

Time to be Counted: COVID-19 and Intellectual and Developmental Disabilities

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An RSC Policy Briefing

Authors

Jennifer Baumbusch	The University of British Columbia
Chantal Camden	Université de Sherbrooke
Barbara Fallon	University of Toronto
Yona Lunsky	Centre for Addiction and Mental Health; University of Toronto
Annette Majnemer (Co-Chair)	McGill University Health Centre Research Institute (Montreal Children's Hospital)
Patrick J. McGrath, FRSC (Co-Chair)	Dalhousie University, IWK Health Centre
Steven P. Miller	The Hospital for Sick Children; University of Toronto
Genevieve Sansone	University of Toronto
Tim Stainton	The University of British Columbia
John Sumarah	Acadia University
Donna Thomson	
Jennifer Zwicker	University of Calgary

Peer Review Monitor

Tom Marrie, FRSC	Dalhousie University
------------------	----------------------

Peer Reviewers

Michael Bach	Institute for Research and Development on Inclusion and Society
Lucyna Lach	McGill University

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Cover Art

Elaine Derkach, *Rise Up*

Elaine is a 52 year-old artist with Down syndrome from Vancouver Island who paints in acrylics and watercolours. Her favourite subjects are sunsets, flowers, and the ocean. She is especially inspired by the beauty of Maui and by the gardens she has visited in England, France, New Zealand, Sweden and Demark as well as many beautiful gardens in the US and Canada. She is a member of the Mt Arrowsmith Rhododendron Society in Qualicum Beach and the American Rhododendron

Society (worldwide) and has friends all around the world. Many of her colourful paintings have been reproduced for her very popular greeting cards. This piece was chosen because of its inspiring imagery that evokes the theme and title of the report.

Land Acknowledgement

The headquarters of the Royal Society of Canada is located in Ottawa, the traditional and unceded territory of the Algonquin Nation.

The opinions expressed in this report are those of the authors and do not necessarily represent those of the Royal Society of Canada.

Background on the Policy Briefing Report Process

Established by the President of the Royal Society of Canada in April 2020, the RSC Task Force on COVID-19 was mandated to provide evidence-informed perspectives on major societal challenges in response to and recovery from COVID-19.

The Task Force established a series of Working Groups to rapidly develop Policy Briefings, with the objective of supporting policy makers with evidence to inform their decisions.

About the Authors

Jennifer Baumbusch, Associate Professor, School of Nursing, University of British Columbia; Canadian Institute of Health Research Chair in Sex & Gender Science

Chantal Camden, Associate Professor, School of Rehabilitation, Université de Sherbrooke; Researcher at CRCHUS and l'IUPLSSS

Barbara Fallon, Professor, Factor-Inwentash Faculty of Social Work, Canada Research Chair in Child Welfare, University of Toronto

Yona Lunsky, Director, Azrieli Adult Neurodevelopmental Centre. Centre for Addiction and Mental Health; Professor, Psychiatry, University of Toronto

Annette Majnemer (Co-Chair), Professor, School of Physical & Occupational Therapy, Vice-Dean, Education, Faculty of Medicine and Health Sciences, McGill University; Senior Scientist, Research Institute of the McGill University Health Centre

Patrick J. McGrath, FRSC (Co-Chair), Emeritus Professor, Psychiatry, Dalhousie University; Scientist IWK Health Centre

Steven P. Miller, Head, Neurology, The Hospital for Sick Children; Professor, Paediatrics, University of Toronto

Genevieve Sansone, Research Associate, Fraser Mustard Policy Bench, University of Toronto

Tim Stainton, Professor, School of Social Work; Director, Canadian Institute for Inclusion and Citizenship, University of British Columbia

John Sumarah, Emeritus Professor, Counselling Psychology, Acadia University

Donna Thomson, Parent, Author, Advocate

Jennifer Zwicker, Director of Health Policy, School of Public Policy, Assistant Professor, Canada Research Chair, Kinesiology, University of Calgary.

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- Gillian Backlin (BC), Writer, & CHILD-BRIGHT National Youth Advisory Panel member

- Mathias Castaldo (ON), Youth Facilitator at Holland Bloorview Kids Rehabilitation Hospital, & CHILD-BRIGHT youth-partner (Metformin in CP project), and National Youth Advisory Panel member
- Hans Dupuis (QC), Air Canada Employee, & CHILD-BRIGHT National Youth Advisory Panel member and Knowledge Translation Committee member
- Lena Faust (QC), PHD student at McGill University and the McGill International Tuberculosis Centre, & CHILD-BRIGHT National Youth Advisory Panel member and Knowledge Translation Committee member

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- Lloyd Chafe, Member, People First of Ontario
- Dale Froese, Self Advocate Consultant & Liaison, Canadian Institute for Inclusion and Citizenship, UBC
- Leanne Froese, Self Advocate Consultant & Liaison, Canadian Institute for Inclusion and Citizenship, UBC
- Joanne Gauthier, President - People First of British Columbia, Canadian Institute for Inclusion and Citizenship Advisory Board Member
- Kevin Johnson, President, People First of Manitoba
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Mandate and Scope

This Policy Briefing focuses on the impacts of COVID-19 across the lifespan for individuals with intellectual and other developmental disabilities (IDD) and provides specific policy

recommendations to mitigate further negative impacts and optimize outcomes for individuals with IDD and their families.

In addition to the Executive Summary and Introduction, there are eight key domains covered in this report, presented in separate sections. Each domain includes a brief summary of challenges experienced by individuals with IDD in the domain of interest prior to the COVID-19 pandemic; emerging evidence on new challenges during the pandemic period; and key policy recommendations to minimize these impacts. These domains or themes of interest were selected based on COVID-19 priorities identified by the following groups or sources: the 2020 Federal Policy Forum hosted by People First Canada and Inclusion Canada (with input with representatives of People First Canada), CHILD-BRIGHT's National Youth Advisory Panel, family members, as well as recent publications articulating priority areas of concern during the pandemic (Government of Canada, 2020; Arim, Findlay, & Kohen, 2020).

The recommendations presented in the report were also reviewed by 16 individuals with developmental disabilities or caregivers, to ensure that the impacts and recommendations optimally resonated with their lived experience. Quotes presented throughout the report also came directly from individuals with lived experience.

Note from the Authors

The authors would like to briefly address the issue of language for persons with disabilities. While many disability advocates have called for identity-first language (e.g. disabled person or autistic person), others have also highlighted the importance of person-first language (e.g. person with disability or person with Down syndrome). We have used person-first language throughout this report, but recognize that both are valid and important perspectives.

This report focuses on the experiences of people with IDD in Canada, but given the limited evidence available from Canada, evidence from other countries has also been included. The authors would like to note that Indigenous communities in Canada may be disproportionately impacted by infectious diseases such as COVID-19, due to higher prevalence of disability and other pre-existing conditions and vulnerabilities among this population (Hahmann, 2021). The existing health inequities and barriers in accessing health services for all individuals with IDD have been amplified during the COVID-19 pandemic, but these barriers may be even greater for Indigenous people with IDD—especially those living in remote or isolated communities (Okonkwo, 2020; Weaver, 2020). While the specific challenges facing these communities are beyond the scope of this report (see the RSC Policy Briefing on COVID-19 and Indigenous Health and Wellness), particular attention must be directed towards considering how the recommendations in this report can be implemented in a culturally appropriate and safe manner for Indigenous peoples with IDD.

We also acknowledge that some individuals with IDD may be at greater risk of suffering more severe COVID-19 outcomes due to the presence of other concomitant and intersecting vulnerabilities, including but not limited to ethnic background and socioeconomic status. Therefore, we strongly recommend that special considerations are also taken to avoid perpetuating or worsening gaps in health outcomes for these population groups.

Considerations of these populations will help to ensure that Canada's policy responses to the COVID-19 pandemic seek to mitigate the harms of the virus on all people in Canada equitably.

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Executive Summary

The COVID-19 pandemic has impacted the lives and well-being of all people globally, with consequences being observed across all domains from physical and mental health to education and employment outcomes, to access to community supports and services. However, the disproportionate impact of the COVID-19 pandemic and its associated public health restrictions on individuals with intellectual and developmental disabilities (IDD) has largely been overlooked. Not only do people with IDD have a greater risk of severe complications and death from the virus as shown in large scale studies, but they also face significant short- and long-term consequences of COVID-related public health measures on their mental health and well-being.

At a time when this vulnerable population is already feeling undervalued, ignored, and forgotten, it is imperative that the risks facing adults and children with IDD – as well as their families and caregivers - are recognized, valued, and addressed through a disability-inclusive approach to Canada's pandemic policy response planning. This requires both a mainstreaming of disability inclusion into all COVID-19 response and recovery policies as well as disability-specific policies to address the unique barriers and challenges encountered by people with IDD during the pandemic. The recommendations in this policy briefing aim to achieve a more inclusive, accessible, and sustainable Canada for people with IDD both during and after the pandemic – an approach that will result in benefits for all of society.

Policy Recommendations

In creating this Policy Briefing and the recommendations presented within it, several themes emerged which crossed several of the domains. In particular, two primary themes were identified as overarching principles that were used to guide the development of the domain-specific recommendations. These **guiding principles** (United Nations, 2020; Government of Canada, 2020) were:

- 1. “Nothing about us without us”** – the disability rights movement slogan which has been adopted by the United Nations Convention on the Rights of Persons with Disabilities and refers to the inclusion and active involvement of persons with disabilities in all pandemic response planning and decision-making that would impact them.
- 2. Accessibility and accommodations** – COVID-19 policies must incorporate the unique needs, challenges, and vulnerabilities of individuals with IDD, including equal access to COVID-19 testing, treatment, health care, and vaccination. All facilities and procedures must be accessible.

The domain-specific recommendations presented below and at the end of each relevant section were created in consideration of these principles and in response to the evidence reviewed in each domain, including any specific gaps in services and supports that were identified and agreed upon by all co-authors as needs that must be addressed through further action. These recommended actions generally fall under the following themes: essential services and prioritization; accessibility of services; data collection and monitoring; funding needs; and information/guidance. In addition, the recommendations are targeted towards different agencies and government ministries at various levels (i.e. national, provincial/territorial, local) and in various domains (i.e. education, public health, social services) who are responsible for policies that affect persons with IDD in Canada. The themes and the specification of relevant stakeholders for each recommendation are

more clearly laid out in the Appendix of the report. Finally, as described further in the Introduction and in the Appendix, the recommendations can also be divided into two types – both of which are essential components of a **disability-inclusive** approach: those that mainstream inclusion of persons with IDD in COVID-19 policy responses and those that address disability-specific considerations.

Summary List of Recommendations:

Recommendation 1: Prioritize persons with IDD of all ages in the distribution of COVID-19 vaccinations in Canada along with other high risk clinical groups, in recognition of their heightened susceptibility to severe complications and death from the virus as well as the disproportionate impact of COVID-related public health measures on their health and well-being.

Recommendation 2: Ensure public health information and communication that addresses the health risks for children and adults with IDD is widely available and adheres to national accessibility standards.

Recommendation 3: Designate services, supports, therapy and support workers for persons with IDD as essential across health and social care sectors.

Recommendation 4: Provide health care accommodations for people with IDD both during the pandemic and post-pandemic recovery.

Recommendation 5: Use and adapt telehealth as needed in an accessible manner, to ensure functioning and well-being of individuals with IDD.

Recommendation 6: Allocate mental health services to address the unique needs of people with IDD and their caregivers who have been disproportionately impacted by the pandemic and ensure support for staff – including appropriate training and access to specialized mental health supports and resources.

Recommendation 7: Develop a data collection strategy of existing adapted and inclusive community programs, to identify community-specific gaps and needs.

Recommendation 8: Synthesize and promote an accessible resource and support guide with information on tools, virtual programs and approaches to promote health navigation, social support and leisure participation and inclusion opportunities for individuals with IDD and their families in local communities which would remain useful post pandemic.

Recommendation 9: Allocate additional funding for community-based participation initiatives for people with IDD to support innovative solutions that are sustainable post pandemic.

Recommendation 10: Ensure appropriate modifications, accommodations and supports are available to enhance the participation, development, and well-being of students with IDD both during and post-pandemic.

Recommendation 11: Monitor the long-term impacts of the pandemic on learning for students with IDD through individualized assessments.

Recommendation 12: Develop a National Disability Income Benefit sufficient to ensure a reasonable minimum income for all Canadians with a disability.

Recommendation 13: Design disability inclusive pandemic income supports. In addition, recognize persons with IDD and their families experience additional costs such as PPE for support staff and technology needs.

Recommendation 14: Enhance emergency caregiver benefits to family members or guardians of persons with IDD who are required to take leave from employment in order to provide care due to COVID-19 or similar pandemics.

Recommendation 15: Invest in post pandemic accessible employment support for people with IDD to support recovery from COVID-19 related job losses and reduced employment.

Recommendation 16: Ensure that guidelines and policies for residential care and congregate care settings are aligned with proposed long-term care standards and that unrestricted access of essential family caregivers to individuals with IDD be embedded in those standards and communicated transparently.

Recommendation 17: Collect, analyze and report surveillance data for people with IDD, including information on COVID-19 prevalence and outcomes for individuals with IDD in public settings, institutional and residential care settings.

Recommendation 18: Ensure continued access to resources for support staff and guarantee safe and affordable housing options for individuals with IDD through greater investment in community-based housing and supports to promote independent living.

Recommendation 19: Ensure that hospital triage protocols and guidelines are inclusive, equitable, transparent, and grounded in an ethical process that is based on human rights principles and informed by patients who would be affected by such protocols, including persons with IDD and their families. Health care providers involved in the critical care triage process must also receive training to reduce the risk of discriminatory bias.

Time to be Counted:

COVID-19 and Intellectual and Developmental Disabilities

Introduction

Intellectual and developmental disabilities (IDD) have been viewed from different perspectives over time, primarily through both bio-medical and social/human rights lenses (Bach, 2017). From a bio-medical perspective (i.e. the “*medical model*” approach), the term refers to a heterogeneous group of developmental disorders which include diverse conditions and etiologies and manifest as a range of limitations in function within individuals, in comparison to normative developmental pathways. This group of disorders is uniform in having a brain-based origin for the disability that occurred in the early developmental period. The etiologies of IDD may include brain malformations or maldevelopment and brain injury to the immature brain and are at times associated with genetic anomalies or genetic predisposition to brain damage or maldevelopment. Critical illness in the newborn period (e.g. preterm birth, congenital heart disease) is also an important risk factor for IDD. These etiologies of IDD typically manifest with limitations in developmental functions that emerge in the first months and years of life, and include impairments in motor, cognitive, language, and behavioural developmental domains.

In the *social or human rights model*, IDD is described as a construct within the social, cultural, and political context and refers to the discrimination and exclusion that people with IDD experience in relation to others (Bach, 2017; Berghs et al., 2016). This approach focuses on removing barriers to full participation in society for this population.

Other models of disability, such as the *biopsychosocial model* adopted by the World Health Organization’s International Classification of Functioning, Disability and Health (ICF), recognize that it is a complex, multidimensional phenomenon in which one’s level of functioning is seen as an interaction between features of both the person and the broader environment (World Health Organization, 2002). Commonalities among the growing number of individuals with IDD, as operationalized in this report, (American Psychiatric Association, 2013; World Health Organization, 2020a; Schalock et al., 2010) include:

- The developmental disability began in early childhood;
- There is a significant impact on adaptive behaviours (activity limitations);
- The brain is affected; and
- The activity limitations associated with the disability persist throughout the lifespan, although their impact may change over time.

Developmental disabilities are associated with age-related activity limitations in mobility, communication, learning, socialization, vocation, self-care and/or independent living (American Psychiatric Association, 2013). These developmental disabilities are referred to as *intellectual disabilities* when the individual has deficits in both intellectual functioning (defined as an Intelligence Quotient (IQ) score below 70, compared to the average score of between 85-115) and in adaptive functioning (American Association on Intellectual and Developmental Disabilities, 2010). Common examples of IDD include: Down syndrome and other specific genetic disorders, autism spectrum disorder, fetal alcohol spectrum disorder, cerebral palsy, specific language impairment, attention deficit hyperactivity disorder (ADHD) and learning disabilities (see Bishop, 2010 for others).

The **prevalence** of IDD has been challenging to estimate, given the lack of current, well-defined population-based data and variations in definitions across countries. While this report focuses on IDD in Canada, it includes studies from other countries that may define IDD in more broad or narrow terms (i.e. some refer strictly to intellectual disabilities while others refer to learning disabilities or disabilities more broadly). In the United States, the estimated prevalence of developmental disabilities broadly defined up until 2008 was approximately 13.9% (Boyle et al., 2011). More recently, prevalence in the United States was estimated at 1 in 6 (16.93%) in children 3-17 years old (Zablotsky et al., 2019). Estimates have also varied in Canada—earlier data from the first cycle of the National Longitudinal Survey of Children and Youth (NLSCY, 1994-95) identified about 9% of children aged 6-9 years as having a neurodevelopmental disorder (NDD) (Arim et al., 2015); more recently, administrative data from British Columbia showed the prevalence of NDD to be 8.3% among children who were aged 6-10 in 2006 (Arim et al., 2017). According to surveys conducted by Statistics Canada, close to 5% of children 5-14 years old have significant activity limitations and 13.1% of children aged 5-17 years have functional difficulties in at least one domain (Statistics Canada, 2006; 2021). Prevalence rates for IDD increase substantially when including more common developmental disorders such as learning disabilities (7.74%, Zablotsky et al., 2019) and ADHD, which is estimated at 6-9% (Perrin, Bloom & Gortmaker, 2007; Zablotsky et al., 2019). The prevalence of intellectual disabilities is between 1% and 5% of the population depending on the inclusion criteria (McKenzie et al., 2016; Government of Canada, 2006). More current estimates of these disorders are much higher, as identification of milder variants has improved: for example, the prevalence of autism spectrum disorder has increased since 2000 and is now estimated as 1 in 54 children (Maenner et al., 2020). Improvements in health care have also contributed to the increase in prevalence of IDD in Canada. For example, medical and surgical advances in neonatal care have resulted in much higher survival rates of very preterm neonates and those requiring complex surgeries and medical care; and advancements in access to health care for medical complications associated with severe disabilities has greatly enhanced life expectancy.

Role of policy, supports and services

Individuals with IDD face multiple challenges across the lifespan, from daily living needs to health and other life outcomes. In Canada, persons with IDD experience poorer educational achievement, employment, independent living and physical and mental health, relative to Canadian averages (Berrigan, Scott & Zwicker, 2020). In addition to activity limitations, individuals with IDD and their families face a number of structural barriers to equal participation to society, including barriers to the justice system, and to needed social supports and health care.

The COVID-19 pandemic has exacerbated these pre-existing challenges, for both individuals with IDD and their caregivers. As articulated throughout this report, the evidence on the *impact* of COVID-19 on individuals with IDD and their caregivers is somewhat limited but is nonetheless quite consistent and is greater than the impact on the general public (Aishworiya & Kang, 2020; Berrigan, Scott & Zwicker, 2020; Government of Canada, 2020; Flory et al., 2009; Lamsal et al., 2018; Sabatello et al., 2020; Zwicker, Zaresani & Emery, 2017) for several reasons:

1. Many individuals with IDD have co-occurring health conditions and multiple complex health care and community-based needs;
2. A disproportionate number of adults with IDD live in congregate settings;

3. Individuals with IDD have been more greatly affected by practices and policies related to prevention of COVID-19 including cessation of essential in-person supports and ongoing health services; restrictions in access for family members, friends and volunteers; and lack of appropriate Personal Protective Equipment (PPE);
4. Resource constraints create challenges in the allocation of lifesaving treatments for COVID-19 patients, with the potential for discriminatory practices in the care and treatment of persons with IDD by health care providers and hospital policies, such as triage protocols; and finally,
5. Persons with IDD and their families are disproportionately represented in lower socio-economic status domains. Persons with disabilities (broadly defined) are two times more likely than the general population to be living in poverty, which is an additional risk factor for increased infection rates.

Prior to the COVID-19 pandemic, Canada committed to providing services and supports to improve personal and societal health outcomes and reduce these barriers to full participation in society, through ratification of the United Nations Convention on the Rights of Persons with Disabilities, the Accessible Canada Act, and individual and family rights for care under the Canada Health Act. In particular, accessibility standards have been implemented across the country through various sub-national bylaws, policies, and guidelines, with the aim of creating barrier-free access to communities, workplaces, and services for people with disabilities. Most recently, federal legislation on accessibility standards came into force in July 2019 through the Accessible Canada Act, which identified seven priority areas in which federally regulated entities should focus on identifying, removing, and preventing barriers to improve access and opportunities for persons with disabilities. This includes the design and delivery of programs and services, and communication, among other domains that affect daily life for people with disabilities. Proposed regulations for the Act are currently under review (Employment and Social Development Canada, 2021).

However, successful attainment of these aims has been further restricted by the pandemic. The Canadian government has undertaken a national effort to meet the particular needs of persons with disabilities during COVID-19 (see Guidance document published online (Hole & Stainton, 2020)). It is therefore imperative that both children and adults with IDD as well as their caregivers be appropriately supported by policies and resources to sustain their health and well-being during the pandemic and beyond.

Recommendations for a disability inclusive policy response

The COVID-19 pandemic is a human crisis impacting the health and well-being of all people globally. As has been seen during other public health emergencies and humanitarian crises (e.g. White, 2009; Fox et al., 2007; Handicap International, 2015), there is a tendency for the COVID-19 rapid policy responses to leave persons with IDD behind, despite being a population that is disproportionately impacted by the pandemic (as detailed in this report).

What is a “disability inclusive” pandemic response?

A **disability inclusive** approach to pandemic response planning is important to meet the commitments of the UN Convention on the Rights of Persons with Disability which would ensure that persons with disability, like everyone else, have access to essential services. The benefits of this approach would also extend to society as a whole. The UN describes how “adopting a

disability inclusive response will provide for more inclusive, accessible and agile systems capable of responding to complex situations, reaching the furthest behind first. It will pave the way for a better future for all” (United Nations, 2020).

Throughout this report, we consider two important components that must be present for a disability inclusive pandemic response, described below:

1. Mainstreaming inclusion of persons with disability in all aspects of pandemic response and recovery efforts

Following the principle of “Nothing about us without us” adopted by the UN Convention on the Rights of Persons with Disability, disability inclusion requires accessible, accountable approaches to be taken in developing population-level COVID-19 responses, incorporating meaningful consultation in all stages of response and recovery. Several policy approaches have been used in Canada by governments and organizations to attempt to “flatten the curve” and reduce the spread of the COVID-19 virus, including: public announcements, emergency funding, social distancing and self-isolation policies, nonessential workplace closures and public event cancellations, administrative flexibility, health facility restrictions, government, community facility and school closures, and public emergency declaration (McCoy et al., 2020). Most recently, strategies for population-level vaccination against COVID-19 are being developed and implemented.

However, to date, many of the COVID-19 response policy approaches in Canada have not been inclusive for persons with IDD. The 2020 report for the Government of Canada COVID-19 Disability Advisory Group highlighted important gaps, such as the need for provision of public health information in plain language, impossibilities of self-isolation policies, inequities over access to health services and education and issues over determination of essential services (Government of Canada, 2020). Disability inclusive responses would help to ensure that approaches maintain respect for “dignity, human rights and fundamental freedoms,” and avoid widening the gap of existing disparities among persons with disabilities (Human Rights Watch, 2020). Fundamentally, there is a need to recognize that these policies are intended for all Canadians, including Canadians with disabilities. To accomplish this, a different approach is needed which includes persons with disabilities in preparedness and response planning, and which requires diligence, creativity, and innovative thinking (Armitage & Nellums, 2020). This report describes important considerations in moving towards this type of response and highlights that an inclusive and accessible approach is fundamentally better for all Canadians.

“Whenever there’s policies being made or whenever we are trying to, as a society, learn how to be more inclusive, it’s really just...a pointless exercise if you have a certain group of experts making recommendations and policies without actually including...the people who have that lived experience...right now it is probably more important to make sure that decisions and policies...are made with our okay and with our input.”

– Jake Anthony, self-advocate

2. Developing policies and programs to address disability-specific considerations, with input from the IDD community and caregivers

Persons with IDD require special consideration during the pandemic response, as they experience additional barriers to participation in society and are disproportionately impacted by the COVID-19

outbreak—both directly through an increased risk of severe health outcomes from COVID-19 infection and indirectly through the impact of public health measures and restrictions on their daily lives and well-being (Kuper et al., 2020). Consequently, disability-specific policies are required as an important component of a disability-inclusive policy response. In this report, we describe some of the factors that put persons with disabilities at higher risk of COVID-19 – including higher risk of infection and adverse outcomes from infection, such as support needs and risk of discrimination in seeking scarce lifesaving procedures. Persons with IDD are also disadvantaged by the socioeconomic impacts of COVID-19, disproportionately experiencing lower income, employment and educational attainment. These factors will be described more in the report and highlight the important additional barriers to participating in COVID-19 response and recovery policies, including access to vaccination.

In sum, a disability-inclusive policy response requires both a mainstreaming of disability inclusion in all COVID-19 response and recovery policies as well as disability-specific policies to address unique barriers encountered during the COVID-19 pandemic. The recommendations in this report aim to achieve a disability-inclusive, accessible and sustainable post COVID-19 Canada, as inspired by the 2020 theme for the International Day of Persons with Disabilities—“Building Back Better”.

Health Risks Associated with COVID-19 for Individuals with IDD

Adults and children with IDD face greater risk of adverse health outcomes, including severe complications and mortality from COVID-19 infection. Stronger efforts are needed to recognize and reduce these health risks for individuals with IDD through disability inclusive health system approaches to COVID-19 response, treatment, and communications.

As of February 2021, COVID-19 has infected over 850,000 Canadians and caused the death of over 21,000 (Government of Canada, 2021). Individuals with intellectual and developmental disabilities (IDD) are at increased risk of more severe disease outcomes from COVID-19 for several medical reasons, including but not limited to: higher prevalence of pre-existing comorbidities, unusual presentations of the disease, and delayed diagnosis—which may result from difficulty identifying or self-reporting symptoms, or fear of visiting a hospital.

Existing evidence suggests that the prevalence, symptoms, and outcomes of COVID-19 tend to be less severe among children in the general population compared to adults. However, children with IDD and other pre-existing health conditions may be at greater risk of developing complications from COVID-19 compared to children without disabilities.

Evidence on COVID-19 health risks for individuals with IDD

Evidence on the risk of contracting COVID-19 and its associated health outcomes among individuals with IDD has been limited overall, especially data on children with IDD. Most of the evidence comes from other countries/jurisdictions, with no studies yet from Canada. Findings from existing studies on the health risks of COVID-19 for individuals with IDD largely support the greater risk of adverse outcomes for this population, including younger average age at death from COVID-19.

Early data from the start of the pandemic suggested higher rates of COVID-19 among people with IDD, especially in certain settings such as congregate care (Landes et al., 2020a). As described below, some more recent studies suggest that COVID-19 infection rates remain higher (Gleason et al., 2021), while others have shown a similar or lower case rate among people with IDD compared to the general population (Landes et al., 2020b; Turk et al., 2020; Chakraborty, 2021). Further analyses suggest that some of the reasons for the differences across studies may be related to additional factors such as type of residence, age, and other demographic variables. For example, with respect to residence, Landes et al. (2020a) found higher rates of COVID-19 infection (7,841 vs. 1,910 per 100,000) and case-fatality (15.0% vs. 7.9%) among individuals with IDD living in group homes in New York compared to the rest of the state, although differences in case-fatality rates were not found outside of the New York City region (see also the Housing and Congregate Care section). Another US study (Chakraborty, 2021) that analyzed social inequities in the distribution of COVID-19 found that people with disabilities who were of a racial/ethnic minority, living in poverty, younger age (5-17 years), and female were significantly overrepresented in areas with a higher incidence of COVID-19, compared to other people with disabilities. For example, after controlling for spatial clustering, living below the poverty line was significantly associated with a 0.148 increase in COVID-19 incidence rates (estimated as the number of confirmed cases per 100,000 people in each county) among people with disabilities. However, this study included all

types of disabilities among the non-institutionalized population and did not examine people with IDD separately.

The importance of age-related differences in COVID-19 trends was highlighted in an analysis of data on COVID-19 patients with and without IDD as of May 2020 from a global network of health care organizations (Turk et al., 2020). The data showed some similarities between patients with and without IDD in that the overall COVID-19 case-fatality rate did not differ (5.1% for patients with IDD vs. 5.4% for patients without IDD). However, there were distinct differences between patients with and without IDD in the age distribution of both cases and deaths. Case rates were much higher for people with IDD (26.4%) compared to people without IDD (2.7%) in the youngest age group of 0-17 years; and the opposite pattern was found in the oldest age group of 75 and over, with lower case rates among patients with IDD (8%, vs. 15.3% in patients without IDD). In addition, the case-fatality rate was higher among those with IDD for the younger age groups of 0-17 (1.6% vs. <0.1%) and 18-74 years (4.5% vs. 2.7%); while there was no difference in case-fatality for patients over 75 (21% for patients with and without IDD). These findings suggest that a disproportionate percentage of individuals with IDD contract and die from COVID-19 at younger ages; yet this association is modified over time such that the difference in mortality risk is attenuated between older adults with and without IDD.

Other evidence supports the increased likelihood of mortality from COVID-19 infection among individuals with IDD. For example, a large analysis of private health insurance claims in the US found that people with IDD were up to three times more likely to die from COVID-19 than the general population (Fair Health, 2020). The overall death rate among all COVID-19 patients from April to August 2020 was 0.6%, compared to 1.22% of those with developmental disorders and 3.37% of those with intellectual disabilities. More recent data from health care organizations across the US up until November 2020 showed that having an intellectual disability was the strongest risk factor for mortality in COVID-19 patients other than age—patients with IDD were almost three times more likely to be admitted to hospital and six times more likely to die compared to patients without IDD, when adjusting for other demographic and clinical variables (Gleason et al., 2021).

Outside of the US, evidence also suggests high rates of COVID-19 infection and death among individuals with IDD. In England, data from two national systems collected up until June 2020 showed that the death rate from COVID-19 among adults with learning disabilities (the term used in the UK for intellectual or developmental disabilities) was 2.3 to 3.1 times higher compared to the general population in this country (Public Health England, 2020). After adjusting for the likely underestimation of reported deaths, people with learning disabilities were up to 4 times more likely to die from COVID-19. However, the results showed differences by age group that were similar to the pattern found by Turk et al. (2020): while the COVID-19 death rate was substantially higher for people with learning disabilities in every age group compared to the rest of the population, the difference was most pronounced in younger age groups (30 times greater among those aged 18-34), and decreased with increasing age (19.2 times greater for ages 35-44; 10 times greater for ages 45-64; 6.7 times greater for ages 65-74; and 2.6 times at older ages). Further data collected up until November 2020 by the Office for National Statistics in England (2021) showed a similar trend to the earlier results whereby the death rate from COVID-19 was 3.7 times greater for both males and females with a medically diagnosed learning disability compared to the general population; after adjusting for other risk factors, the mortality risk remained significantly greater (1.7 times for both males and females). Moreover, the excess risk of death experienced by people

with learning disabilities did not significantly change between the first and second waves of the pandemic (Office for National Statistics, 2021).

A collaborative network of academic and care organizations in the Netherlands called Stronger on Your Own Feet has collected data on COVID-19 infection and outcomes from patients with intellectual disabilities since March 2020. Data as of January 2021 shows a high rate of infection among this population (25% had tested positive) with more individuals contracting COVID-19 in the second wave; while the mortality rate was high overall (5%), it was lower in the second wave (2%) compared to the first wave (14%), with a similar pattern in hospitalizations (Stronger on Your Own Feet, 2021a,b).

Comorbidities and its relation to complications and death

Part of the reason for higher rates of complications and death from COVID-19 among people with IDD is the presence of comorbidities among this population, which not only worsens the health impact of COVID-19 but also increases the risk of transmission through the greater need for in-person health care (Campanella et al., 2021). It is known that populations with identified underlying or pre-existing health conditions face a greater risk of developing more severe disease outcomes from COVID-19 infection, and individuals with IDD tend to have a higher prevalence of some of these risk factors, including obesity, diabetes, and respiratory conditions (CDC, 2020a; Turk et al., 2020; Landes et al., 2020a). Recent studies among COVID-19 patients have demonstrated that patients with IDD have higher prevalence of pre-existing conditions often associated with poorer COVID-19 disease outcomes (i.e. circulatory, endocrine, pulmonary) (Turk et al., 2020; Gleason et al., 2021).

Other comorbidities that can increase the risk of mortality, either alone or in combination, include epilepsy and Down syndrome. Data on COVID-19 deaths over a two-week period in the UK and Ireland showed a high rate of risk factors including severe to profound ID, epilepsy, mental illness, dysphagia, Down syndrome, and dementia among people with intellectual disabilities who died of COVID-19 (Perera et al., 2020). The average age of death was also younger compared to the general population (64 vs. 90 years and over).

In particular, several studies have shown a higher susceptibility of individuals with Down syndrome to COVID-19 infection and more severe disease outcomes (Illouz et al., 2021). An analysis of data from January to June 2020 in the UK found a 4-fold increased risk of hospitalization and a 10-fold increased risk of death from COVID-19 among adults with Down syndrome compared to the general population (Clift et al., 2020). The risk of death was also greater among adults with Down syndrome than for adults with other types of learning disabilities (Adjusted Hazard Ratio of 10.39 vs. 1.27). More recent data from the UK on COVID-19 patients collected from April to October 2020 found that patients with Down syndrome (especially those aged 40 and older) had a higher risk of complications from the virus and a three-fold increased risk of mortality, compared to the general population (Hüls et al., 2021).

Evidence from studies in the US and Italy comparing individuals with and without Down syndrome among hospitalized or deceased COVID-19 patients also demonstrates that individuals with Down syndrome who contract COVID-19 are more likely (i) to be younger, (ii) to have comorbidities (i.e., epilepsy, dementia, obesity, autoimmune disease), and (iii) to have more severe disease outcomes and complications than those without Down syndrome (Villani et al., 2020; Malle et al., 2020). These findings, combined with more recent clinical review research (Illouz et al., 2021),

suggest that premature aging, which is common in individuals with Down syndrome, as well as the presence of comorbidities, can increase the risk of complications from COVID-19. Indeed, among hospitalized patients in New York, individuals with Down syndrome were more likely to suffer from complications such as acute respiratory distress syndrome and sepsis; had longer hospital stays; and more severe disease progression than patients without Down syndrome (Malle et al., 2020). The incidence of bacterial superinfections in hospital was also found to be more common among those with Down Syndrome in the sample of deceased COVID-19 patients in Italy (Villani et al., 2020).

Evidence for children with IDD

While studies on the health risks of COVID-19 among children with IDD are limited, the evidence thus far indicates that like adults, children with IDD are more likely to have comorbidities that increase their risk of complications from COVID-19, and to develop more severe disease outcomes from COVID-19 infection (Turk et al., 2020; Dugas et al., 2020). As described earlier, Turk et al. (2020) found a significantly higher COVID-19 case rate and case-fatality rate for children aged 0-17 years with IDD compared to children without IDD. An update to a rapid review by the SPOR Evidence Alliance (Dugas et al., 2020) examining evidence on COVID-19 risk and outcomes in children with brain-based developmental disabilities determined that children with brain-based disabilities have a greater risk of developing severe COVID-19 disease, and are overrepresented in hospitalization numbers compared to children without disabilities. In addition, while the overall mortality rate from COVID-19 among children is low, the case-fatality rate appears to be higher in children with disabilities. However, most of the data on children with IDD comes from children that were hospitalized and may not reflect undiagnosed or asymptomatic cases among children.

Conclusion

The limited but compelling evidence thus far on the health risks of COVID-19 for individuals with IDD demonstrates the need for strong public health measures to reduce the risk of transmission and associated adverse outcomes of the disease. Disability-inclusive health system responses that recognize the specific risks adults and children with IDD face when infected with COVID-19 are essential. Furthermore, adults and children with IDD as well as their families and caregivers need better access to accessible and affordable treatment including vaccination with tailored information addressing the various factors that increase their health risk in order to make more informed health care decisions. The data available to date also make a strong case for the need for more research and resources devoted to understanding, preventing, and treating this disease in this population.

“How do we know what’s right and what’s wrong? We see so much on TV - this doctor says something, and this doctor says something.”

– Self-advocate, on the need for clear information about COVID-19 and vaccination

Recommendation 1: Prioritize persons with IDD of all ages in the distribution of COVID-19 vaccinations in Canada along with other high risk clinical groups, in recognition of their heightened susceptibility to severe complications and death from the virus as well as the disproportionate impact of COVID-related public health measures on their health and well-being.

Recommendation 2: Ensure public health information and communication that addresses the health risks for children and adults with IDD is widely available and adheres to national accessibility standards.

Access to Non-COVID-19 Related Health Care Services

Access to support services is essential for maintaining the quality of life and participation in society for individuals with IDD and needs to be deemed essential during the pandemic.

Access to health and social care services for persons with IDD before the pandemic

Across the life course, individuals with IDD interact with many services and support activities as they experience transitions and changes in their environment and service provision, often associated with changing social roles (e.g. changing schools, or moving from pediatric to adult services). Despite the **potential access** (available services) of health and social services for individuals with IDD, there are low rates of **realized access** (actual use of these services) in childhood and even less in adulthood (Aday & Andersen, 1974; Sullivan et al., 2018). Prior to the COVID-19 pandemic, these access challenges resulted from several factors: environmental factors (e.g., different priorities, mandates and approaches to service delivery across ministries; inconsistent policies); individual factors (e.g. distinct eligibility criteria); and a lack of data on service use across the continuum of care (Kuo et al., 2011; Quigley et al., 2014; Clark, Seel, & Clark, 2009).

Access challenges can vary across age groups. **Children** with IDD in Canada have higher rates of healthcare service utilization, including more physician and specialist visits, compared to children without IDD (Arim et al., 2017). However, key challenges for children with IDD to access these health and social services remain, including: the waiting period from pre-diagnosis to diagnosis; the length of time to receive interventions (clinical, special education, disability supports); and the presence of co-morbidities. A late diagnosis impacts children's access to services, as these services often require a diagnosis (Campbell, 1997). Early intervention (such as speech therapy, occupational therapy and behavioural support) is also essential for providing the foundation for addressing lifelong challenges with participation, with resources allocated to early childhood believed to have a greater impact across the lifespan than later support (Heckman, 2012; Campbell, 1997). Finally, co-morbidities such as epilepsy, psychiatric disorders, sleep impairments and gastrointestinal issues increase the need for access as these children often require regular interaction with healthcare providers throughout the life course.

The key challenges for **adolescents** and **adults** to access services result from a multitude of service changes as individuals transition from child-based to adult-based to senior-based care. This includes healthcare transitions (e.g., from pediatric to adult healthcare services) and educational/employment transitions (e.g. from high school to post-secondary life). The complexity of these transitions makes them difficult for persons with IDD and their supporting families to navigate, resulting in a decrease in support service use after age 18 (Alberta Government, 2014; Dunn & Zwicker, 2018; Hodgetts et al., 2013; Child and Youth Data Laboratory, 2019). The loss of in-person educational, vocational, recreational and medical supports can have adverse implications, adding substantially to caregiver burden and compromising an individual's overall health and well-being. However, sustaining services in adulthood can be complex, with the design of some disability support programs discouraging participation in work and society. Many adults with IDD do engage in meaningful community activities and routines (both work-related and recreational, as discussed in the section on *Leisure Participation and Community Inclusion*), but they are less likely to pursue employment, participate in social activities, and experience poorer health outcomes compared to

adults without disabilities (Arim & Frenette, 2019; Berrigan, Scott & Zwicker, 2020). They continue to need clinical supports in adulthood, typically accessed in community and sometimes hospital settings. Additional complications occur as adults age and transition into senior-based care services, which tends to occur at a younger age for many individuals with IDD compared to their peers without disabilities. For example, in Ontario, adults with developmental disabilities have shown signs of frailty as early as age 50 that are comparable to levels seen among older adults aged 80 and over without developmental disabilities (Ouellette-Kuntz & Martin, 2014).

Disruption of services during the COVID-19 pandemic

Persons with IDD have faced significant disruption of their usual essential supports and services due to the COVID-19 pandemic. The access challenges that they, along with their families and caregivers, already experienced have been exacerbated during the pandemic as many of these essential services were either cancelled, decreased or realized differently (e.g. through telehealth) (Barnert et al., 2017; Thomson et al., 2016; Craig et al., 2016). The types of services impacted by COVID-19 restrictions include: diagnostic evaluations and necessary specialized disability-related medical care and rehabilitation services, home and school-based therapies, outpatient care in specialized clinics related to associated health conditions, personal care assistance, and preventative “non-essential” care. As a result, individuals with IDD and their families and caregivers have been isolated and left either without access to support services or tasked with providing most or all care needs themselves, and may face additional risks of paid support persons becoming infected and/or quarantined (World Health Organization, 2020b). In other cases, restriction measures sometimes limited the ability of family members or other support staff to engage in care, resulting in many youth and adults with severe disabilities going through intensive care emergency appointments without adequate support.

“I find it very important to have a family member or someone very close to you, or a worker, to be able to come into the doctor’s office, or to the hospital with you. It is very important.”

—Self-advocate

Benefits and limitations of telehealth as a tool for accessing services

The COVID-19 pandemic has brought in a new era of telehealth. The potential benefits and adverse consequences of increased use of telehealth will be differentially experienced by persons with IDD, given the heterogeneity of the population. Telehealth has many potential advantages for persons with IDD, such as expansion of access to health services when transportation, scheduling caregivers or accessibility of medical facilities is a barrier (Pharr, James, & Yeung, 2019; Camden & Silva, 2021). The use of telehealth often increases access to specialists (particularly for those in rural communities) and provides the opportunity to observe patients in their home environment (Zhou & Parmanto, 2019; Annaswamy, Verduzo-Gutierrez, & Frieden, 2020). This is especially important for people who find being outside of their own setting to be stressful. Video-based telehealth also allows for different ways for patients to communicate concerns (visual, audio and text based), and for several members of a team to participate from different settings at one time. Learning and skills development and access to technology have been observed in people with IDD and caregivers during the pandemic.

Despite these benefits, the reliance on telehealth can leave gaps in critical aspects of the delivery of appropriate services for some individuals with disabilities. In many cases, in-person care is still required (Lunsky et al., 2021). This includes persons with IDD with behavioural challenges or physical therapy needs; those with certain health issues or respite need, and some individuals who have a very difficult time with virtual care. In addition, telehealth technology is often designed, implemented, and contextualized in a way that is inaccessible to persons with IDD (Valdez et al., 2020). Software—both web-based and app-based—needs to be redesigned so that technologies are accessible and responsive to the unique ways in which people with disabilities might engage others in their health care. For example, closed-captioning, alt text, audio description, and large text options must be provided. Lack of access to adequate bandwidth and up-to-date hardware is another limitation with telehealth services and can result in canceled appointments, disconnection, and misinterpretation (Lunsky et al., 2021; Wooton et al., 2020).

Increased risk of mental health issues due to COVID-19 pandemic for persons with IDD

“This pandemic has put an emotional strain on mental health when people live alone. They feel scared, they can’t hug anyone. I want to feel someone hug me.”

– Self-advocate

People with IDD are more vulnerable to the negative mental health consequences of the pandemic, and this is on top of already very high rates of mental health issues and inadequate mental health services in this population in both childhood and adulthood (Lunsky et al., 2018). Whereas at the start of the pandemic, individuals with IDD and their families were still adjusting to the uncertainty, sudden loss of routines and structures as well as clinical supports, the extension of prolonged closures and reliance on informal supports has led to increased depression and frustration as well as high levels of anxiety (Tromans et al., 2020). Across Canada, several efforts have been initiated to address these growing mental health issues in the general population, but they have not been adapted to people with IDD. Particular challenges have been experienced by people with IDD who do not benefit from virtual activities and continue to have no in-person activities. Critical steps forward include supporting community-based mental health programs to adapt their care to this group through additional funding, as well as enhanced mental health supports in social care, and increased specialized mental health care when mainstream services are not sufficient.

Conclusion

Maintaining access to services and supports during the pandemic and in future pandemics is critical for reducing barriers to participation in society across the life course for persons with IDD. This includes rehab, primary care, acute care, community and home care services, as well as informal supports and mental health supports. It also includes allowing support persons and caregivers or family members to attend in-person health care appointments and hospital stays, as they are essential supports for persons with IDD. Ensuring that monitoring and check-ins continue to take place for persons with IDD (even if they occur virtually) is critical in order to understand how individuals with IDD have been impacted by the COVID-19 pandemic and to find approaches to foster access to services as required, including access to mental health if needed. Finally, redesigning accessible telehealth services, both web-based and app-based, is an important step in ensuring that technologies are accessible and are responsive to the unique ways in which people with disabilities engage with others.

Recommendation 3: Designate services, supports, therapy and support workers for persons with IDD as essential across health and social care sectors.

Recommendation 4: Provide health care accommodations for people with IDD both during the pandemic and post-pandemic recovery.

Recommendation 5: Use and adapt telehealth as needed in an accessible manner, to ensure functioning and well-being of individuals with IDD.

Recommendation 6: Allocate mental health services to address the unique needs of people with IDD and their caregivers who have been disproportionately impacted by the pandemic and ensure support for staff—including appropriate training and access to specialized mental health supports and resources.

Leisure Participation and Community Inclusion

To address inequalities in the impact of COVID-19 for people with IDD, strategies are needed to minimize the additional barriers imposed by the pandemic on leisure participation and community inclusion – which are essential for physical and mental health and well-being.

Participation and community inclusion prior to the pandemic

Participation in active-physical, social and other recreational activities in the community is essential in promoting physical and mental health and well-being, especially for individuals with IDD. The benefits of leisure participation on physical health outcomes in particular, including lower rates of obesity, cardiovascular disease, diabetes, and high blood pressure, are especially important for individuals with IDD who are more likely to have these co-occurring health conditions (Johnson, 2009). For **children** with IDD, leisure activities are meaningful in providing freedom of choice, enjoyment and pleasure, fulfilment of skill competencies, identity formation, friendship and connectedness. Children with IDD are more likely to exhibit restrictions in participation in leisure activities of their choosing, particularly active-physical activities and socialization with peers (Moore & Phelan, 2021; Powrie et al., 2015). Barriers to participation are numerous and include developmental impairments, sociodemographic factors, and key environmental barriers such as accessibility issues, resource supports and negative societal attitudes and behaviours (Shikako-Thomas et al., 2008; Louw, Kirkpatrick & Leader, 2020). Participation in recreational and leisure activities is a right for all individuals, and overcoming environmental barriers for people with IDD should be a societal priority (Velauthapillai, Gonzalez, & Shikako-Thomas, 2020; Moore & Phelan, 2021; Louw, Kirkpatrick & Leader, 2020).

For **adults** with IDD, the opportunity to exist as a contributing member of the community and participate in activities of one's choosing continues to be paramount for health and well-being (United Nations, 2006). Social inclusion has been defined in different ways in the literature, but generally refers to two overlapping domains—interpersonal relationships and community participation. While social inclusion is experienced differently depending on one's level of disability, both domains are important for fostering a sense of belonging within a social network and the community, as well as greater quality of life (Simplican et al., 2015; Louw, Kirkpatrick & Leader, 2020). As more people with IDD were de-institutionalized and living in the community, research has focused not only on their physical inclusion within the community but also their social inclusion, as well as factors that promote or limit their full inclusion (Amado et al, 2013).

Not all persons with IDD have the housing and social support they need to live fulfilling lives in the community; many adults who lack resources or income to live independently are living at home with aging parents or relatives who worry about their offspring's future and their ability to support them (Canadian Association for Community Living, 2018). Findings from the 2017 Canadian Survey on Disability (Statistics Canada, 2020a) highlight the importance of social networks and inclusion for people with disabilities. For example, 21% of adults with disabilities in Canada lived alone in 2017, and over one-third of those who needed regular help relied solely on people from outside their household. Among those who considered themselves housebound, 38% said it was due to limited social connections outside the home. Furthermore, about one-fifth of Canadians

with disabilities said they did not use the internet, thereby limiting their ability to stay informed and connected through technology.

Impact of COVID-19 on participation and community inclusion

Studies have documented the negative consequences of the pandemic and lockdown measures on the physical and mental health of the population as a whole (Brooks et al., 2020; Lippi et al., 2020). However, individuals with IDD may be disproportionately affected, given their greater healthcare and community-based resource needs and mental and physical health vulnerabilities which place them at greater risk of adverse outcomes from COVID-19 (Aishworiya & Kang, 2020; Sabatello et al., 2020). The benefits of leisure and community participation on health and well-being are thus even more profound in this period of the pandemic (Anaby et al., 2021). Despite these benefits, social inclusion for people with IDD is limited by mandated public health restrictions that prioritize health and basic needs over leisure activities and limitations on social interactions that can increase loneliness and social isolation (Navas et al., 2021; Constantino et al., 2020; Brotman et al., 2021).

“I rarely go out because I am more at risk. Isolation has definitely had an impact on my mental health.”

—Youth with developmental disability

For example, recreational activities, including team sports, have been cancelled and many sports facilities, fitness centers, and even parks have been closed to the public, making it more difficult for people with IDD to stay physically active (Yarimkaya & Esenturk, 2020b). In addition, even when social/recreational engagement is possible in the community, the use of masks can limit non-verbal communication and social cues. A lack of appropriately adapted leisure activities in the home and community in the context of the pandemic can be frustrating and minimizes social opportunities. Among children, school and daycare closures have also contributed to a disruption in daily routine, known to be important for their social-emotional development.

The impact of public health measures on social inclusion is further exacerbated by restrictions in visits by home-based respite, health and social service providers, which are often critical to a person’s active involvement in home and community-based leisure activities (Chanchlani et al., 2020; Constantino et al., 2020; Brotman et al., 2021). As a result, anxiety, sleep difficulties and depression—already common in people with IDD—are heightened; and caregiver stress is also elevated, as they are expected to juggle multiple roles including promoting community-based activities for their family members in these difficult times (see sections on *Access to Non-COVID-19 Related Health Care Services* and *Caregiver Support* for further description of these mental health impacts).

Evidence of the impact of COVID-19 on participation for children with IDD

Preliminary evidence suggests that children with IDD have experienced important reductions in their ability to participate in physical, social and other recreational activities at home and in the community as a result of COVID-19 (Arim, Findlay & Kohen, 2020; Cacioppo et al., 2020; Esenturk, 2020; Garcia et al., 2020; Yarimkaya & Esenturk, 2020a). This was due, in part, to cancellations of arts/sports programs, closure of public spaces, and changes in routine (Esenturk, 2020). In a survey of 1000 parents of children with cerebral palsy and other physical disabilities in France, many negative effects of the lockdown on morale, behaviour, and social interactions were reported.

For example, 55% had no contact with other children, and 44% had stopped physical activities (Cacioppo et al., 2020). Among adolescents with autism spectrum disorder, lockdown measures have been associated with changes in health behaviours compared to prior to the pandemic, including a decrease in physical activity (from 4.2 to 2.3 days per week of one hour or more) and an increase in screen time (from 3.7 to 6.3 hours per weekday) (Garcia et al., 2020).

Findings from a Canadian survey of over 32,000 parents, 19% of whom have at least one child with a disability including IDD, indicate that participation is more restricted for children with disabilities, compared to those without disability (Arim, Findlay & Kohen, 2020). Results on parental concerns about impacts of COVID-19 among parents of children with vs. without disability showed that parents were very/extremely concerned about: physical health (21.6% without disabilities, 27.6% with disabilities), mental health (42.8% without, 60.4% with), loneliness (51.6% vs 63.0%), lack of opportunities to socialize (70.2% vs 73.8%), screen time (61.7% vs 72.6%), and physical activity (35.5% vs 49.4%). Child participation in leisure activities was greater for children without disabilities compared to those with disabilities: reading (65.7% without, 47.5% with); games (24.4% vs 17.2%); music/drama/arts (22.6% vs 16%); physical activities (63.2% vs 49.9%). Furthermore, parents of children with disabilities were highly concerned about their ability to manage their child's stress, anxiety, emotions and behaviour; more so than parents of children without disabilities (Arim, Findlay & Kohen, 2020). Parent education as well as expert and resource supports are needed to guide parents of children with IDD through new ways to conduct physical activities within a pandemic context (Esenturk, 2020). Technologies such as telehealth have emerged as a viable approach to coach parents in fostering health-promoting physical, social and recreational activities (Camden & Silva, 2021; Goldschmidt, 2020).

Evidence of the impact of COVID-19 on participation for adults with IDD

Qualitative research from Canada and other countries has described the impact of pandemic restrictions on leisure participation among adults with IDD, including the negative consequences of the lack of participation. In an online survey of people with IDD in Spain on supports during the pandemic, almost half of respondents (45%) reported that recreational or leisure activities was one of the forms of support they missed during lockdown (Navas et al., 2021). Younger age groups and older adults who lived in group homes or residential facilities (vs. on their own or with family) were more likely to report missing these activities. In addition, when asked what supports made them feel good during lockdown, almost two-thirds (63%) referred to the performance of online or at-home leisure activities (Navas et al., 2021). In a descriptive study of the experiences of a small sample of people with mild intellectual disability in the Netherlands during the COVID-19 lockdown, missing social contact and the impact of being housebound on daily life were reported as major themes by participants, including the inability to go outside to take part in activities with others (Embregts et al., 2020). A study on the impact of the closure of recreational facilities on the ability of people with disabilities to participate in sports and physical activity in Canada and Scotland underscored the importance of safety issues, as many participants reported feeling unsafe engaging in activities in outdoor public spaces as well as having safe access to transportation and public restrooms to support participation (Kamyuka et al., 2020).

Need for improved strategies to accommodate leisure participation

Strategies are needed to mitigate the compromised physical and mental health associated with decreased leisure and community participation for individuals with IDD (Neece, McIntyre & Fenning,

2020; Patel, 2020). Furthermore, strategies must recognize that individuals with intellectual, communication, attention, behavioural and mobility limitations require specific accommodations to participate meaningfully in preferred activities (Aishworiya & Kang, 2020; Sabatello et al., 2020). Otherwise, responses to help support physical activity during the pandemic will continue to amplify the inequalities facing people with disabilities by excluding them from opportunities to participate in sports and recreational activities (Fitzgerald, Stride & Drury, 2020; Kamyuka et al., 2020). For example, new online resources to promote physical activity at home, such as virtual training or fitness sessions, can be adapted to be more inclusive and accessible and may even provide a more enjoyable and meaningful experience compared to pre-pandemic alternatives (Fitzgerald, Stride & Drury, 2020). There is also a need for greater capacity-building within community organizations and mainstream leisure programs (e.g. YMCAs), in terms of adapting existing offerings to accommodate individuals across the lifespan with IDD, in the context of a pandemic and beyond. There is a general lack of resource supports and service offerings by rehabilitation specialists who are equipped to assist in adapting activities and overcoming barriers for participation in community-based activities. Many excellent resource and support guides and virtual programs exist (e.g. CHILD-BRIGHT COVID-19 resources; Canadian Disability Participation Project; Special Olympics Canada's Healthy at Home resources), but they are not adequately disseminated nationally to the public and community organizations.

Conclusion

Solutions are needed that overcome barriers to participation both now and post pandemic. Participation is a right, and this vulnerable population should not be left behind, particularly when one considers the health promoting benefits of leisure participation and community engagement. To ensure that solutions to optimize participation and community inclusion are successful, individuals with disabilities and their caregivers should be involved in their design and implementation.

Recommendation 7: Develop a data collection strategy of existing adapted and inclusive community programs, to identify community-specific gaps and needs.

Recommendation 8: Synthesize and promote an accessible resource and support guide with information on tools, virtual programs and approaches to promote health navigation, social support and leisure participation and inclusion opportunities for individuals with IDD and their families in local communities which would remain useful post pandemic.

Recommendation 9: Allocate additional funding for community-based participation initiatives for people with IDD to support innovative solutions that are sustainable post pandemic.

Inclusive Education

The COVID-19 pandemic has exacerbated existing inequities for students with IDD. Additional support for students, families and schools is required to decrease these inequities and comply with the right to quality education for children and youth with IDD.

The United Nations Educational, Scientific, and Cultural Organization (UNESCO) promotes global inclusive education that respects diversity and removes barriers for students with disabilities (UNESCO 2009; 2017). Inclusive education is grounded in social justice, including the mandate to include students with learning exceptionalities and disabilities in all aspects of educational policy, programming, and delivery (Canadian Council on Learning, 2007). This approach commits to educating students with IDD in mainstream classrooms along with their peers while removing barriers to learning and participation through individualized supports (Ainscow & Cesar, 2006).

Despite the shift to inclusive education in most school systems, students with IDD continue to experience educational inequities. Evidence shows that more services are needed in order to maximize benefits from inclusive education, yet a lack of support to students with IDD and their teachers is still reported, resulting in health, participation, and academic challenges for students (Anaby et al., 2019). This is perhaps most obvious in the observed lower rates of high school completion and graduation as well as enrollment in post-secondary education among students with IDD, which are considered as key measures of success of the individualized supports put in place for these students (Kirby, 2017). For example, a longitudinal, population-based study of students in British Columbia found that 73% of students with moderate to profound IDD and 79% of those with mild IDD completed high school with 'any' type of certificate, compared to 80% completion rate for all students who held special education designations during that period. Students with IDD were much more likely to receive a high school completion certificate than a graduation diploma (i.e. completion of personal learning goals without completing the provincial graduation requirements) (Lloyd & Baumbusch, 2019). A similar pattern of lower graduation rates has been shown in Quebec (Kalubi et al., 2015). Data from the National Longitudinal Survey of Children and Youth across Canada also found lower high school completion rates (70% vs 94%) and post-secondary enrollment by age 24-25 (71% vs 96%) among children and youth with IDD compared to those without IDD (Sentenac et al., 2019).

Inequities in inclusive education relate not only to the availability of support services, but are also rooted in teachers' attitudes, the need for better professional development, the need for more staff resources to support inclusive education, and barriers to social engagement between students with disabilities and their peers (Van Miegheem et al., 2020).

Impact of the pandemic on school access and learning

The impact of the COVID-19 pandemic on education systems across Canada began in mid-March 2020, when the majority of K-12 and post-secondary education systems shifted to online/hybrid learning. This change mirrored the international shift to online learning in response to the pandemic, which the United Nations Human Rights (2020) highlighted as a potential source of further discrimination and exclusion of people with disabilities.

The pandemic has magnified existing inequities for students with IDD, particularly in the areas of school access and learning. In a study about children with medical complexity (71.8% of whom

had an IDD diagnosis) in British Columbia, Baumbusch and colleagues (2020) found that 61.1% of school-aged children did not attend school at all during the initial period of the pandemic (March to May 2020) and only 10.6% returned to school in-person, full-time in June 2020. Parents may choose to keep their children at home for longer periods due to the heightened risks of COVID-19 infection for individuals with IDD, as described in this report.

With the shift to online learning, there is also growing recognition that this mode of instruction may not be appropriate for students with disabilities, and that educators and school staff are poorly prepared to address their unique learning needs online. This concern has been identified internationally; for example, a study from Serbia and Montenegro discussed the impact of gaps in the development of online learning and teaching strategies and guidelines specific to students with disabilities on students' learning and inclusion during the pandemic (Scepanovic & Nikolic, 2020). A further issue is that online learning occurs in the home, thereby shifting much of the instructional responsibility onto parents/caregivers. Coupled with working from home during the pandemic, many parents felt unprepared to support their children's online learning (Maelen et al., 2021). A study of Canadian parents found that parents of children with disabilities may need to spend more time—up to 10 hours more per week - assisting with school activities, compared to parents of children without disabilities (Greenlee & Reid, 2020). Additional issues that may create inequitable access to online/hybrid instruction for students with IDD include: access to technology, lack of appropriate training to use online platforms, lack of teaching and school staff training, and family situations (Navas et al., 2021). These multi-faceted factors highlight the urgent need to develop capacity within school systems to teach students with IDD online more effectively.

"[It's] harder for students with disabilities, [when] you don't have that person interaction. It would be harder online."

—Self-advocate

For those students with IDD who do return to in-person instruction, there may be additional challenges amplified by the pandemic. These include an increase in anxiety due to general disruptions to routines and therapies, as well as from school-based changes as part of the new pandemic-response practices such as social distancing, use of personal protective equipment and sanitation measures (Constantino et al., 2020; Yates & Dickinson, 2021). Many students experienced a decline or loss of individualized supports at school such as one-on-one support workers, assistance with personal care, and access to allied health professionals, among other resources (Dickinson et al., 2020). The impact might have been greater for those with attention and behavioural issues, and parents have reported that both in-school and at-home individualized support was required to compensate for the additional learning, health and social challenges that students with IDD have experienced during the pandemic (Camden et al., 2020).

Summary of consequences of the pandemic on education

The short- and long-term consequences of the pandemic on students with IDD are significant. In the short term, students with IDD and their families have experienced greater stress and anxiety related to adapting to new routines, managing the requirements of online/hybrid instruction, and accessing useful information about school-related pandemic responses (Dickinson et al., 2020). A Statistics Canada study found that parents of children with disabilities were more concerned about the impact of the pandemic on their children's academic success and mental health than parents of children without disabilities (Arim, Findlay & Kohen, 2020). In the long term, there may be an

impact on outcomes such as high school completion and graduation rates. A Norwegian study with high school students found that low-achieving students were less motivated and engaged when learning from home, which raises concerns about the potential for a widening gap with other learners (Maelen et al., 2021). Monitoring these short and long-term consequences will be crucial, as well as the monitoring the impact of measures to mitigate the negative consequences created by the COVID-19 crisis.

Conclusion

Students with IDD were already at risk of experiencing greater educational challenges prior to the COVID-19 pandemic, both in terms of school participation and academic success. The COVID-19 pandemic has exacerbated existing inequities for students with IDD. Additional support for students, families and schools is required to decrease these inequities and comply with the right to quality education for children and youth with IDD by ensuring that all students are provided with equitable, inclusive, and accessible learning opportunities regardless of the mode of instruction (e.g. in-person, online/hybrid) or the type of setting (inclusive or segregated schools). These supports would include and not be limited to: access to technology and training for teachers and support staff to facilitate online/hybrid learning; training for students and parents/caregivers to support engagement with individualized curriculum; and collaboration with health and social services providers involved in students' development.

Recommendation 10: Ensure appropriate modifications, accommodations and supports are available to enhance the participation, development, and well-being of students with IDD both during and post-pandemic.

Recommendation 11: Monitor the long-term impacts of the pandemic on learning for students with IDD through individualized assessments.

Income and Employment

Pandemic income supports and employment considerations for all Canadians—and specifically for individuals with IDD—need to recognize that persons with disabilities experience pandemic related income shocks just like all other Canadians and are equally deserving of pandemic specific income supports and programs.

The social determinants of health (SDH) are social factors driving health disparities. These are the societal conditions into which people are born, grow, live, work and transition through the life course. It is widely recognized that inequities in power, money and resources are important contributors to inequities in health, disease and mortality (Donkin et al., 2018). In Canada, these inequities are greater among persons with IDD and a complex, interdependent and underrecognized relationship between an individual's SDH and disability exists (Wolbring, 2011; Working Group for Monitoring Action on the Social Determinants of Health, 2018). Adults with IDD and youth transitioning to adulthood have higher rates of school incompleteness, lower labor force participation, and higher rates of poverty than those without IDD (see Table 1). Families of children with IDD in Canada also had consistently lower household income compared to families of children without IDD according to national surveys conducted between 1995-2009 (Rothwell et al., 2020).

Table 1: Total socioeconomic characteristics for persons with developmental disability, any disability or no disability in Canada prior to the COVID-19 pandemic

	Developmental Disability	Any disability	No disability
Average before tax income (age 15-64) (Including earned income and government transfers)	\$16,283	\$40,106	\$49,235
% Low income using Market Basket Measure	28%	17%	10%
% Not in labour force	63%	38%	34%
% Not completing high school	40%	18%	9%

Source: data from Employment, Education, and Income for Canadians with Developmental Disability: Analysis from the 2017 Canadian Survey on Disability (Berrigan, Scott, & Zwicker, 2020)

Impact of the COVID-19 pandemic on income and employment

“Even before COVID-19 some people had a hard enough time to find a job, but now it’s going to be double hard to find a job—not just because of a disability but for other people too because so many people got laid off—it’s not just going to be hard for us but for everybody.”

—Joanne Gauthier, self-advocate

The COVID-19 pandemic has exacerbated these pre-existing inequalities in SDH (Armitage & Nellums, 2020; World Health Organization, 2020b). In a recent Statistics Canada survey of persons with disabilities during the COVID-19 pandemic, almost one-third (31%) said their overall household income had decreased since the start of the pandemic shutdown, and over

half (56%) of those whose income declined reported that it decreased by more than \$1000 per month (Statistics Canada, 2020b). Households with children were more likely to report that their household income decreased (37%). Survey participants with long term conditions or disabilities most commonly identified a moderate to major impact of COVID-19 on their ability to meet food and grocery needs and personal protective equipment needs. During the pandemic, the most commonly reported source of non-employment income for persons with disability was disability benefits (23%), followed by COVID-19 related support (17%) for persons with disability (Statistics Canada, 2020b).

In addition to having lower overall employment rates, people with IDD also remain in jobs for shorter periods and are more likely to work in jobs at or near the minimum wage (Berrigan, Scott, & Zwicker, 2020). The top three industries that people with IDD were employed in according to the 2017 Canadian Survey on Disability were retail; healthcare and social assistance; and accommodation and food services, which are all sectors greatly impacted by COVID-19 restrictions (Berrigan, Scott, & Zwicker, 2020). Data from Canada and the UK suggests that the COVID-19 pandemic has resulted in greater financial hardships for people with disabilities including job loss and reduced hours, with a disproportionate impact on young workers:

- **Disproportionate job loss:** Among all participants aged 15 to 64 in Canada with a long-term condition or disability in the 2020 Statistics Canada survey, two-thirds (66%) reported being employed prior to the start of the pandemic, while only 55% reported being currently employed (Statistics Canada, 2020b). Among participants who were employed before the start of the pandemic, over one-third (36%) reported experiencing a temporary or permanent job loss or reduced hours since March. Those who reported multiple long-term conditions were more likely (41%) to report a temporary or permanent job loss or a reduction in hours since March compared with those who reported one long-term condition (31%). Data from an annual household survey in the UK also showed that people with disabilities were less likely to be employed before the pandemic (55% vs. 83%), and more likely to experience reduced hours and financial stressors in the first three months following the lockdown compared to working age adults without disabilities (Emerson et al., 2021).
- **Disproportionate impact on young workers:** Compared with other age groups, young participants with a long-term condition or disability in Canada were more likely to report that their work situation changed from being employed prior to the shutdown to being currently unemployed or not in the labour force (Statistics Canada, 2020b). Over half (55%) of participants aged 15 to 24 reported being employed prior to the start of the pandemic, compared with 39% who reported being currently employed. This aligns with findings from the Labour Force Survey, which indicate that youth and students have been disproportionately affected in terms of employment during COVID-19.

COVID-19 specific income support for persons with disabilities

Each province and territory provides its own disability income assistance programs (some combined and some separate from income assistance), with different rules and eligibility requirements (Petit & Tedds, 2020). In response to the COVID-19 pandemic, the federal government developed the Canada Emergency Response Benefit (CERB), a temporary cash benefit of \$2,000/month to workers whose earnings were reduced to below \$1,000/month due to the pandemic. Disability income assistance clients who receive the temporary CERB are treated differently during the

COVID-19 pandemic depending on where they live. Table 2 describes the different approaches across provinces for determining how CERB payments impacted their disability income assistance programs (all disability income assistance programs are below the \$2000/month amount provided by CERB). For example, the Yukon, Northwest Territories and British Columbia allowed disability income assistance clients to receive the entire CERB amount while Alberta and Quebec partially exempted CERB income. The remaining provinces did not exempt CERB income, which would mean that disability income assistance clients could keep some or none of their disability assistance benefits.

Given that the CERB benefit is a temporary benefit in response to severe economic circumstances, fully exempting CERB income recognizes that persons with disability experience the same financial shocks as other Canadians during the pandemic and could benefit from reduced income volatility. This is especially important in view of past experience with flu/pneumonia which suggests that disability income assistance recipients faced higher risk of hospitalization and mortality (Scott, Russell, & Zwicker, 2020).

Table 2: Disability income assistance across provinces and CERB classification

Jurisdiction	Program (maximum monthly benefit)	Classification and treatment of \$2000 monthly CERB payment (Note: clawback refers to amount of income exempt for those on disability income assistance)	Max disability income assistance per month when receiving CERB
British Columbia*	Disability Assistance (\$1183)	Exempt income (no clawback)	\$1183
Alberta	Assured Income to the Severely Handicapped (\$1685)	Passive business income (\$300 exempt, remaining 25% exempt =75% clawback rate)	\$410
Saskatchewan	Assured Income for Disability (\$1064)	Non-exempt other income (Deducted one for one from benefits)	\$0
Manitoba	Employment and Income Assistance (\$1039)	Earned income (\$200 is exempt, remaining 30% is exempt =70% clawback)	\$0
Ontario	Ontario Disability Support Program (\$1169)	Earned income (Amount less than earnings exemption is exempt; amounts above earnings exemption clawed back at 50%)	\$0
Quebec	Sociale Solidaritie (\$1088)	Earned income (\$200 is exempt; remainder will be clawed back at 100%)	\$269
Nova Scotia	Disability Support Program (\$850)	Non-exempt other income (deducted one for one benefits)	\$0
New Brunswick	Enhanced Assistance (\$797)	Non-exempt other income (deducted one for one benefits)	\$0
Newfoundland	Income support (\$906)	Non-exempt other income (deducted one for one benefits)	\$0
PEI	AccessAbility Supports (\$1163)	Non-exempt other income (deducted one for one benefits)	\$0

Yukon	Social Assistance (\$1,342 (Nov.– Mar.), \$1,285 (Apr.– May, Oct.), \$1,227 (June–Sept.)	Exempt income (no clawback)	\$1285
Northwest Territories	Income Assistance (\$2383)	Exempt income (no clawback)	\$2383

*For those who did not receive CERB in income assistance in BC, a \$300 top up was provided to disability assistance at the outset of the pandemic, reducing to \$150 in January and ending in March 2021. Source: adapted from Petit & Tedds, 2020

Income support for students with disabilities

In addition to CERB, the federal government offered the Canada Emergency Student Benefit (CESB) which provided financial support to post-secondary students, and recent post-secondary and high school graduates, for a maximum of 16 weeks. Eligible persons who met the conditions of having a disability received a \$750 top-up to the \$1,250 CESB payment provided for each 4-week period.

Income support for caregivers

Caregivers of individuals with IDD provide essential support to reduce barriers to full participation in society. In 2017, over 50% of caregivers for persons with IDD in Canada were family members the individual lives with, while 28% were family members the individual does not live with (Berrigan, Scott, & Zwicker, 2020). During the COVID-19 pandemic, caregivers have been required to provide additional support because many support workers, respite and community programs were cancelled. This has had significant impact on caregivers, including mental health concerns and substantial financial strain (Dhiman et al., 2020). To address some of the financial concerns and productivity losses among caregivers, the Government of Canada developed the COVID-19 Canada Recovery Caregiving Benefit for those who can no longer work because they need to care for a child or family member for reasons related to COVID-19, but who don't qualify for EI. To qualify for the Caregiving Benefit, caregivers can't be on paid sick leave or receive money from a workplace sickness benefit and must lose at least 50% of their work for the week due to caregiving responsibilities. Eligible recipients can receive \$500 per week for up to 26 weeks (must be confirmed weekly). Unfortunately, caregivers who were unemployed prior to the pandemic due to the caregiving needs of their child (which is the case for many caregivers of youth with IDD) are ineligible for this benefit.

Adults with IDD and considerations for a disability inclusive CERB response

Recipients of disability income assistance are not inclusive of the entire population of persons with disabilities; however, disability income assistance offers a strong platform to implement COVID-19 policies that, at the very least, are appropriate for many at-risk persons with disabilities.

The disability benefit was designed to offset some of the barriers to participation in society experienced by individuals with IDD. This federal government program was a one-time tax-free payment of up to \$600 for persons with disability who were: Disability Tax Credit recipients (DTC) recipients, eligible applicants of the DTC who applied before Dec 31, 2020, and beneficiaries of the Canada Pension Plan Disability, Quebec Pension Plan Disability or Veterans Affairs Canada disability (\$300 to those with DTC and Old Age Security (OAS) pension and \$100 for Canadians with DTC, OAS pension and the Guaranteed Income Supplement). Notably, with the exception

of Alberta and the territories, this \$600 one-time benefit when combined with monthly provincial disability assistance does not total a monthly income over the CERB amount of \$2000/month.

In principle, the DTC could be an efficient way to administer pandemic related support; however, the design issues limit its utility. The DTC is a federal non-refundable tax credit that recognizes the additional costs that persons with severe disabilities may face. It also acts as a screen or “gateway” for a range of other disability-related programs and services. In some provinces, less than 40% of individuals with qualifying disabilities are estimated to have CRA-deemed eligibility to the DTC (Dunn & Zwicker, 2018). Issues accessing the DTC include problems with the eligibility criteria and assessment, complex application procedures, inconsistent communications and coordination with other benefits, and low incentives for those with low income due to its non-refundable design (Dunn & Zwicker, 2018). This suggests that the DTC in its current form is not an appropriate mechanism for administering a disability COVID-19 benefit.

Conclusion

It is clear that pandemic income supports and employment considerations for all Canadians, and specifically for persons with disability, need to recognize that persons with disabilities experience pandemic related income shocks just like all other Canadians and are just as deserving of pandemic specific income supports and programs. This should include recognition of the insufficiencies of the Disability Tax Credit and the variability of provincial disability assistance programs, with the aim of providing accessible and equitable income supports to eligible persons with disabilities across the country. It is notable that the CERB benefit, which presumably was set at what was considered a minimum level of livable income, was greater than all current provincial and territorial Disability Assistance programs. A national benefit at or above this threshold would not only raise the minimum income level of PWD to a modest livable level, but also help provide insurance in case of future pandemics. This type of national program would also offer a strong platform to implement COVID-19 or other disability specific policies in a way that is not currently possible within existing federal and provincial programs.

Recommendation 12: Develop a National Disability Income Benefit sufficient to ensure a reasonable minimum income for all Canadians with a disability.

Recommendation 13: Design disability inclusive pandemic income supports. In addition, recognize persons with IDD and their families experience additional costs such as PPE for support staff and technology needs.

Recommendation 14: Enhance emergency caregiver benefits to family members or guardians of persons with IDD who are required to take leave from employment in order to provide care due to COVID-19 or similar pandemics.

Recommendation 15: Invest in post pandemic accessible employment support for people with IDD to support recovery from COVID-19 related job losses and reduced employment.

Caregiver Support

The burden on caregivers of adults and children with IDD has significantly increased during the COVID-19 pandemic with the loss of supports and services that are essential for the health and well-being of not only individuals with IDD, but also their caregivers. There is a need for increased access to health care and social supports for family caregivers to mitigate the impact of the pandemic on caregiver strain.

Almost all young children with IDD in Canada live with their parents. Some extremely medically fragile children live in medical facilities, but they frequently have the support of parents who are designated as essential family partners in care. As children with IDD move into adolescence, most continue to live in their family home, although some – because of their needs in combination with parental aging – may be cared for in congregate settings. In adulthood, some people with IDD continue to live with their parents or with siblings, while others live independently or reside in congregate care. Regardless of where an individual with IDD resides – whether it is with family or in supported living arrangements, their parents or siblings are usually intimately involved with their care. Family and friend caregivers are thus invaluable in the wellbeing of persons with IDD.

Caregiver challenges prior to COVID-19

Caregivers of persons with IDD (defined in this section as non-paid caregivers, i.e. family or friends) have faced a considerable burden even prior to the COVID-19 pandemic; although the level of burden can vary depending on contextual factors such as socioeconomic status, behavioural problems and severity of disability, availability of social support, and coping strategies and strengths of the caregiver (Raina et al., 2004). For example, evidence from Canada suggests that both neurodevelopmental disorders and behavioural problems in children combine to negatively affect the health of caregivers in an additive manner (Lach et al., 2009). Caring for a child with IDD often involves higher than average demands on time, health related costs, employment constraints, and childcare challenges. For example, while most caregivers in Canada (64%) spent less than 10 hours per week on caregiving duties in 2018, caregivers of children with a disability spent over 14 hours per week on caregiving activities (Statistics Canada, 2020c). As a result, physical and mental health outcomes—including psychosocial problems, physical activity limitations, chronic conditions, as well as family functioning and reported levels of social support—are poorer and rates of healthcare service utilization are higher among caregivers of persons with IDD than for comparable caregivers (Brehaut et al., 2004, 2009; Masefield et al., 2020; Lach et al., 2009; Arim et al., 2019).

Support services are essential to improve health and reduce chronic stress among caregivers of individuals with IDD. Indeed, evidence from Canada shows that both formal and informal sources of social support are associated with improved health and lower levels of biomarkers of inflammation among caregivers of children with autism spectrum disorder (Gouin et al., 2016). However, prior to COVID-19, many caregivers in Canada still reported having unmet needs. In 2018, the most common types of support that caregivers said they would have liked to have received were: financial support, government assistance, and tax credits (68%); followed by home care or support (40%), information or advice (39%), and help from medical professionals (36%) (Statistics Canada, 2020c).

Impact of COVID-19 on caregivers

“I am not OK if my son is not OK. And he is not OK during COVID-19. We lost the life we had before.”

—Pamela L., mother of a son with IDD

Caregiver strain has increased during the COVID-19 pandemic for several reasons. The cessation of in-person school, employment (for adults with IDD), home care services and respite due to COVID-19 measures means that many family caregivers have been shouldering the full burden of care since March 2020. Concerns about the precarious physical and mental health of loved ones with IDD, as well as financial stress from lack of employment, job insecurity and increased expenses during COVID-19 have also added to the burden experienced by caregivers. Furthermore, pandemic restrictions have challenged their ability to connect with friends, extended family, and other community members – which are important forms of support and belonging for caregivers. This reduction in both formal and informal supports, combined with the closure of drop-in centres and stay-at-home orders, has considerably exacerbated the experience of social isolation for persons with IDD and their caregivers. Not only have family caregivers been separated from other family members and friends, but also from those they care for due to blanket no-visitor policies in residential and congregate care settings during COVID-19. The Canadian Foundation for Healthcare Improvement (CFHI, 2020) has identified serious physical and psychological harm caused by isolating patients/residents from their families and provided a roadmap for reintegration of family caregivers as essential partners in care.

Evidence on increased caregiver burden during COVID-19

Evidence on increased caregiver burden during the COVID-19 pandemic comes from various surveys in Canada and other countries. For example, findings from an online survey of people with IDD in Spain revealed the need for a variety of supports including family members during the pandemic (Navas et al., 2021). While the majority of respondents (82%) reported that they had received support during the lockdown, the nature of supports received varied by living context: those living with their family largely relied on supports provided by family members and missed professional support due to the pandemic. Findings also showed that persons with IDD played an active role in providing support to the people they live with during the pandemic as well.

A recent survey of 26 agencies involved with persons with IDD in the UK highlighted some of the challenges faced by caregivers during the pandemic by identifying priority concerns for people with IDD across three domains: mental health; physical health; and social circumstances and support (Tromans et al., 2020). Caregiver strain was identified as one of the priority concerns relevant to mental health. Other concerns that could also increase caregiver strain included the reduction of available social support services and respite care due to COVID-19.

The impact of increased caregiver strain on mental health has also been evidenced by various survey findings. For example, a survey of carers of individuals with IDD in the UK found that carers of adults—and especially children—with IDD had much higher rates of moderate to severe anxiety (43% of carers of children with IDD) and depression (45%) during the initial lockdown period compared to parents of children without IDD (8% and 11% respectively for anxiety and depression), and compared to their pre-pandemic levels (Willner et al., 2020). Another UK survey of parents of preschool children with moderate to severe developmental delays also found high

levels of stress and deterioration of mental health among parents, as well as a lack of access to formal and informal supports during the pandemic (Paulauskaite et al., 2021). Evidence from a study from India also shows that caregiver strain has increased during the pandemic, with a high percentage of caregivers (62.5%) suffering from depression (Dhiman et al., 2020).

An international survey of 818 parents of children with IDD (Jeste et al., 2020) found that most reported a loss of at least some educational or health care services as a result of COVID-19 restrictions, adding to caregiver burden. For example, almost three-quarters (74%) of parents reported that their child lost access to at least one therapy or education service, and 36% lost access to a healthcare provider. Only 56% reported that their child received at least some continued services through tele-education, and caregivers highlighted the need for improvements in the delivery and adaptation of telehealth services.

These international findings are also supported by Canadian data. According to a Statistics Canada survey, 58% of parents of children with disabilities reported being very or extremely concerned for their children's school year and academic success during COVID-19, compared to only 36% of parents of children without disabilities (Arim, Findlay & Kohen, 2020). Parents of children with disabilities were also more likely to be very or extremely concerned for their children's mental health compared to parents of children without disabilities (60% vs. 43%). A survey of siblings of adults with IDD in Canada also highlighted the need for more resources and supports for families of persons with IDD (Request et al., 2021). The majority (95%) of respondents were concerned about their siblings' health and well-being during the pandemic, with the most common concern related to the disruption of routine and activities for their sibling with IDD. Many respondents also indicated that the availability of supports for their sibling—including practical, emotional, financial, and informational supports—was helpful to them.

Supports for caregivers

There is less evidence on the forms of support that have been shown to be helpful for family caregivers of adults and children with IDD during the COVID-19 pandemic. However, some evidence suggests that both social and practical forms of support may help to reduce caregiver strain. For example, Willner et al. (2020) found that higher levels of social support reported by carers of adults and children with IDD during the pandemic were associated with lower levels of carer stress, anxiety, and depression. Redquest et al. (2021) also examined sources of help for siblings of individuals with IDD during the pandemic and found the following resources were reported to be helpful for families: prioritizing their own self-care; drawing strength from their relationships with others; and the provision of informational, financial, and other forms of support to their loved one with IDD. There is a need for more research to understand how families of individuals with IDD are adjusting and coping during the pandemic and which forms of support are most useful to them in order to provide more effective resources for family caregivers (Rose et al., 2020).

Conclusion

The COVID-19 pandemic has exacerbated the already high levels of strain among caregivers of adults and children with IDD. Despite the importance of supports and services for the health and well-being of family caregivers, evidence suggests that COVID-19 restrictions have reduced the availability of these supports for caregivers and have further isolated them from friends, family,

and community. As a result, caregivers have not only experienced greater concerns for the mental and physical health of their loved ones during the pandemic, but also harm to their own mental health. There is a need for increased access to health care and social supports for individuals with IDD as well as their caregivers to ensure that the burden of care does not result in greater harm during and after the pandemic.

Recommendation 16: Ensure that guidelines and policies for residential care and congregate care settings are aligned with proposed long-term care standards and that unrestricted access of essential family caregivers to individuals with IDD be embedded in those standards and communicated transparently.

Recommendation 6 (see pg.23): Allocate mental health services to address the unique needs of people with IDD and their caregivers who have been disproportionately impacted by the pandemic and ensure support for staff—including appropriate training and access to specialized mental health supports and resources.

Recommendation 8 (see pg. 27): Synthesize and promote an accessible resource and support guide with information on tools, virtual programs and approaches to promote health navigation, social support and leisure participation and inclusion opportunities for individuals with IDD and their families in local communities which would remain useful post pandemic.

Recommendation 14 (see pg. 35): Enhance emergency caregiver benefits to family members or guardians of persons with IDD who are required to take leave from employment in order to provide care due to COVID-19 or similar pandemics.

Housing and Congregate Care

The type of residence that individuals with IDD live in affects their risk of COVID-19 infection and mortality, with higher risks shown for those living in both congregate care settings and more individualized settings compared to the general population. Strong preventive measures are needed to protect the health and safety of both residents and staff in these settings during the pandemic, while also ensuring the needs and rights of individuals with IDD continue to be met.

Living arrangements for individuals with IDD are varied. In Canada, relatively few people with IDD live in the formal system of residential care facilities where they rely on paid care (Crawford, 2008). This includes larger congregate care settings such as institutions, rehabilitation or assisted living centres, or nursing/seniors homes; as well as smaller community-based group homes of various sizes. Increasingly, other than the family home, most adults with IDD reside and receive supports in more individualized settings such as semi-independent living or shared living arrangements with non-related persons who provide support. Those living outside of care facilities tend to have less intensive support needs and better health outcomes (Landes et al., 2020b). However, publicly available data about such smaller living arrangements is limited, as Statistics Canada has only collected national data on residential care facilities, defined as those which have four beds or more (Statistics Canada, 2011).

Even prior to the COVID-19 pandemic, many individuals with IDD in Canada were living in unsuitable accommodations due to rising housing shortages. Across Canada, over 100,000 people with IDD cannot access affordable housing and supports in their community, and Canadians over age 15 with developmental disabilities are more than twice as likely as the rest of the population to have “core housing need” (defined as deficient housing affordability, suitability, and/or adequacy) (Canadian Association for Community Living, 2018a; 2018b). This has resulted in “institutionalization by default” for many (Ombudsman of Ontario, 2016). For example, an estimated 10,000 adults with intellectual disabilities in Canada live in hospitals, nursing homes, or long-term care facilities despite being under age 65, due to the lack of affordable housing (Alzheimer Society of Canada et al., 2017). Evidence also suggests that people with IDD are overrepresented among homeless populations (Canadian Association for Community Living, 2018a; Durbin et al., 2018).

COVID-19 risk factors in congregate care

Compared to long-term care facilities for the elderly, congregate living facilities for people with IDD may pose lower risk due to their typically smaller size and lower average age of residents; however, these facilities also tend to cluster those with underlying health conditions or illnesses, which puts them at higher risk of infection and complications due to COVID-19 (Yang, 2020). In addition to pre-existing health conditions or co-morbidities, individuals with IDD who live in congregate care settings face an increased risk of infection due to other factors, such as challenges with following public health guidance and maintaining physical distancing (Centers for Disease Control and Prevention, 2020b; Landes et al., 2020a; Public Health England, 2020; Shapiro, 2020; Yang, 2020; Navas et al., 2021). For example, people in group homes often share living spaces or rooms, putting them in close proximity to other residents and staff; and have limited ability to isolate or quarantine if necessary. Depending on the nature of their disability, some may also

have difficulty understanding the need for infection control measures, such as hand washing and mask requirements. Finally, the reliance on close contact with personal support workers or group home staff—many of whom support multiple individuals in the same place and may work in multiple homes; or who may have other outside jobs and use public transportation to travel to and from each of these settings—increases the risk of exposure to other individuals who are themselves vulnerable to infection. Given this reliance of residents on the agencies and staff who are responsible for ensuring COVID-19 safety protocols are enforced, it is even more important to provide residents with the appropriate supports to keep them safe and healthy and a mechanism to flag when they have concerns.

“My concern [is] that staff go from one place to another place.”

—Kevin Johnson, self-advocate, on the need for protection of staff and residents in congregate care

Public policy decisions earlier in the pandemic may have also played a role in increasing the health risks for people with IDD living in congregate care. While there has been a strong focus on reducing the risk in nursing and long-term care homes, the lack of attention to group homes and other residences serving people with developmental disabilities resulted in challenges with accessing adequate personal protective equipment (PPE) and pay for staff in some settings (Shapiro, 2020; Landes et al., 2020a). In addition, the absence of clear guidance and support from the government for the IDD community earlier in the pandemic led many facilities and agencies to proactively develop their own individual protocols and restrictions. However, attempts to adapt guidelines from other sources, such as long-term care homes, posed challenges for some independent or supported living settings, including the lack of medical doctors on-site and the inability to enforce certain restrictions when residents are classified as tenants (Yang, 2020). Moreover, the extent to which various types and sizes of group homes are subject to regulations and accreditation standards varies across jurisdictions, further contributing to differences in guidelines between settings.

Evidence on the impact of COVID-19 in congregate care settings

Evidence on the health risks of COVID-19 for people with IDD living in residential or congregate care settings is limited—especially for children, as there is a lack of publicly reported data for these settings. In Canada, cases in long-term care homes are reported, but many public health units do not distinguish cases in other congregate living settings. There is some evidence from studies in the US and the UK which suggests that adults with IDD living in group homes or receiving services may be more likely to contract COVID-19 and have a higher risk of death if they do contract it, compared to the general population.

Landes et al. (2020a) analyzed data from New York and found that adults with IDD living in group homes were about four times more likely to contract COVID-19, and about twice as likely to die from it (15.0 vs. 7.9% case-fatality) compared to the general population in the state; although the difference in case-fatality rates was only found around the New York City area. The mortality rate for COVID-19 among the population was also much higher among individuals with IDD in residential group homes compared to the rest of the state. In another study using data from California, Landes et al. (2020b) found that people receiving IDD services had a 60% lower case rate, but 2.8 times greater case-fatality rate for COVID-19 compared to the rest of the population who were not receiving services. Importantly, the Californian study showed that COVID-19 outcomes for

individuals with IDD varied by residence—those living on their own or in a family home had the least severe outcomes, while both case rates and mortality rates were the highest in settings that had the largest number of residents. In addition, case-fatality and mortality rates were higher in settings that provided the most intensive skilled nursing care.

An analysis of COVID-19 prevalence in a population healthcare facility for individuals with IDD in Pennsylvania also found a high rate of infection—about 20% of the residents tested positive for COVID-19 from March to June 2020. Furthermore, a number of individuals who tested positive had been asymptomatic, suggesting that the prevalence of infection may be even higher than what is reported in studies (Spreat et al., 2020).

Data from the UK collected over a 5-week period from April to May 2020 showed that adults with learning disabilities in residential care had a significantly higher death rate from COVID-19 compared to people with learning disabilities generally (1.5 times higher after adjusted for likely under-notification) and compared to the general population (5.5 times higher) (Public Health England, 2020). The higher death rate in residential care may reflect the greater age, disability severity and medical complexity of these individuals. These findings were supported by more recent UK data collected up until November 2020 which showed that place of residence (living in a care home or communal setting) had the largest effect on the increased risk of death from COVID-19 among people with learning disabilities (Office for National Statistics, 2021).

Despite the needs of people with IDD in residential care being different than those of seniors in long term care, and the homes themselves being smaller, and with a higher staff to resident ratio, most of Canada has tended to adopt similar visiting policies in both settings during COVID-19 (Inclusion Canada, 2020). As discussed throughout this report (see the *Caregiver Support* section), these restrictions have had an impact on the mental health and emotional well-being of many adults and children with IDD as well as their families and staff who support them. Isolation and separation from loved ones due to visitation bans and restrictions on public outings have resulted in mental and emotional distress among both residents and family caregivers, or have exacerbated existing mental and physical health conditions (Perry et al., 2020; Lunskey, 2020; Hewitt et al., 2020). Moreover, the potential trauma caused by these measures may go undetected and untreated, as some individuals with IDD may not be able to communicate their needs and feelings to caregivers (Seucharan, 2020). Communication issues have been noted among individuals with IDD who live in residential care settings and are limited to virtual or window visits. As many of these individuals are nonverbal, the lack of face-to-face contact is a significant barrier to their development and they may face cognitive and functional declines if they are unable to adapt to these alternative communication methods (Abel & Lai, 2020; Lunskey, 2020).

The health and well-being of residents with IDD also affects the staff who support them. Evidence from Canada and the US shows increased rates of stress among direct support professionals (DSPs) during the pandemic due to factors such as staff shortages, increased hours, financial impacts of the pandemic, concerns about infection prevention and control, and managing the mental health and challenging behaviours of the people with IDD who they support (Bobbette et al., 2020; Hewitt et al., 2020).

COVID-19 risk factors in more individualized settings

While the larger numbers in group settings presents a significant health risk, people with IDD living in more individualized settings are also at higher risk than the general public for several reasons.

One reason relates to support staff entering the home on a regular basis and providing a range of support and care services including personal care in many cases. Often these support staff are not associated with agencies or facilities and would have limited access to training and PPE. A more general risk factor is given that these individuals live a more integrated community life, they are at risk of being missed by health authorities with regards to PPE and vaccine priorities. Finally, isolation and consequent potential mental health impacts can be heightened in individualized settings as access to community supports and programs may be restricted during the pandemic, creating a highly isolated environment.

Conclusion

The challenge for agencies and service providers is to find an appropriate balance between ensuring the needs and rights of individuals with IDD living in all types of residential care or individualized settings continue to be met during the pandemic while also enforcing strong preventive measures to control the spread of the virus and protect the health and safety of both residents and support staff. People with IDD have the right to a safe and healthy living environment and quality of care, including access to resources and supports to ensure that any support staff are following the necessary health and safety protection measures. More data and information on the impact of COVID-19 on people with IDD in different living arrangements is also needed in order to fully understand and address the risks facing this population.

Recommendation 17: Collect, analyze and report surveillance data for people with IDD, including information on COVID-19 prevalence and outcomes for individuals with IDD in public settings, institutional and residential care settings.

Recommendation 18: Ensure continued access to resources for support staff and guarantee safe and affordable housing options for individuals with IDD through greater investment in community-based housing and supports to promote independent living.

Recommendation 6 (see pg. 23): Allocate mental health services to address the unique needs of people with IDD and their caregivers who have been disproportionately impacted by the pandemic and ensure support for staff—including appropriate training and access to specialized mental health supports and resources.

Recommendation 16 (see pg. 39): Ensure that guidelines and policies for residential care and congregate care settings are aligned with proposed long-term care standards and that unrestricted access of essential family caregivers to individuals with IDD be embedded in those standards and communicated transparently.

Population-Level Approaches to Health

Population-level evidence on the prevalence and outcomes of COVID-19 among adults and children with IDD in Canada is lacking. Improved health surveillance data would contribute to more appropriate and accessible policy responses to reduce health inequities for people with IDD, especially with respect to Canada's COVID-19 vaccination distribution.

Integrating IDD in population health

The Public Health Agency of Canada defines population health as “an approach to health that aims to improve the health of the entire population and reduce health inequities among population groups.” (Government of Canada, 2012). Public health has been slowly engaged in promoting the health of people with disabilities and including them in data, programs, and policies (Krahn & Fox, 2016). A framework for the ten essential public health services initially released in 1994 and revised in September 2020 by the Centers for Disease Control and Prevention describes three core functions to promote optimal health for all and achieve equity: assessment, policy development and assurance (CDC, 2020c; PHNCl, 2020). The suggested contributions of a public health perspective for the future of people with IDD (Krahn & Fox, 2016) include:

- **Awareness through surveillance:** improved data on prevalence, health status and health disparities at the population level by applying a structured framework to identify IDD in datasets;
- **Accuracy in knowledge:** Within the health disparities framework, disability is increasingly considered a risk factor that predicts health outcomes, and not solely an outcome to prevent;
- **Action for intervention:** The inclusion of people with IDD within generic health promotion and service delivery systems, and mobilizing partner organizations and agencies to incorporate health promotion in their activities.

A disability-inclusive public health response to COVID-19

As shown throughout this report, the severity of COVID-19 and its associated outcomes do not affect everyone equally. According to the experience from prior pandemics and disaster emergencies, to ensure that people with disabilities (broadly defined) are not disproportionately impacted by COVID-19, three main areas of need from a public health perspective must be addressed (Boyle et al., 2020):

1. Identify types of data that are needed to clarify and mitigate risks for people with disabilities;
2. Improve health protection measures for people with disabilities by incorporating their needs; and
3. Address issues of equity in access to health care and quality of medical care.

A disability-inclusive public health response may decrease challenges for people with IDD through appropriate public health messaging, preventing disruption in service provision and limiting segregation or institutionalization. Inclusive responses enable people with IDD to meet their daily living, health care and transport needs while maintaining their employment and educational commitments (Armitage & Nellums, 2020).

Population data on COVID-19 for individuals with IDD

In recent years, scholars have raised concerns about inadequate population-level health data on adults and children with IDD in the US (Krahn, 2019), Canada (Arim, Findlay & Kohen, 2016), and globally (Black & Lawn, 2018), emphasizing the absence of robust and sustainable data collection methods and analyses. This information is necessary to support planning and policy development to address the challenges for this population and is fundamental to a public health approach. In Canada, Lunskey and Jiwa (2021) noted that although collecting and reporting information on vulnerable groups is mandatory, data collection and reporting is lacking for people with developmental disabilities. The COVID-19 pandemic has highlighted this information gap further.

As deaths from COVID-19 rose, evidence from many studies indicated that people of different races and ethnicities were disproportionately impacted (Siegel et al., 2021; Greenway et al., 2020; Patel et al., 2020; Laurencin & McClinton, 2020). This led to a call to explore public health responsiveness to disparities, specifically racial and ethnic disparities. However, studies of disparities among COVID-19 patients that include IDD are limited. One recent study in the US (Chakraborty, 2021) demonstrated that greater COVID-19 incidence rate among people with disabilities (not specific to IDD) is associated with race (Black, Asian, Hispanic, Native American), poverty (under the poverty line), age (under 18 years) and sex (female) after controlling for spatial clustering. The scarcity of studies on inequality in public health services and outcomes for people with IDD during the pandemic is evidenced by the available literature (Turk & McDermott, 2020).

COVID-19 testing, treatment, and vaccination considerations for people with IDD

“We have to be able to accommodate everybody and not have a ‘one size fits all’ approach.”

—Jake Anthony, self-advocate

In Canada, federal guidance on health care for people with disabilities during the COVID-19 pandemic has underlined the importance of accessibility of facilities for COVID-19 testing and the need for adaptations and accommodations for individuals with IDD. Specifically, the guidance includes: no waiting for testing, a private room with light and noise sensitivity considerations, alternatives to the nasopharyngeal swab, allowing a support person to remain with them, and assessments at or in their vehicle (Ofner et al., 2020). Moreover, adequate information about the process should be provided in a functional, multi-lingual and culturally appropriate way for people with IDD and their caregivers. For example, in Toronto, Holland Bloorview Kids Rehabilitation Hospital and the Hospital for Sick Children (SickKids) have collaborated to make COVID-19 testing for children with developmental conditions and their families more convenient and less stressful through new testing sites that adhere to the above recommendations. This includes offering testing in vehicles, in outside tents, or at home if necessary. These centres also provide timely and suitable access to pediatric resources and accommodations for communication, mobility, behavioural and other specialized health care needs at the time of testing (Holland Bloorview, 2020).

In addition to the need for accessible testing, a concern regarding the provision of medical care and treatment for people with IDD who develop COVID-19 is the potential for discrimination by health providers and hospital policies (Constantino et al., 2020). The pandemic has intensified challenges with allocation of scarce resources for providing appropriate and often life-saving

treatment to patients. In the context of a major surge in demand that exceeds health care capacity, triage protocols that determine which patients to prioritize for receiving critical care resources (i.e., ICU beds, ventilators, doctors) based on assessments of their short-term likelihood of survival may need to be enacted. While protocols such as Ontario's emphasize that triage decisions should not be based on other factors such as patient demographic characteristics, perceived quality of life, and other non-relevant health conditions, some disability advocates in the US have called attention to policies that do not follow these standards in practice or that exclude patients with disabilities (Constantino et al., 2020; Mello et al., 2020). As COVID-19 cases and patients continue to rise and place further strain on health care systems in many countries including Canada, it is imperative that treatment and triage guidelines are attentive and adaptive to the needs and interests of people with IDD to ensure equal care both during and after the pandemic (Thompson et al., 2021).

This report has noted the greater risk of morbidity and mortality from COVID-19 for individuals with IDD in comparison to the general population. Some countries such as the UK, the US, Sweden, Germany, and the Netherlands have recognized this increased risk by including adults with developmental disabilities as a priority group in the early phases of their COVID-19 vaccination plans (Lunsky & Jiwa, 2021). In the US, prioritizing vaccination for people residing in group homes varies for every state (Weintraub, 2021). However, in Canada, people with IDD have not yet been identified as a priority group for vaccination at the federal level. In addition to prioritizing people with IDD and their caregivers, any vaccine distribution and administration plan must be accessible and follow the same guidance offered for COVID-19 testing and assessment centres to ensure that inequities are reduced as much as possible for individuals with IDD (Campanella et al., 2021).

Conclusion

Population-level evidence on the prevalence and outcomes of COVID-19 among adults and children with IDD is limited, due to insufficient data gathering and analysis efforts. Existing research from other jurisdictions on the impact of COVID-19 on people with IDD must be incorporated into our current vaccination planning and prioritization frameworks. However, until we begin tracking and documenting this information in Canada, we will not have a complete understanding of the needs and priorities for people with IDD in our pandemic response planning.

Recommendation 17 (see pg. 43): Collect, analyze and report surveillance data for people with IDD, including information on COVID-19 prevalence and outcomes for individuals with IDD in public settings, institutional and residential care settings.

Recommendation 19: Ensure that hospital triage protocols and guidelines are inclusive, equitable, transparent, and grounded in an ethical process that is based on human rights principles and informed by patients who would be affected by such protocols, including persons with IDD and their families. Health care providers involved in the critical care triage process must also receive training to reduce the risk of discriminatory bias.

Appendix I

Policy recommendations by theme, stakeholder, and type

Legend: Blue= disability-inclusive policy; Pink = disability-specific policy

Theme	Recommendation	Section of Report (Rec #)	Stakeholder
Essential services and prioritization	Prioritize persons with IDD of all ages in the distribution of COVID-19 vaccinations in Canada along with other high risk clinical groups, in recognition of their heightened susceptibility to severe complications and death from the virus as well as the disproportionate impact of COVID-related public health measures on their health and well-being	Health risks (Rec #1)	Federal and provincial/territorial government
	Designate services, supports, therapy and support workers for persons with IDD as essential across health and social care sectors	Access (Rec #3)	Provincial and territorial health and social service ministries
	Ensure that hospital triage protocols and guidelines are inclusive, equitable, transparent, and grounded in an ethical process that is based on human rights principles and informed by patients who would be affected by such protocols, including persons with IDD and their families. Health care providers involved in the critical care triage process must also receive training to reduce the risk of discriminatory bias.	Population Health (Rec #19)	Provincial, territorial and local health service providers
Accessibility of services	Provide health care accommodations for people with IDD both during the pandemic and post-pandemic recovery	Access (Rec #4)	Local health and social care services
	Use and adapt telehealth as needed in an accessible manner, to ensure functioning and well-being of individuals with IDD	Access (Rec #5)	Provincial, territorial and local health and social service providers
	Ensure appropriate modifications, accommodations and supports are available to enhance the participation, development, and well-being of students with IDD both during and post-pandemic	Education (Rec #10)	Provincial and territorial education ministries and school boards
	Invest in post pandemic accessible employment support for people with IDD to support recovery from COVID-19 related job losses and reduced employment	Income (Rec #15)	Federal government
	Ensure continued access to resources for support staff, and guarantee safe and affordable housing options for individuals with IDD through greater investment in community-based housing and supports to promote independent living	Housing (Rec #18)	Federal and provincial/territorial government

Data	Collect, analyze and report surveillance data for people with IDD, including information on COVID-19 prevalence and outcomes for individuals with IDD in public settings, institutional and residential care settings	Housing; Population Health (Rec #17)	Public health units and related systems
	Develop a data collection strategy of existing adapted and inclusive community programs, to identify community-specific gaps and needs	Leisure (Rec #7)	Provincial/territorial and local government
	Monitor the long-term impacts of the pandemic on learning for students with IDD through individualized assessments	Education (Rec #11)	Ministries of Education
Funding	Allocate mental health services to address the unique needs of people with IDD and their caregivers who have been disproportionately impacted by the pandemic and ensure support for staff – including appropriate training and access to specialized mental health supports and resources	Access; Caregivers; Housing (Rec #6);	Provincial and territorial governments
	Allocate additional funding for community-based participation initiatives for people with IDD to support innovative solutions that are sustainable post pandemic	Leisure (Rec #9)	Provincial and territorial government
	Develop a National Disability Income Benefit sufficient to ensure a reasonable minimum income for all Canadians with a disability.	Income (Rec #12)	Federal Government
	Design disability inclusive pandemic income supports. In addition, recognize persons with IDD and their families experience additional costs such as PPE for support staff and technology needs	Income (Rec #13)	Federal and provincial/territorial governments
	Enhance emergency caregiver benefits to family members or guardians of persons with IDD who are required to take leave from employment in order to provide care due to COVID-19 or similar pandemics	Income; Caregivers (Rec #14)	Federal government
Information and guideline availability and accessibility	Ensure public health information and communication that addresses the health risks for children and adults with IDD is widely available and adheres to national accessibility standards	Health risks (Rec #2)	Federal and provincial/territorial government and health organizations
	Synthesize and promote an accessible resource and support guide with information on tools, virtual programs and approaches to promote health navigation, social support and leisure participation and inclusion opportunities for individuals with IDD and their families in local communities, which would remain useful post pandemic	Leisure; Caregivers (Rec #8)	Federal government
	Ensure that guidelines and policies for residential care and congregate care settings are aligned with proposed <u>long-term care standards</u> and that unrestricted access of essential family caregivers to individuals with IDD be embedded in those standards and communicated transparently	Caregivers; Housing (Rec #16)	Federal Government

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The Royal Society of Canada

282 Somerset Street West
Ottawa, Ontario K2P 0J6
www.rsc-src.ca
613-991-6990

La Société royale du Canada

282, rue Somerset ouest
Ottawa (Ontario) K2P 0J6
www.rsc-src.ca
613-991-6990