al., 2020). Additional stressors for staff supporting people with ID during the pandemic included the fear of infection, concerns over the availability of effective PPE, a sense of responsibility towards the vulnerable population they serve (Embregts et al., 2020), and financial uncertainty. For example, one respondent to our survey for service providers indicated that their entire organization took a 20% reduction in pay during the early stages of the pandemic. While more research is needed to determine the effects of worker stress and burnout on the workforce in Canada, studies from Europe have shown that these factors can result in staffing issues due to increased illness, absenteeism, and staff departures (Bignal & Cassani, 2020).

With little evidence for best practices and a lack of experience in public health emergencies, many organizations were forced to rapidly develop strategies to support staff during the pandemic. Results from our survey for service providers suggest that employers in the sector strove to take an empathetic and flexible approach towards their staff, particularly during lockdown stages. Many indicated that they allowed staff to work from home whenever possible, and provided significant training to increase their capacity to use online communications platforms. These efforts were often coupled with additional news updates, team meetings, and reporting to make up for the lack of face-to-face contact. Service providers also commonly reported the extensive efforts they took to reduce the risk of infection for their staff. Strategies included providing personal protective equipment, increasing the ability to socially distance in the workplace where possible, and implementing vaccine mandates for those accessing services. Further analysis is needed to determine the effectiveness of service provider supports and their relationship to employee wellbeing and retention.

Triage Protocols

The Covid-19 pandemic has placed policy makers and health care providers in an immensely difficult situation. Not only are they responsible for preventing the spread of a novel and deadly disease, but they are also forced to make decisions about who gets access to potentially lifesaving treatment during times of resource scarcity. Fortunately, as of the time of writing, BC has not needed to implement its triage policy to deal with Covid-19 caseloads beyond restrictions related to PCR testing (Watson & Kulkarni, 2021). However, at various stages in the pandemic, health care systems around the world experienced shortages of staff, medications, hospital beds, and medical devices that resulted in a failure to provide care for all patients in need. The neighboring province of Alberta, for example, experienced a shortage of life-saving ventilators as recently as September, 2021 (Bennett, 2021). Likewise, the province of Saskatchewan came within a few patients of needing to restrict access to critical care in October, 2021 (CTV News, 2021). With this in mind, it’s important to understand the process by which decisions about resource allocation are made to ensure that people with ID are not excluded from treatment as a result of their disability.

Despite public calls for clarification from the Disability Alliance BC (Robb & Pritchard, 2020), it remains unclear if BC has adequate protections in place to avoid discrimination against people with ID if triage protocols are implemented. The BC Centre for Disease Control released a document in December, 2020 titled ‘COVID-19 Ethical Decision-Making Framework’, which does explicitly state that disability should not be used as exclusionary criteria (Ministry of Health, 2020). Likewise, the federal government released its own ethics framework concerning public health during the Covid-19 pandemic which also contains specific reference to disability (PHAC, 2021). However, both documents are designed only to be tools to help policy-makers develop triage protocols, and do not contain any binding or enforceable provisions. It is also not known publicly if medical professionals and administrators have received sufficient training and education to implement triage protocols without discrimination. The dangers of insufficient training and education were recently illustrated in the UK where GP’s mistakenly sent letters to group homes stating that people with ID were unlikely to be prioritised for mechanical ventilation, directly contravening policy guidance issued by the National Institute for Health and Care Excellence in the process (Thomas, 2020).

Policies which have the potential to discriminate against people with ID in decisions about resource allocation are alarmingly common. One recent study from the US analysed the ‘healthcare rationing policies’ in 30 states, and found that all but five had provisions that could harm people with disabilities (Whyte, 2022). In other jurisdictions, discrimination against people with ID is explicitly stated in the text of triage guidance or protocols. For example, the Working Group of Bioethics of the Spanish Society of Intensive, Critical Medicine and Coronary Units published triage guidance that explicitly specifies “severe baseline cognitive impairment” as a justification for exclusion (Oakley et al., 2021) (La Sociedad Científica Española de Enfermería, 2020). Elsewhere, discrimination is more discreet but nonetheless still present. Such is the case in Saskatchewan, where the provincial health authority has listed an individual’s ‘social role’ as criteria in a tie-breaker situation (Saskatchewan Health Authority, 2020). While it is incorrect to assume that an individual with ID plays a less significant ‘social role’ than their peers in the general population, studies have shown that professional attitudes towards the population are mixed (Jones et al., 2008), potentially leading to biased decision-making.

A particular area of concern is the use of frailty indicators in triage protocols, which is widespread throughout the western world (Oakley et al., 2021). Initially designed to assess frailty in elderly people, frailty indicators measure the extent to which an individual is dependent upon others for daily support needs and their likelihood of survival of their current illness (Rockwood, 2005). Due to the nature of their disability, many people with ID require such assistance throughout their lifespan regardless of their overall health status or likelihood of adverse outcomes from a given illness (Verdugo et al., 2020). Furthermore, people with ID are more likely to require such support at earlier ages when compared to the general population. If assessed using standard frailty indicators, a typical individual with ID will experience frailty at age 50 that is comparable to a member of the general population at age 80 (Oullette-Kunz & Martin, 2014). For these reasons, there was significant backlash in the UK after the National Institute of Health and Care Excellence published guidelines recommending the use of frailty indicators (Kleinman, 2020). The guidelines were quickly revised to clarify that frailty indicators should not be used for young people or people with ID (NICE, 2022). It is important that policy makers in BC publicly state whether frailty indicators are recommended in the current triage protocols, and if they are, set clear guidelines concerning their applicability to people with ID.

Vaccines

Due to the increased likelihood of severe illness and mortality from Covid-19, coupled with an increased risk of contracting Covid-19 (Gleason et al., 2021), it is critically important that people with ID are vaccinated. Yet much like the general population, many people with ID struggle to navigate the plethora of misinformation concerning vaccination that is available online and is present in public discourse. According to recent studies, people with ID are generally more willing to receive a Covid-19 vaccine than the general population. In New York State, a survey found that approximately 75% of people with ID intended to get a vaccine when it was made available to them (Iadarola et al., 2022). Likewise, in the UK researchers found that 87.1% of supporters of individuals with ID indicated that the person in their care was willing to get a vaccine. The same study found that vaccine intent was associated with white ethnicity, having a pre-existing condition that can result in adverse outcomes from Covid-19, having had a flu vaccine, having known someone who died from Covid-19, and having had to isolate during the pandemic (Hatton et al., 2021). For comparison, a study analyzing vaccine hesitancy across 11 countries found that only 60.1% of adults in the general population stated that they would willingly get vaccinated (Kukreti et al., 2022). However, it is important to note that there can be wide discrepancies in rates of vaccine hesitancy between regions. For example, in our survey of people with ID, 13.6% of respondents stated that they were “very hesitant”, and a further 27.3% reported being hesitant, but “only a little”. Reasons for hesitancy provided by respondents ranged from fear of pain during the procedure, to concerns about side-effects for people with pre-existing heart conditions. Vaccine hesitancy amongst respondents to our survey for caregivers was likewise inconsistent with the findings of international studies. Only 7.3% of respondents disagreed that available vaccines are safe and effective for the individual they support. For this reason, it is important to study the effects of vaccine hesitancy on people with ID in British Columbian communities

The following three quotes come from Special Olympics BC athletes, all of whom have received considerable health education and training through various SOBC programs. They illustrate the reasoning of some individuals with ID who were hesitant prior to being vaccinated. It is important to note that all three eventually accepted vaccination after receiving information directly from experts whom they trusted.

"When I got my shot for the first time, I didn't know what to expect and I didn't know what the side effects will be. That was my concern before I got mine. I had to ask my doctor, I had to ask everyone what their thoughts were in the health care area."

"I admit at first I fell for some of the anti-vaccine talk. 'Oh you don't know what's in it'….. I kind of fell for the like, 'everybody is making a big deal out of nothing'……. That was before I came around."

"There's a big divide that's happened, there's the ones that are all 'get the vaccine, protect one another' and then there's the ones that 'this is a big scamdemic, the vaccine is a big conspiracy, new divide, new world order'….and it's gotten nasty….and um, I'm divided. Mixed feelings."

Efforts to educate about the benefits and processes of vaccination need to extend beyond people with ID to their families, supporters, and caregivers. Many people with ID have limited health literacy, and therefor depend on others for access to health care (Geukes et al., 2018). Furthermore, given the need for close proximity in the provision of many daily support needs, the vaccination of caregivers is particularly important to protect individuals with ID. In a study of professional staff working with people with ID in Canada, 62% of said they were very likely to get a vaccine, 20% said they were likely, while 18% stated they were unlikely to get a vaccine (Lunsky et al., 2021). It is also critical that health education concerning vaccination considers the unique needs of people with ID. For example, there are indications that protection from vaccination for people with Down syndrome may fade quicker than it does for the general population, which has implications for lifestyle choices prior to booster shots becoming available (Eijsvoogel et al., 2017). A second example is the need for individuals with ID, or their supporters, to inform vaccine providers about having epilepsy if applicable (ILAE, 2021), which is very prevalent amongst people with ID (Robertson et al., 2015).

As vaccines and booster shots first became available in Canada, there was a need to determine which population groups should be prioritized for vaccination as sufficient doses were not immediately available for everyone. Despite intellectual disabilities being the highest predictor of mortality after age (Gleason et al., 2021), people with ID were not uniformly prioritized across the country. Ontario, for example, included individuals with ID in the high risk category and allowed for a single caregiver who provides sustained support for daily living to be prioritized as well (Ontario, 2021). BC, alternatively, prioritized individuals who are "extremely clinically vulnerable", including "adults with very significant developmental disabilities that increase risk", but not all individuals with ID or their caregivers (Judd, 2021) (Campanella et al., 2021). Saskatchewan, Prince Edward Island, and Newfoundland and Labrador have similarly limited prioritization to subgroups of individuals with ID based on severity, residence, or other factors (Campanella et al., 2021). The failure to universally protect individuals with ID across Canada has led to multiple calls for reform (Inclusion Canada, 2021) (O'Donovan, 2021) (Carpenter, 2021), which unfortunately, have largely gone unanswered. Moving forward, all people with ID in BC should be included as a priority group for boosters without any limiting language.

While prioritization and education are necessary to help protect people with ID from Covid, they are not sufficient to meet everyone's needs. Many people with ID face additional barriers to vaccination that are not experienced by the general public. For example, some individuals with ID have sensory issues that can prevent them from entering mass vaccinations sites which can be quite loud and overwhelming (Brohman, 2021). Additional barriers may include a lack of internet access and ability to use online booking systems, mobility restrictions, and insufficient transportation (Campanella et al., 2021). Across North America, jurisdictions have approached these concerns in vastly different ways with some making only seemingly trivial efforts, and others implementing creative and extensive solutions. In the US state of Missouri, for example, a disability advocate was present during all vaccination planning efforts at the state level which ensured that the needs of people with disabilities were considered prior to implementation (Plourde et al., 2021). Other states revised policies related to non-emergency medical transport to allow for better access to mass vaccinations sites, while some states opted to boost reimbursements or partnered with pharmacies to allow for home visits (Plourde et al., 2021). Similar efforts were made by the City of Toronto which provided mobile vaccination sites, transportation to vaccination sites, and assistance booking appointments through a partnership with the Toronto Public Library (Campanella et al., 2021). Further, despite vaccination policy being left to individual states, the Centers for Disease Control and Prevention recognized a need for increased support and created a website specifically for practitioners who are providing vaccinations to individuals with ID (CDC, 2022). On it, practitioners can find tips for effective communication, suggestions for booking appointments, educational resources for individuals with ID, and further reading for practitioners themselves.

Conclusion

More than five years have passed since Special Olympics BC released the British Columbia Framework for the Advancement of Health Outcomes for People with Intellectual Disabilities. The document laid out the current knowledge concerning the alarming health disparities faced by individuals with ID in the province, and included recommendations for potential interventions. Following its release, stakeholders of all backgrounds pledged to proactively consider their role in achieving health equity, and to work collectively with other stakeholders to change the status quo. There are countless examples of success stories that resulted from the newfound awareness brought by the Framework Document. This includes the creation of an inclusive policy-making checklist which aimed to assist policymakers in considering the needs of people with ID in their work. Another example was the sustained engagement by stakeholders of groups representing primary care providers, which focused on educating practitioners about the health disparities faced by the population. Yet despite these efforts, there is little evidence to show that health outcomes for people with ID in the province have improved.

In the early days of the pandemic, it became clear that many initiatives that would benefit people with ID would no longer be continuing. In some cases, funding cuts stemming from the uncertain landscape meant programs were placed on hold or cancelled. In other situations, professionals responsible for implementing programs for people with ID were transferred to work on projects related to the pandemic, for example, to participate in contact tracing. Sadly, the loss of existing programs and initiatives was not countered by the creation of new programs and initiatives. It was clear to many observers that once again, people with ID were being largely forgotten, despite the pre-existing health disparities and the increased risk of adverse results from Covid-19. Advocates and supporters were left to fight for even the most common-sense interventions, such as the inclusion of people with ID on vaccination priority lists. For many family members, supporters and individuals with ID, this wasn't just discouraging or disappointing – it was downright scary. British Columbia was failing to meet the needs of people with ID when they needed support the most, and the results were fatal.

Here in BC, we can, and must, do better! We have the resources, expertise and networks needed to create sustained change and eliminate the health disparities faced by individuals with ID. There is no more time for endless discussions, claims of ignorance or continued failure. If by reading this report you became outraged, pledge to be part of the solution. Every one of us has a role to play in achieving health equity, and it will take all of us to make it a reality. We need governments and health authorities to develop a long-term framework to advance health outcomes for the population and to support them during future health crisis. We also need community groups and NGO's to actively consider means by which they can alter or supplement programs to empower people with ID to live a healthier lifestyle. Research institutions are needed to increase the current understanding of health inequities and to monitor progress moving forward. Health care practitioners are needed to reduce barriers to health care access that people with ID face on a daily basis. Lastly, individual residents in BC are needed to create communities that welcome people with ID and promote inclusion. In other words, we need you!

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