



# THE SCHOOL OF PUBLIC POLICY

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**MASTER OF PUBLIC POLICY**

**CAPSTONE PROJECT**

Advancing Inclusive Policies for Children and Youth with  
Disabilities in Alberta

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Submitted in fulfillment of the requirements of PPOL 623 and completion of the requirements for the Master of Public Policy degree.



# THE SCHOOL OF PUBLIC POLICY

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## Executive Summary

The COVID-19 pandemic revealed significant gaps in disability-inclusive policy. Children and youth with disabilities encountered heightened difficulties due to barriers already in place at the onset of the pandemic. While policy responses to public health crises tend to offer “universal” measures, individuals with disabilities face intersecting vulnerabilities that require targeted attention. Policies in place before and during the pandemic failed to provide the necessary supports to navigate these challenges effectively. The pandemic revealed an urgent need for comprehensive and targeted disability policies that consider intersectional vulnerabilities, diverse healthcare needs, and barriers to access.

This study aimed to explore how lessons learned from the pandemic can guide the creation of equitable policies that support children and youth with disabilities in Alberta. A virtual focus group was conducted using the Nominal Group Technique. Participants included youth with disabilities, families of children and youth with disabilities, and non-profit stakeholders. The goal of the focus group was to better understand the challenges and barriers that disabled children, youth, and their families faced during the pandemic to inform future inclusive disability-policy recommendations. Data gathered from the focus group was transcribed to text so that participant responses to policy recommendations could be effectively analyzed.

Based on the focus group findings and current literature, the following policy recommendations are offered to policymakers in Alberta:

1. Recognize disability services as essential services to ensure continuous access.
2. Design fair and sustainable economic supports for parents/caregivers of children & youth with disabilities
3. Co-design policy with relevant stakeholders, including children & youth with disabilities, their families, service providers, and community organizations.
4. Implement a flexible design for disability programs and healthcare services, prioritizing a patient-centric approach.
5. Reduce reliance on the education system to provide all types of services.

*Keywords: disability, disability policy, pandemic, co-design, patient-centred care, inclusion*

## Introduction

Based on Statistics Canada's 2017 Survey on Disability, nearly 16 per cent of Canadians have a disability, including over 200,000 children and youth (Statistics Canada 2017). According to the latest Statistics Canada data gathered in 2018, there are approximately 680,000 people with disabilities in Alberta aged 15 and older (Statistics Canada 2018). The exact number of children and youth with disabilities in Alberta is unknown. A rough estimate can be made using data from Alberta Education and the Family Support for Children with Disabilities (FSCD) program. The Covid-19 pandemic hindered families from receiving diagnoses, and the total Active FSCD Caseload as of December 2021 of 15,213 is likely an underestimate of the number of children with disabilities in Alberta (Government of Alberta 2022).

Children and youth with disabilities are subject to discrimination and marginalization that create barriers to accessing education, healthcare, and other vital supports (Green et al. 2005). They are often bullied and stigmatized by their peers (Earnshaw et al. 2018). Additionally, facilities that most children regularly access, such as schools, parks, playgrounds, and libraries, are often inaccessible for disabled children (Brown et al. 2021). This can be due to physical inaccessibility or needing support with communication; for example, no wheelchair-friendly entrances or washrooms or a lack of accessible communication options. The presence of negative social attitudes towards neurodiverse children who behave different from their neurotypical peers, for example, stigmatizing, further compounds the barriers these children face. If children and youth with disabilities or their parents identify as a racialized minority, refugee, immigrant, indigenous person, low-income, foster child, or LGBTQ+, the marginalization they face is further compounded (Ontario Human Rights Commission 2018). Disability-inclusive policies help address the systemic barriers and discrimination that children and youth with disabilities encounter in their everyday lives.

Currently, there is not enough information on priorities for an equitable recovery-driven policy that impacts youth with disabilities and their families. This lack of information means that youth with disabilities and their families are falling through the cracks, particularly regarding their unique and complex needs. To create disability-inclusive policies, people with disabilities must be given a chance to voice their perspectives and needs and to be listened to when they speak.

This key research question this study aims to address is: *how can the lessons learned from the pandemic guide the creation of equitable policies impacting children and youth with disabilities in Alberta?* This paper has two objectives: first, to bridge the existing gap between children and youth with disabilities and policy by actively involving those with lived experience. Second, it seeks to acquire insights into the experiences of children and youth with disabilities, their families, and relevant Non-Governmental Organizations (NGOs) during the COVID-19 pandemic. These insights will inform the creation of equitable and inclusive policies impacting disabled children and youth in Alberta. Through these two goals, the study hopes to pave the way for a more inclusive and supportive environment for persons with disabilities in policymaking and implementation processes.

To provide context, this paper begins with an overview of disability policy and includes a literature review of the impact of the Covid-19 Pandemic on children and youth with disabilities. A modified Nominal Group Technique (NGT) process was used to conduct a virtual focus group. The paper will examine the NGT process and analyze the focus group data. Finally, the key policy recommendations and takeaways will be discussed.

## What is Disability-Inclusive Policy?

Policy serves as a fundamental tool of governance within an institution, establishing key principles, values, and intent (Government of Canada 2021). It provides a framework for consistent decision-making and resource allocation regarding specific issues (Seixas, François, and Mitton 2021). Policy instruments are essential tools employed to advance specific policies to meet predetermined goals (Hettiarachchi and Kshourad 2019). These instruments are designed to engage all stakeholders involved in the specific issue being addressed. For the purpose of this paper, disability policy is defined as the actions that governments and other decision-making entities choose to either do or not do that impact people with disabilities and their families. It is also important to define the term “inclusion” as it will be used in this paper. Inclusion is a state of fostering belonging, where individuals from diverse backgrounds and identities are authentically valued and equitably welcomed as active participants and collaborators (UNESCO 2022). Inclusion enables people to have the opportunity to thrive and experience a sense of belonging. While diversity initiatives are important, they alone do not establish inclusive environments. Inclusion goes beyond mere representation; it embraces the idea of accepting individuals as they are, without the pressure to assimilate.

Disability-inclusive policy is developed through a collaborative co-design process involving individuals with lived experience of disabilities and various stakeholders. Co-design is a collaborative and inclusive approach that actively involves diverse stakeholders, including patients, families, researchers, and service providers, recognizing their unique insights and perspectives (Purple Orange 2021). The goal of this approach is to incorporate as many perspectives as possible in the policy-making process so that the resulting policies are representative of the diverse disability community. The process of co-design seeks to identify and address any unintended consequences that may have negative impacts on people with disabilities and their families (D’Cruz et al. 2022). The process focuses on building connections and trust among stakeholders, encouraging open communication and mutual respect to better understand each other’s needs and concerns (Purple Orange 2021). Ongoing collaboration throughout the design and development process allows for continuous improvement based on feedback and real-world experiences.

It is also crucial to define other key terminology used in this paper. The majority of language used is person-first, for example “person with a disability”, as it centers the inherent personhood of those with disabilities. Identity-first language, for example “disabled person”, is also used, as many disabled people prefer to lead with their identity as disabled (National Disability Practitioners 2016). The purpose of identity-first language is to emphasize how integral disability is to the lived experiences of disabled people, and many communities of disabled people prefer identity-first language (Brown 2011). The phrase “autistic” will be used instead of “person/child with autism” for this reason, as the autistic community overwhelmingly prefers identity-first language. Both person-first and identity-first ways of using language are important and both serve a purpose, so the author has chosen to use these terms interchangeably. The definition of disability used in this paper comes from critical disability theory, which combines complex social and medical understandings of disability and a person’s ability to fully participate in society (Geoffrey 2014). Critical disability theory states that intersecting identities create a

“matrix of domination” in which people with multiple marginalized identities experience marginalization differently than those with other combinations of marginalized identities (Annamma et al. 2018). As Alberta’s disabled community is diverse both in terms of the diagnoses that people have and in terms of other identities such as race, gender, sexual orientation, and Indigeneity, critical theory is the most accurate theoretical foundation for this analysis.

## Disability-Inclusive Policy Considerations & Guidelines

This section outlines key international treaties, federal legislation, and provincial legislation that guide the creation of disability-inclusive policies in Canada. It is important to understand the policy context surrounding disability-inclusive policies before appropriate recommendations can be made.

### The United Nations

*The Convention on the Rights of the Child (UNCRC)* is an international human rights treaty created by the United Nations General Assembly in 1989 and ratified by 196 countries, including Canada in 1991. The UNCRC establishes the fundamental rights and safeguards that must be guaranteed for every child regardless of their race, religion, nationality, or social background (United Nations 1989). Ratifying nations are obligated under the treaty to provide access to education, health care, rehabilitation, and other services to facilitate social integration and individual development. The assistance provided to children with disabilities should be free of charge according to the CRC which includes potential economic strain placed upon parents and caregivers (United Nations 1989).

*The Convention on the Rights of Persons with Disabilities (UNCRPD)* is an international human rights treaty created by the United Nations General Assembly in 2006 and ratified by over 182 countries. Its goal is to protect the rights and dignity of individuals with disabilities by ensuring their inclusion, accessibility, and nondiscrimination (United Nations 2006). Canada ratified the UNCRPD in 2010, demonstrating its formal commitment to upholding the rights of persons with disabilities.

Some of the key articles in the UNCRPD will be highlighted, though this is not an exhaustive examination of all articles within the convention. Article 3 emphasizes general principles such as dignity, autonomy, non-discrimination, and accessibility (United Nations 2006). Article 4 places obligations on States to ensure human rights for persons with disabilities (United Nations 2006). Articles 5 through 9 discuss the importance of creating awareness about disability-specific issues, including intersectionality and accessibility (United Nations 2006). Articles 10 through 30 describe in detail an array of rights in key areas, including but not limited to the right to equal recognition before the law, protection from exploitation and violence, living independently and inclusion in the community, education, health, and an adequate standard of living and social protection, and participation in cultural life, recreation, leisure, and sport (2006).

*The UN Disability Inclusion Strategy (UNDIS)* is foundational to sustainable and transformative advancements in disability inclusion across the United Nations' key pillars of work: peace and

security, human rights, and development (Mitra and Dominik 2022). The strategy enables the UN to support the implementation of the UNCRPD and other relevant international human rights agreements. UNDIS has four core areas of responsibilities: Leadership, Strategic Planning and Management; Inclusiveness; Programming; and Organizational Culture.

## Canada

*The Canadian Charter of Rights and Freedoms* has been integral to Canada's legislative framework since 1982. It entrenches the fundamental rights and freedoms that are inherent to all Canadians. Section 15 of the Charter addresses the rights of people with disabilities by stating: *"Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability"* (Canadian Charter of Rights and Freedoms 1982).

*The Canadian Human Rights Act* was enacted in 1977. This Act's purpose is to ensure that all Canadians have equal opportunity to lead their lives free from discrimination based on various factors that include race, religion, age, and disability (Canadian Human Rights Act 1985).

*The Accessible Canada Act* was passed in 2019 with the goal of "making Canada barrier-free by 2040". The act stresses that laws, policies, programs, services, and structures must consider the intersections of different barriers and discrimination (Accessible Canada Act, 2019). It also mandates the involvement of persons with disabilities in the development and design of these laws, policies, programs, services, and structures (Accessible Canada Act, 2019). Additionally, the Act emphasizes that accessibility standards and regulations should be aimed at achieving the highest level of accessibility.

## Alberta

*The Alberta Human Rights Act* refrains from providing a singular, all-encompassing definition of disability. It instead defines disabilities as physical or mental based on examples specified in the legislation. The interpretation and application of these definitions can evolve over time through case law and legislative amendments. Other legislation and policies in Alberta may offer additional definitions or specific criteria for disability in specific contexts, such as disability support programs or accessibility regulations.

## The Impacts of the COVID-19 Pandemic on Children and Youth with Disabilities

The COVID-19 pandemic is a global health crisis caused by the spread of the infectious SARS-CoV-2 virus. The first outbreak was reported in December 2019 and it has since taken the lives of nearly 7 million people (World Health Organization 2023). As of July 2023, the WHO reported 4,695,593 confirmed cases of COVID-19 in Canada resulting in 53,086 deaths (World Health Organization 2023). Alberta recorded nearly 634,000 confirmed cases and 5,818 deaths (Government of Alberta 2023).

Government messaging about infection risks during the COVID-19 pandemic stated that children and youth were at a lower risk for COVID-19 infections and resulting complications. This directly contradicted evidence that people with disabilities and non-disabling health conditions faced higher risks of adverse outcomes from COVID-19 infections (Yates and Dickinson 2021). Inadequate information on protecting immunocompromised people and



failures in disseminating accessible public health information increased the difficulties that disabled children faced during the pandemic (Yates and Dickinson 2021).

The largest negative impacts of the COVID-19 pandemic are on people with intersecting marginalized identities, and in education, access to essential services, health and wellbeing, and the economy. Caregivers also faced unique challenges due to the pandemic.

### Intersectionality

The pandemic disproportionately affected vulnerable populations, including the elderly, immunocompromised people, the homeless, people with disabilities, refugees, immigrants, prisoners, LGBTQ+ communities, and low-income families. Significant disparities in healthcare access and healthcare quality were also observed in racialized children living in high-income nations (Shapiro and Bassok 2022). These racial disparities in healthcare led to decreased health service use, reduced likelihood of receiving family-centered or subspecialty care, greater likelihood of facing barriers in accessing healthcare, and receiving diagnoses at older ages alongside poorer quality of care once diagnoses were formalized (Shapiro and Bassok 2022). Additionally, ethnically, and linguistically diverse families encountered further obstacles in accessing adequate care, resources, and support for their children, which accentuated disparities in pandemic responses between different social groups (Neece, McIntyre and Fenning 2020).

Many children and youth with disabilities encountered social and economic barriers beyond those faced by abled peers, including heightened food insecurity, increased rates of unemployment, and larger declines in mental health (Shikako 2023). A lack of targeted support left them struggling to navigate the challenges of the pandemic. Children and youth with disabilities often face a higher risk of vulnerability during emergencies, are less likely to receive critical assistance following disasters or conflict and are often overlooked in emergency plans (Peek 2008). This compounds disparate outcomes when applying universal or generalized supports. The COVID-19 pandemic was a global emergency that yielded predictably disparate outcomes for youth with disabilities. Policy responses to COVID-19 failed to consider the specific vulnerabilities of different populations, particularly those experiencing multiple layers of intersectional marginalization such as children and youth with disabilities.

### Education

The COVID-19 pandemic had significant implications for children with disabilities due to disruptions in school-based routines. Disruptions in routine and the accompanying social isolation were identified as risk factors for increased mental distress (Shikako 2023). School closures had additional consequences by depriving children of in-person school-based supports. Most health and social supports for children with disabilities in Canada are provided within schools (Shikako 2023). Repeated school closures and reopenings were unpredictable, which increased the stress felt by children with disabilities and their families. Access to technology for remote learning was also a significant barrier, especially for children with disabilities from households with less economic resources (Arbour-Nicitopoulos et al. 2022). The largest barrier to acquiring remote learning technology was cost, as adaptive

communication technology and high-speed internet are both cost-prohibitive (Gonzalez et al. 2022).

The lack of access to education and necessary services during the pandemic accentuated academic achievement gaps between children with disabilities and children without disabilities, which further perpetuates socioeconomic inequity and social isolation of disabled people (Arbour-Nicitopoulos et al. 2022). Achievement gaps contribute to lower high school graduation rates, lower college attendance, and reduced employment (Arbour-Nicitopoulos et al. 2022). Disability services and medical appointments are often scheduled primarily during school hours, which prevents children with disabilities from attending school regularly. Poor school attendance and persistent absences also had detrimental effects on academic progress, mental health, and future opportunities (Totsika et al. 2023). Intermittent attendance particularly affects children with neurodevelopmental conditions such as intellectual disabilities and autism (Totsika et al. 2023).

### Access to Essential Services

At the beginning of the pandemic, health and rehabilitation services not deemed essential were cancelled to prevent the spread of COVID-19. Many of these services gradually transitioned to virtual appointments (Currie et al. 2022). Some services, such as physical, occupational, and speech therapies require in-person, or “hands-on”, approaches to treatment and were not adequately substituted by virtual appointments (Currie et al. 2022). As a result, many of these crucial services were postponed for extended periods of time or cancelled altogether. These cancellations created long backlogs in appointment requests, leaving people with disabilities without necessary supports for Activities of Daily Living (ADLs). Many therapies that support children with multiple diagnoses require a hands-on approach from their care professionals. Children with multiple diagnoses also often rely on physical equipment for their ADLs, much of which is not regularly available in their homes (Allison, Kristen, and Levac 2022). Telehealth-only services had a disproportionate negative impact on the daily lives of these children when compared to children with disabilities who had a lesser reliance on hands-on therapeutic techniques and equipment.

### Health and Wellbeing

#### *Physical Health*

Lockdown restrictions led to increased reports of weight loss and muscle weakness among children with disabilities, indicating the adverse effects of reduced physical activity and limited access to the outdoors (Yates and Dickinson 2021). The pandemic also created changes in administration of medication to children with disabilities. Almost one fifth (18.8 per cent) of families reported an increase in the amount of medication prescribed for their child during this period, potentially influenced by factors such as limited access to healthcare facilities and concerns about COVID-19 exposure (Masi et al. 2021). Consequently, some families resorted to increasing their child's medication dosage without proper medical supervision, raising concerns about the unintended consequences of such actions (Masi et al. 2021). They saw their children's physical and mental well-being decline and believed increasing their medication dosage would help.

The changes in therapeutic services during the pandemic significantly impacted the functioning of children with disabilities. Over half of the participants in one study reported "some" or "significant" decline in their child's functioning across various domains, including communication skills, social skills, and behavior (Allison, Kristen, and Levac 2022). These declines were attributed to disruptions in therapeutic services and other necessary supports, highlighting the broader implications of the pandemic on the well-being of children with disabilities. To adapt to the situation, access to virtual phone-based health care (called "telehealth" or "teletherapy") was increased during the pandemic and resulted in increased telehealth service usage. This shift had mixed outcomes, with over 40 per cent of parents reporting declines in their child's motor, behavioral, social, and communication skills due to changes in the delivery of therapy services (Allison and Leave 2022). These declines disproportionately impacted children with multiple diagnoses. The pandemic also introduced new restrictions to opportunities that children with disabilities previously had for engaging in community participation, including leisure, play, and school. Youth with disabilities were prevented from participating in activities where they were previously able to be socially and physically active (Currie et al. 2022).

### *Mental Health*

Negative emotions, uncertainty, disruptions to daily routines, and the pervasive global state of stress and alarm all contributed to mental health challenges for children and youth with disabilities as well as their caregivers. Public health guidelines added to uncertainty, particularly for children who would be unable to fully follow public health guidelines, such as those unable to wear masks due to multiple chronic conditions or children who required specialized medical attention to participate in daily activities (Shikako et al. 2023). Additionally, the unpredictability surrounding school closures and the related rehabilitation services further heightened anxiety and fear. Research indicates that social distancing measures during the pandemic led to increased anxiety, depression, and behavioural dysregulation among all children, but particularly children with disabilities (Yusuf et al. 2022).

Increased aggressive behaviours and self-harm were observed as a result of the social isolation related to public health measures, along with low mood states, sedentary behaviours, and regression in social and academic learning (Currie et al. 2022). With altered daily routines affecting sleeping, eating, and physical activity patterns, individuals faced significant adjustments to their normal lives which created feelings of helplessness (Masi et al. 2021). Parents reported decreases in focus, attention span, and ability to regulate disruptive behaviours in their children.

Reduced access to health and social supports further exacerbated mental health challenges for children with disabilities and their families. The loss of daily routines and disruptions to essential supports resulted in decreased cognitive ability and social skills, loneliness, and frustration among children (Currie et al. 2022). Autistic youth and their caregivers in particular perceived their days as quite stressful or extremely stressful, reporting twice the stress levels observed in the general population during non-pandemic times (Bıyık et al. 2021). Autistic people rely on routines more than allistic people and were therefore dysregulated more by changes in routine.

The pandemic also had a more severe impact on the mental health of families with lower incomes. The stress and uncertainties of the pandemic combined with ongoing financial hardships contributed to heightened levels of anxiety and depression among low-income households (Gonzalez et al. 2022). Comparative lack of resources and support systems made it challenging for low-income families to cope as effectively with the various challenges created by the pandemic.

### *Social Isolation*

Children and youth with disabilities experience greater social isolation than to their peers. For students with cognitive, emotional, and/or behavioral disabilities, integration into “traditional” classrooms during classes such as physical education, music, and art provides important opportunities for direct social interaction with classmates (Arbour-Nicitopoulos et al. 2022). Some children with disabilities rely on environments such as the classroom and after-school activities for social interactions since their peers' homes may not be accessible to them (Arbour-Nicitopoulos et al. 2022). The closure of schools during the pandemic resulted in a loss of crucial opportunities for children with disabilities to interact with their peers. This absence of social interaction and personalized support had a significant impact on disabled children in particular. For some, the difficult decision to continue with online schooling due to health vulnerabilities while their peers returned to in-person classes posed a significant challenge socially. Children and youth reported experiencing symptoms of depression due to feeling isolated and disconnected from their social networks (Lim et al. 2021).

### *Economic Challenges*

The COVID-19 pandemic has had a profound impact on the everyday lives of people and industries worldwide. The pandemic disrupted economies around the world by causing supply chain shortages, unemployment, and global financial struggles (Naseer et al. 2023). Front-line workers including healthcare professionals, first responders, grocery clerks, educators, transportation workers, janitorial staff, and childcare providers were at an increased risk of contracting and spreading the virus (Nguyen et al. 2020). Children and youth with disabilities were at a higher risk for socioeconomic hardships, homelessness, poor nutrition, domestic violence, sexual exploitation, and cyberbullying as compared to peers without disabilities (Shikako 2023).

### *Food Insecurity*

The COVID-19 pandemic has exacerbated food insecurity for many families (Karpur et al. 2022). As schools faced closures and instruction shifted to remote delivery, school nutrition programs had to operate on an emergency basis. This meant that children could only have access to meals if they were able to physically go to school to pick them up. The disruption to school-based nutritional support systems further intensified the challenges faced by families, especially those already experiencing financial hardship and food insecurity.

Based on analysis done by the National Survey of Children's Health (NSCH) prior to the COVID-19 pandemic, autistic children, especially those with comorbid intellectual disabilities, had the highest likelihood of experiencing food insecurity compared to families without children with disabilities (Karpur et al.2022). This data highlights the pre-existing vulnerabilities faced by these groups of children and their families even before the pandemic struck. The COVID-19

crisis further compounded these challenges, exacerbating food insecurity for many families with children and youth with disabilities. Children and youth with disabilities who did not have financial barriers to accessing proper nutrition continued to face other challenges. Research states that between 30 and 70 per cent of patients with autism spectrum disorder have functional gastrointestinal disorders (FGIDs) (Javaid et al. 2021). Examples of FGIDs include irritable bowel syndrome, reflux symptoms, functional diarrhea/constipation, cyclic vomiting, and heartburn (Javaid et al. 2021). To manage FGIDs a diet high in fiber, protein, fruits, and vegetables is recommended (Cozma-Petrut et al. 2017). During the pandemic when supply chains were impacted, access to these foods became challenging, once again disproportionately impacting low-income families who could not afford the increased cost of these food items. The disparities in food access and security underscore the need for targeted support and interventions to address the unique needs of vulnerable populations, particularly during times of crisis and upheaval.

### *Impact on Caregivers*

Caregivers of children with disabilities faced many challenges and hardships during the COVID-19 pandemic. They experienced a loss of access to their support networks, educational and therapy specialists, and daily routines (Brandenburg et al. 2020). Many parents struggled to find mental health supports for themselves during the lockdowns, which led to increased stress and feelings of burnout. Balancing work with childcare and family responsibilities was particularly challenging for 75 per cent of caregivers, making it difficult to establish and adhere to new routines (Masi et al. 2021).

Infection control protocols at medical facilities, for example visitor restrictions and reduced staff, added stress for parents who were already struggling to navigate their children's medical needs (Nicholas et al. 2022). Families of hospitalized children who were critically ill or at the end-of-life experienced additional stress due to limited visitors and social distancing measures (Nicholas et al. 2022). Many parents, especially fathers, expressed a lack of time to spend with their families due to work demands during lockdowns imposed as a response to the pandemic (Meral 2021). Working mothers juggled employment and increased domestic responsibilities compared to their male partners due to the absence of stable childcare and in-person schooling (Kirwin and Ettinger 2022).

The pandemic exacerbated existing disparities in health service access for children with disabilities. Caregivers with lower educational attainment, those working part-time, single parents, and families with lower income were less likely to receive telehealth and clinical support services for their children (Gonzalez 2022). Parents of children with disabilities took on additional roles during the pandemic, serving as their child's educator, therapist, and social skills coach, often with limited support from professionals. The prolonged pandemic and repeated cycles of school closures and social distancing measures added to caregivers' suffering, with mothers and other female caregivers bearing most of the added caregiving burden (Lim et al. 2021).

Caregivers of children with disabilities reported higher levels of stress compared to parents with abled children pre-pandemic (Lim et al. 2021). During the pandemic nearly 40 per cent of youth

with disabilities and their caregivers perceived their days as quite stressful or extremely stressful, which is twice the rate reported by the general population pre-pandemic (Valderrama 2022). This included higher levels of anxiety, depression, and health problems, particularly among those caring for children with developmental disabilities including autism spectrum disorder and attention deficit hyperactivity disorder (Lim et al. 2021).

### Knowledge Gaps

The impact of the pandemic on children and youth with disabilities helps identify several crucial policy knowledge gaps that need to be addressed. These gaps include the urgent need for policies that consider intersectional vulnerabilities, acknowledging the unique challenges experienced by disabled people with multiple marginalized identities. More research is needed to learn how to mitigate disruptions in school-based routines for children with disabilities, particularly during crises. Technology's impact on this knowledge gap must also be explored further. Additionally, there remains a gap in how essential services are established and to what extent children and youth with disabilities are considered during the process.

Moreover, the gap between the adverse physical and mental health outcomes children with disabilities faced during the pandemic and how policy can reduce these impacts remains under-explored. Policies were created during the pandemic that led to social isolation, especially for youth with disabilities; however, policymaking facilitating socialization during crises must also be investigated. Economic challenges require targeted policies to address the socioeconomic hardships faced by children and youth with disabilities must be explored further. Additionally, caregivers of children with disabilities experienced substantial stress throughout the pandemic. Exploring how policy measures can be employed to study and mitigate this stress is crucial. Ultimately, more research is required to address these policy knowledge gaps.

### Disability Policy and the Pandemic

There is a lack of disability-inclusive policy and legislation implemented in Alberta to navigate the impact of the COVID-19 pandemic on children and youth. Families reported feeling forgotten during this pandemic. For example, when personal protective equipment (PPE) was given to frontline workers, caregivers reported that safety concerns for the children and youth they provided care to were not addressed. Early COVID-19 policies in hospitals mandated that patients went into appointments alone, meaning people with developmental disabilities couldn't bring a support person to help them communicate and understand what was happening (Nicholas et al. 2022). Additionally, children and youth with disabilities were not prioritized when the vaccine rollout began. Some people with developmental disabilities were not able to properly wear a mask or physically distance, making them more vulnerable during the global pandemic.

Co-designing policy with people with disabilities was not a priority during the pandemic. People with disabilities were not consulted during many key policy shifts, such as when public health measures were implemented. Moving forward it is imperative to recognize the importance of inclusivity and collaboration in policy development, placing persons with disabilities at the center of decision-making processes. People with disabilities are the experts of their lives and their experiences, and this expertise must be respected. One way of including people with disabilities is ensuring that government guidelines, resources, and mandates are made available in multiple

formats (e.g., braille, sign language, easy-to-read materials) to ensure accessibility for all individuals in future pandemics (Yates and Dickinson 2021). Embracing this will pave the way for a more equitable, resilient, and compassionate decision-making framework that leaves no one behind. The pandemic has exposed existing gaps in disability-inclusive policies and created a policy window to close them. As we move towards pandemic recovery, we can take the lessons learned from the pandemic and incorporate them into the future creation of disability-inclusive policies for children and youth with disabilities.

## Methods

### Literature Review

The systematic literature search aimed to investigate the effects of the Covid-19 pandemic on children and youth with disabilities. The search was conducted in the MEDLINE(OVID) database using the keywords "Disability AND Children AND Covid-19", leading to an initial yield of 365 results. After the keyword-based search, 14 records were eliminated through digital filters built into the database. These filters followed exclusion criteria determined by the author, which were: non-English language, no abstract included, and publication before 2010. Following this initial filtering, 279 results were further excluded after manual review of titles and abstracts for relevancy to the research question. The remaining 63 results were reviewed in their entirety for adherence to the inclusion criteria. Search results were included if they specifically addressed the concrete impacts of the COVID-19 pandemic on disabled children and youth. This resulted in the identification of 25 journal articles that were considered relevant and informative for the project. A PRISMA chart of the literature review process is included below.

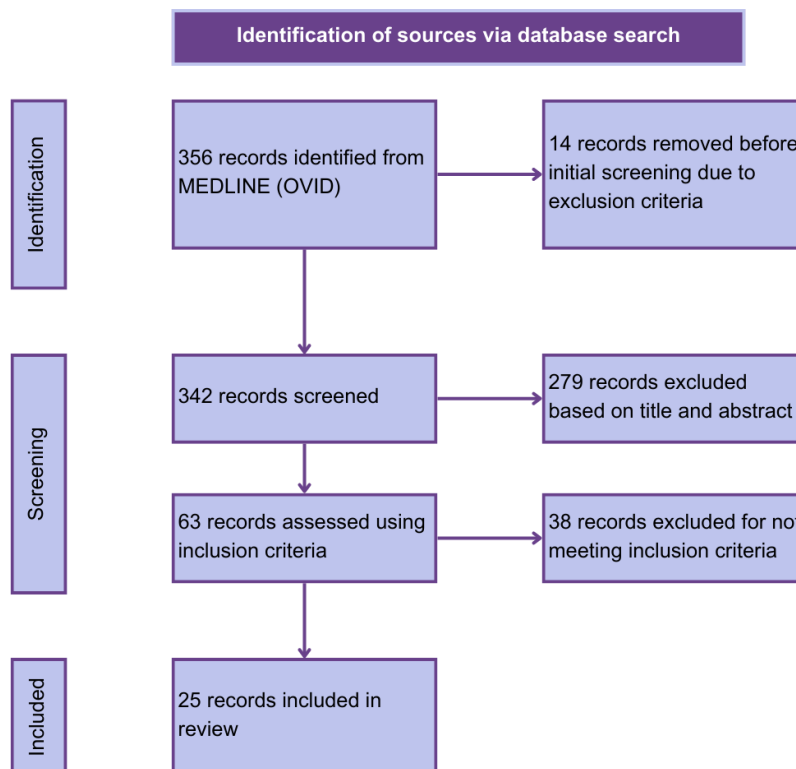


Figure 1 – PRISMA chart of literature search results.

However, it is important to acknowledge a limitation in this literature review process which is that the results were only screened by a single reviewer due to time constraints. Because of this limitation there is a higher chance that the results included in the analysis are biased in some way, relevant studies may have been overlooked, and there were no checks for human error. Additionally, the absence of collaborative discussions around the inclusion and exclusion of texts based on criteria set before the search could further impact the comprehensiveness and reliability of the review. To improve future studies in this area, it is advisable to introduce more independent reviewers and facilitate collaborative discussions on which search results to include.

## Study Design

This study had three phases: A recruitment phase, preparation phase and focus group phase.

### Recruitment Phase

In the recruitment phase, we assessed participants' eligibility through online recruitment surveys. A copy of the survey questions is available in the Appendix.

People with disabilities or those who had provided care to people with disabilities were recruited using two methods: the snowball approach and the purposive approach (Plinkas et al. 2013). The snowball approach consists of sharing recruitment materials with the entire research team for them to then share to their networks. The purposive approach consists of reaching out to specific non-governmental organizations (NGOs) and participants from previous research studies to get their support with recruitment.

The research team leveraged existing contacts as well as our network of researchers based across Canada. Youth with disabilities and parents of youth with disabilities that have previously participated in research with our team were also contacted to complete the recruitment survey.

Qualtrics and REDCAP were used to administer this survey. REDCAP was used until the team switched to Qualtrics to accommodate accessibility concerns. The survey was used to collect sociodemographic information as well as to assess participants' familiarity with disability policy and their experience discussing policy solutions. This helped us determine whether we needed to provide additional background information to the participants to ensure that background knowledge was as levelled as possible across participants.

We assigned a neutral, non-identifying ID number to each participant. This ID number was used across study phases to ensure anonymity during analysis. A master list linking the code and identifiable information was kept separate from the research data. All data for this study was stored either on the REDCap or Qualtrics platforms, as well as secure servers at the University of Calgary.

Online polling software "whenisgood" was used to find a date and time for the focus group that worked for all participants. The focus group was held through Zoom video conferencing software. The Zoom meeting had a call-in option for those with limited access to the Internet. The focus group was 90 minutes in duration and recorded to facilitate the analysis process after the focus group concluded.

### Preparation Phase

A trained, independent facilitator was hired to moderate the focus group using a modified Nominal Group Technique (NGT) process. NGT is a stepwise consensus-building democratic



process to develop a list of collective priorities and was chosen for several reasons. First, it is an effective collaborative method that provides the group with a structured brainstorming model that encourages every member of the group to contribute. Second, this method is designed to offer each member the ability to equally contribute to group discussions. Equal participation was critical for this study, as it leverages expertise from a diverse group of stakeholders that have a potential power imbalance. Third, NGT has advantages over other group techniques by mitigating the dominance of more vocal or more powerful group members. NGT is also efficient in that it uses few resources in a short period of time to collect a significant amount of information from participants.

Our team completed a previous comprehensive study from 2020 to 2022 that focused on the experiences of people with disabilities during the COVID-19 pandemic. This study was conducted by McGill University and the University of Calgary, each with their own coordinating research goal. The team at McGill University analyzed policy documents related to COVID-19 to assess the inclusion of people with disabilities and revealed that there was extremely limited consideration of their needs. The team at the University of Calgary conducted interviews with parents, caregivers, and people with disabilities to understand the pandemic's impact on their daily lives, their ability to access services, their mental health, and their education. Based on the combined results of this study, we formulated 12 disability-inclusive policy that were deemed vital for inclusive policy development. The goal of the recommendations is to enhance the lives of youth with disabilities and their families in Canada. They propose flexible disability programs and healthcare services, recognizing disability services as essential for continuous access. Additionally, the recommendations suggest reducing reliance on the education system for services, promoting inclusive education, providing economic support for caregivers, improving mental health services, fostering community accessibility, involving stakeholders in policymaking, and ensuring inclusive public communication, especially during emergencies. Recommendations generated based on findings from this previous study were presented to participants in this study for discussion. We also provided background material on policy and policymaking, and the link to the Zoom meeting.

### Focus Group Phase

We allotted ten minutes for introductions, 75 minutes for the modified NGT, and five minutes at the end to wrap-up and provide information about the next steps. The NGT steps include Silent Generation, Round Robin, Review, Clarification, and Ranking. An additional discussion step was added at the end, modifying the traditional NGT process.

During the Silent Generation step, participants engaged in a Zoom meeting where the facilitator shared the policy recommendations on Microsoft PowerPoint, labelled with a letter for clarity and in no particular order. Participants were prompted with the central question: "How can we use the lessons we have learned from the COVID-19 pandemic to move forward and create policy that is more disability inclusive?" Participants were encouraged to identify any missing recommendations from the list displayed on the screen and were given five minutes to silently note down their ideas.

The Round Robin step involved participants sharing their ideas one by one, and each contribution was recorded. During this step, participants were not allowed to interrupt somebody

else’s turn to discuss, ask questions, or comment. Their task was to provide unique ideas that had not been mentioned before or to offer a different perspective on the existing ideas. Members of the research team present for the focus group recorded the new ideas, which were added to the PowerPoint in real-time by the facilitator.

During the review step, participants were given 3 to 5 minutes to thoroughly examine the list of recommendations. They were instructed to use the Zoom chat to express any recommendation number that did not resonate with them. The clarification stage was next, when participants engaged in discussions to further elaborate on the ideas they had discussed. They also addressed any items on the list where they may have had differing opinions (as identified in Step 3). Participants also determined the relative importance of the various recommendations during this step.

After this came the ranking phase, where participants used an online voting tool called the Condorcet Internet Voting Service. In this step participants ranked all 12 policy recommendations by priority, with 1 being the highest priority and 12 being the lowest. To conclude the focus group, there was a discussion where participants were asked to share their thoughts about the final rankings and the next steps.

At the end of the focus group, all participants were thanked for their participation and received a \$50 e-gift card using the University of Calgary EverythingCard System as an honorarium for their time. They were invited to reach out to the research team with any questions or concerns that may arise after the focus group concluded.

## Study Population

### Selection Criteria

Each focus group included participants from each of the following three categories: youth with disabilities, parents and/or caregivers of youth with disabilities and NGO stakeholders. Inclusion criteria for each of the three categories is described in Table 1.

<b>Youth with disabilities</b>	<ul style="list-style-type: none"> <li>○ Language spoken: English.</li> <li>○ Age: 18-30 years (inclusive)</li> <li>○ Diagnosis: Any physical, intellectual/neurodevelopmental, vision, or hearing impairment/disability or mental health condition</li> <li>○ Lived in Canada for the duration of the COVID-19 pandemic.</li> <li>○ Note – only individuals with the capacity to consent were included.</li> </ul>
<b>Parents &amp; Caregivers of youth with disabilities</b>	<ul style="list-style-type: none"> <li>○ Language spoken: English.</li> <li>○ Age of youth with disability: 0-30 years (inclusive)</li> <li>○ Diagnosis of youth: Any physical, intellectual/neurodevelopmental, vision, or hearing impairment/disability or mental health condition</li> <li>○ Lived in Canada for the duration of the COVID-19 pandemic.</li> </ul>
<b>Community &amp; non-profit stakeholders</b>	<ul style="list-style-type: none"> <li>○ Language spoken: English.</li> <li>○ Currently working in at a community service provision or non-profit organization, has experience working at this type of organization during the COVID-19 pandemic</li> <li>○ Direct experience working or interacting with youth with disabilities during the COVID-19 pandemic.</li> <li>○ Lived in Canada for the duration of the COVID-19 pandemic.</li> </ul>

Table 1- Selection Criteria

The initial survey results were analyzed to make sure that respondents met the inclusion criteria. If they did not meet the language, age, diagnosis, or location criteria as outlined in the above table, they were excluded from the study. Additionally, the responses to each question were examined to ensure they were appropriately answered. The research team had to exclude certain respondents with inappropriate responses as they were identified as automated bots. After this, the responses that indicated participants had relevant policy experience were highlighted and those participants were prioritized to be contacted for the focus groups.

## Data Analysis

The video recording of the focus group was transcribed using Rev.com. After the transcript of the dialogue was generated, the text was anonymized by the team to ensure that participants' confidentiality was upheld. The transcript was then divided into the NGT steps outlined above, with the addition of the discussion and next steps stage also discussed above. After this division, the dialogue from each step was carefully read and reviewed. Direct quotes and excerpts were taken from the transcripts to be used to faithfully illustrate participants' perspectives and recommendations.

## Results

Five participants ultimately joined the virtual focus group on the scheduled date. Of the attendees, one was a male youth (21 years old) who had diagnoses of autism, ADHD, and anxiety. Two were female parents and caregivers of 10-year-old children diagnosed with autism spectrum disorder and dyslexia respectively. The remaining two participants were female non-profit workers that advocated for and provided services to children and youth with disabilities.

Participant	Age	Age of child with disability	Gender	Community Size	Ethnicity
1	21	N/A	Male	Large urban (100,000 people or more)	Caucasian
2	N/A	10	Female	Small (1,000 to 29,999 people)	Caucasian
3	N/A	10	Female	Large urban (100,000 people or more)	Caucasian
4	N/A	N/A	Female	Large urban (100,000 people or more)	Caucasian
5	N/A	N/A	Female	Large urban (100,000 people or more)	Caucasian

Table 2 – Summary of participant demographics.

One moderator was present to actively guide the focus group and one research team member was present to inform participants about the study. Two additional research team members were present to observe the focus group and take notes with their cameras off and microphones muted.

During the Round Robin phase of the modified NGT process, all group members shared their top three and bottom three recommendations generated in the previous study. The resulting top five recommendations were A, C, B, K, H, and D. (as shown below).

<b>Recommendations 1 through 5</b>	A: Implement a flexible design for disability programs and healthcare services, prioritizing a patient-centric approach
	C: Reduce reliance on the education system to provide all types of services
	B: Recognize disability services as essential services to ensure continuous access
	K: Co-design policy with relevant stakeholders, including individuals with disabilities and their families, service providers and community organizations
	H: Adopt widespread specialized childcare, workplace accommodation, and job protection policies for working parents of youth with disabilities
<b>Recommendations 6 through 10</b>	D: Adopt individualized educational plans for students with disabilities
	F: Implement flexible approaches to teaching and learning in all education systems to ensure youth with disabilities are able to learn in a way that aligns with their needs
	G: Design fair and sustainable economic supports for parents/caregivers of youth with disabilities
	I: Increase access to affordable and inclusive mental health supports for youth with disabilities and their families
	J: Promote accessibility and inclusion in the community as a means of mental health promotion for youth with disabilities
<b>Recommendations 11 and 12</b>	E: Ensure education systems have plans in place to support rapid and inclusive adaptations during future emergencies
	L: Promote inclusivity in public communication and public education initiatives

Table 3 – Rankings after the “round robin” stage.

Participants were then encouraged to elaborate on ideas that they may not agree with. They were encouraged to question the rankings and suggest any changes.

One participant justified their choice of having recommendation C as their top choice by stating “if things aren’t covered by government, then like, if something’s not covered by the education system, then does it fall to the nonprofit sector where we are underfunded and overworked?” Another participant agreed saying “I think it’s not fair to have the school side responsible for like what the healthcare sector should be doing.”

The youth participant advocated to prioritize recommendations B, I, and K, which would increase access to affordable support services that are co-designed with stakeholders who recognize disability services as essential. “Okay so, integrating health and education together

would be very beneficial cause it's always at-risk getting cuts 'cause it's so expensive. I know like even at the end of the school year, there were some students trying to run a petition to make sure that it didn't get shut down the next year type of thing. So, it was just kind of a constant concern, worry of everyone there.”

One NGO representative advocated for recommendation G based on their work experience: “My field of work is in social work and I tend to work with a lot of folks with financial barriers and a lot of financial vulnerability. And it had been my experience supporting folks that one of the biggest barriers they faced was a wealth disparity. And so, for, for me making sure that designing fair and sustainable economic supports for parents and caregivers with disabilities I think is really important.”

As a result, changes were made. Recommendation G moved up to the top 5 list and H moved down from the top 5. Recommendation L moved up from the bottom 2 and F moved down to the bottom 2.

<b>Recommendations 1 through 5</b>	A: Implement a flexible design for disability programs and healthcare services, prioritizing a patient-centric approach
	G: Design fair and sustainable economic supports for parents/caregivers of youth with disabilities
	C: Reduce reliance on the education system to provide all types of services
	B: Recognize disability services as essential services to ensure continuous access
	K: Co-design policy with relevant stakeholders, including individuals with disabilities and their families, service providers and community organizations
<b>Recommendations 6 through 10</b>	D: Adopt individualized educational plans for students with disabilities
	H: Adopt widespread specialized childcare, workplace accommodation, and job protection policies for working parents of youth with disabilities
	I: Increase access to affordable and inclusive mental health supports for youth with disabilities and their families
	J: Promote accessibility and inclusion in the community as a means of mental health promotion for youth with disabilities
	L: Promote inclusivity in public communication and public education initiatives
<b>Recommendations 11 and 12</b>	E: Ensure education systems have plans in place to support rapid and inclusive adaptations during future emergencies
	F: Implement flexible approaches to teaching and learning in all education systems to ensure youth with disabilities are able to learn in a way that aligns with their needs

Table 4 – Rankings after the “clarification” stage.

Finally, participants were sent a confidential link where they ranked all the recommendations with 1 being their most preferred and 12 being their least preferred. The recommendations are listed in ranked order below.

1.	B: Recognize disability services as essential services to ensure continuous access
2.	G: Design fair and sustainable economic supports for parents/caregivers of youth with disabilities
3.	K: Co-design policy with relevant stakeholders, including individuals with disabilities and their families, service providers and community organizations
4.	A: Implement a flexible design for disability programs and healthcare services, prioritizing a patient-centric approach
5.	C: Reduce reliance on the education system to provide all types of services
6.	H: Adopt widespread specialized childcare, workplace accommodation, and job protection policies for working parents of youth with disabilities
7.	I: Increase access to affordable and inclusive mental health supports for youth with disabilities and their families
8.	J: Promote accessibility and inclusion in the community as a means of mental health promotion for youth with disabilities
9.	F: Implement flexible approaches to teaching and learning in all education systems to ensure youth with disabilities are able to learn in a way that aligns with their needs
10.	L: Promote inclusivity in public communication and public education initiatives
11.	E: Ensure education systems have plans in place to support rapid and inclusive adaptations during future emergencies
12.	D: Adopt individualized educational plans for students with disabilities

Table 5 – Final ranking of policy recommendations.

**Recommendation B** was ranked highest. The COVID-19 pandemic revealed what services Alberta considers to be essential - disability services were not included. Focus group participants identified this recommendation as the top priority. A youth participant emphasized their high opinion of this option. *“B had stood out to me, the one that was talking about making disability essential. My school was not protected in the first place, so they can just remove it at any point and there's no consequences to it. So, it kind of opened my eyes just to how much there's lacking in disability protection.”*

A parent echoed this sentiment and expressed the opinion that not prioritizing recommendation B during the pandemic negatively impacted her children. *“Their socialization has been stunted in the way that they don't know any better because it's something that they didn't have the opportunity to get to adulthood to understand what's normal and not. So, combine that with*

*having a special disability and not have any external introduction of to balance out what they're seeing from their parents.”*

**Recommendation G** was ranked second. *“When the education system fails, like it did for so many families and students, where in the community can people go to next? Some people were able to jump over and have their needs met and others were isolated, and they really suffered some serious consequences.”*

**Recommendation K** was ranked third. A parent in the focus group emphasized the importance of this recommendation: *“Nothing about us, nothing for us, without us, has to be in policymaking.”* Another participant agreed, stating: *“Codesign is so essential in making policies in the first place.”*

**Recommendation A** was ranked fourth. One participant explained. *“For me, A is the winner Okay. Patient centric or a person first approach? We don't see a person for their disability to see who they are. It's, it's making sure that we have person, like people first approaches when you're making policy.”*

**Recommendation C** was ranked fifth. Participants discussed how school closures during the pandemic helped them come realize that the education system should not be relied on to provide all key services for their children. *“When I had finally found a school, a public school could accommodate me in the way I needed, I had found out that it could be shut down at any time, just due to budgeting in the first place 'cause it's not a cheap program to run. It's run by the school, not the healthcare sector.”*

Parents discussed how reducing reliance on the education system would make them more resilient when access to education system was compromised, such as how schools closed during the pandemic. Another parent shared their concern about reliance on the school system for disability support services, stating that it would make the transition difficult for their child as they age out of the school system. *“All of those community connections that he made are, are basically severed from a school perspective once he graduates and now, he goes he's busted out of our community. And then he'll just, my fear is he'll slip through the cracks and as I age and my husband ages and you know, maybe he has less and less family as time goes on and he goes into further into adulthood who's going to support him anymore.”*

One proposal made by parents and NGO participants was to advocate for the creation of a Disability Services ministry in the province. *“Being able to diversify the reliance on one ministry in order to provide the services because that would delineate the, the, the risk for this to happen again”.* Another parent said, *“We need adopt these concerns into a different ministry that can provide a suite of stuff instead of having the silos where there's a chain link that breaks and you may never know where to you can hook back on”.* This would reduce the burden faced by the education ministry when creating policies and making decisions that will have disproportionate effects on children and youth with disabilities. *“When we have strong inclusion policies, all Canadians benefit from that.”*

Almost all of the recommendations were consistent with the group ranking after the discussion stage except for recommendation, D which was ranked twelfth in the anonymous final ranking but was placed in the top 5 in the group discussion.

Another recommendation that was made throughout the focus group but not included in the list of recommendations participants ranked was to educate and equip people without disabilities on how they can be inclusive and support those with disabilities. *“I don't think, oh, the vast majority of people out there realize just how much is wrong with the system currently so having that public awareness of it will definitely help drive change on the policy and government level.”* Other participants agreed and proposed mandatory disability and neurodiversity training for community members such as employers. Another participant emphasized that educating abled people on disabilities will help create an inclusive environment for everyone. *“We have to integrate sort of educating people about disability even if they don't have that personal attachment or motivation to do it. Because I think that that sort of stems and branches into all of these other areas that will be better supported if sort of our whole society gets on board.”*

By educating and training abled people on what disabilities people face and how to become inclusive allies, one participant expressed that it would create a safer environment for people with disabilities to become more active participants in society. *“A lot of people that have disabilities you don't see it much out there in day-to-day life. And a lot of that is just due to lack of accessibility. So, when that accessibility actually comes into the picture and more and more, more people will be able to get outta their house more and be able to contribute back to society.”*

Participants were asked for their reactions to the ratings that were adjusted after discussion as well as their thoughts on any next steps. Overall, all participants were content with the top 5 selected. One parent shared how they initially prioritized investing in the education system when picking their top recommendations, but their perspective changed after discussing with the group. *“I was surprised when I read the recommendation to reduce reliance on educational systems to provide all types of service. I think the reason I put it as not a priority was because I thought we could really put a lot of investment into the education system to create like a hub for all the types of services children need. But then in this conversation, my thoughts shifted a little bit that, that perhaps it's not the right system for that responsibility. So, I am surprised, but like in a good way, and I can definitely live with these top five.”*

Another participant expressed disappointment that recommendation J was not in the top 5. *“I do think perhaps that promoting accessibility and inclusion in the community and as means a mental health promotion should be ranked just a bit higher just because for long-term and even when they're young too.”*

The youth participant believed recommendation K should be ranked higher. *“I just personally think that k the co-design policy should maybe be second just 'cause it's so essential in making these policies in the first place.” but yeah, apart from that I'm pretty happy with it.”.*

## Discussion and Implications

The focus group discussion identified the top five disability inclusive policy recommendations.

Based on the focus group discussion, participants' top 5 disability-inclusive policy recommendations were identified in the following order:



## 1. Recognize disability services as essential services to ensure continuous access.

There have been 83 ministerial orders issued in Alberta in response to the COVID-19 pandemic. Of the 83 orders issued, only 8 somewhat addressed adults with disabilities, and none mentioned children or youth with disabilities. 5 orders were made by the Minister of Children's Services to modify or suspend the application of the Child Care Licensing Act (CCLA) to enforce stricter regulatory requirements for childcare programs. There was no mention of the children with disabilities who attended these programs. Stricter requirements for childcare programs during the pandemic included: social distancing, masking, and getting immunized. Many children with disabilities do not have the ability to socially distance themselves from their support staff (Fontanesi et al. 2020). They require assistance with activities such as eating, walking, and using the bathroom. When classes transitioned back to in-person delivery with restrictions, many children could not attend as their disability did not enable them to wear masks. Children with neurodevelopmental disabilities who could wear a mask struggled to recognize classmates and interpret their peers' emotions (Toseeb et al. 2020). Many students with disabilities are also immunocompromised and cannot risk being infected. During the pandemic these children were not eligible for the vaccine at the same time as their peers, which prevented them from attending in-person school (Balduzzi et al 2021).

182 Public Health Orders were issued during the COVID-19 pandemic in addition to the orders listed above none of which addressed children or youth with disabilities. Chief Medical Officer of Health (CMOH) Order 04 - 2020 allowed essential workers access to childcare. However only the director of the Childcare Licensing Act had the authority to determine which childcare programs were allowed to operate under this order. No legislation was implemented to ensure that childcare for children with disabilities was offered. Essential workers who had children with disabilities were not guaranteed care that met their child's specialized needs. Spots were limited in the programs that did cater to the needs of disabled and neurodiverse children (Aishworiya et al. 2021). Many essential workers reduced their hours or exited the labour force entirely to care for their children (Masi et al.2021).

Recognizing that disability-specific services are essential will not only ensure continuous access to these services during future emergencies but will also help governments to prioritize people with disabilities when important decisions are made.

## 2. Design fair and sustainable economic supports for parents/caregivers of youth with disabilities.

Students from low-income households are more likely to receive inaccurate diagnoses and are subsequently more likely to be placed in classroom settings separate from other students (Aylward, Gal-Szabo and Tataman 2021). Additionally, low-income families with disabled children and youth are often unable to access support services not paid for by the government or the public education system (Gonzalez et al. 2022). Services such as specialized childcare are often privately funded and are unaffordable for low-income families. These families are often faced with the challenging decision of one parent leaving the workforce altogether to become full-time caregivers for their children, which decreases household income.

Designing fair and sustainable economic supports for parents and caregivers of youth with disabilities is important to ensure the needs of their children is met. Increasing funding to key

areas such as support services, specialized equipment, comprehensive childcare, and flexible employment policies will help alleviate the financial strain that parents and caregivers face. Support services can provide essential assistance, guidance, and training, enabling parents to better care for their children with disabilities. Specialized equipment which can be cost-prohibitive is critical for improving the mobility and quality of life of children with disabilities (Allison and Levac 2022). Comprehensive childcare options tailored to the unique needs of children with disabilities are essential in providing a safe and nurturing environment. Increasing specialized childcare services will enable parents and caregivers to pursue employment and other commitments (Zhang, Sauval, and Jenkins 2023). Flexible employment policies offer necessary work-life balance, enabling caregivers to fulfill their parental responsibilities without sacrificing their livelihoods.

### 3. Co-design policy with relevant stakeholders, including individuals with disabilities and their families, service providers, and community organizations.

Co-designing policy alongside relevant stakeholders was identified as the third most important recommendation. Co-design and consultation are two different approaches to involving stakeholders in decision-making. Consultation is a process of seeking input from stakeholders to understand their perspectives, but decisions are made by a separate group (Purple Orange 2021). Co-design is more collaborative and actively involves stakeholders in shaping policies to achieve inclusive and effective outcomes (D’Cruz et al. 2022). Co-design could involve inviting children and youth with disabilities and their parents as participants, not just observers, at policy-making discussions. It could also involve workshops, meetings, focus groups, or collaborative sessions where stakeholders brainstorm ideas, share insights, and collectively problem-solve. The co-design process will also ensure accessibility is built into the proposed policy. For example, materials being debated and discussed will need to be in an accessible format suitable for use by those with visual or hearing impairments.

### 4. Implement a flexible design for disability programs and healthcare services, prioritizing a patient-centric approach.

This policy recommendation supports creating disability and healthcare services that cater to the individual needs and preferences of children and youth with disabilities. In person-centered care relationships, the person is at the center of communication, planning, and decisions regarding their care (Ryan 2021). This might require additional time and supports to meet individual needs. For children under 18 years old who are legally unable to make their own medical decisions, their parents would help facilitate this care relationship. Central to this approach is performing comprehensive assessments that consider the person's physical, emotional, social, and developmental needs (Ryan 2021). Instead of solely targeting specific medical issues, healthcare professionals work together with the individual and their family to craft thorough care plans encompassing all aspects of their life. This would include collaboration with educational institutions, social services, and related service providers. Promoting effective communication is crucial in patient-centered care, especially for children and youth with disabilities who communicate in non-traditional ways such as with sign language or AAC devices (Kwame and Petrucka 2021). Additionally, allowing for flexible appointment scheduling and durations acknowledges that individuals with disabilities often need more time and assistance. This could mean extended time slots for appointments and follow-up consultations

to ensure thorough addressing of concerns. A relaxed atmosphere can further reduce anxiety and enhance productive communication.

## 5. Reduce reliance on the education system to provide all types of services.

This recommendation highlights the importance of reducing reliance on the education system to provide the disability services needed by children and youth with disabilities including speech-language, behavioural, physical, and cognitive therapies. Policymakers should focus on designing alternate, more sustainable models of service delivery to ensure their continuity and effectiveness over time. This could include exploring funding mechanisms, evaluating outcomes of current programs, and adapting strategies based on feedback from stakeholders. A significant recommendation put forth by parents and non-governmental organization (NGO) participants is the establishment of a dedicated Ministry of Disability Services within the province. The goal of this ministry is to alleviate the burden faced by the Ministry of Education to manage policy that supports children with disabilities. Distributing this burden to a specialized ministry would lead to more effective and equitable outcomes. Such a ministry could specialize in addressing the unique needs of people with disabilities by creating comprehensive and sustainable support systems.

Establishing mentorship programs and peer support networks outside of school can be instrumental in guiding students through their educational journey and their transition into adulthood. Peer support networks supervised by health and education professionals, including peers with and without disabilities, can provide a forum for sharing experiences, mutual encouragement, and skill development.

Additionally, the use of technology platforms can extend the reach of support services. Virtual therapy, mentorship programs, online skill-building workshops, and digital resources for self-directed learning can provide flexibility and accessibility, ensuring that children and youth have access to guidance and resources even when faced with disruptions.

Partnering with local businesses can also create mutually beneficial opportunities. Businesses can offer internships, apprenticeships, and job-shadowing experiences, allowing students with disabilities to gain hands-on experience in various industries. These partnerships not only enhance students' career readiness but also foster a sense of community involvement.

## Limitations

The study, while valuable in obtaining disability inclusive policy recommendations from relevant stakeholders, did have its limitations.

First, the sample size in the focus groups was small, limiting the generalizability of the results. Although the NGT technique works best in a group of 6 to 8 people, only 5 people took part in this study's focus group.

Additionally, the gender distribution among participants was imbalanced, with a higher representation of females than males. This discrepancy may have influenced the diversity of perspectives shared during the discussions. However, the higher participation females in the study was consistent with the higher proportion of females who completed the screening survey. None of the participants indicated that they identified as transgender or LGBTQ+, which further limits the diversity of perspectives shared.

Finally, only one youth with a disability over the age of 18 participated in the focus group. While two other parents shared experiences of their children, they were advocating on behalf of their children and may not have accurately represented their children's lived experiences.

Despite these limitations the study still offers valuable qualitative insights, providing a contextual understanding of the participants' viewpoints and experiences within the studied group.

It is also important to note that researchers will still view things through a lens of their own experiences and their own social location. While the study methodology attempted to reduce researcher bias, it is impossible to fully account for all implicit bias.

## Conclusion

Analysis of the focus group revealed valuable insights into disability-inclusive policy recommendations. The focus group participants engaged in the modified NGT process, offering their perspectives and preferences on various recommendations. Recognizing disability services as essential, designing fair economic supports for caregivers, co-designing policies with stakeholders, and adopting a patient-centric approach to disability programs and healthcare were among the top-ranked recommendations. The discussions also highlighted the need for public awareness and training on disabilities to foster inclusivity and support for individuals with disabilities. Despite some limitations in the study, the qualitative insights gathered contribute to a deeper understanding of the stakeholders' viewpoints and experiences regarding disability-inclusive policies. These findings can guide future policy development and decision-making to better support and meet the needs of individuals with disabilities and their families.

## Appendix: Survey Questions

1. Full Name:
2. Email:
3. Phone Number:
4. Preferred method of communication
  - a. Phone
  - b. Email
5. Pronouns (for example: she/her, they/them, he/him, etc.):
6. Which of the following describes you? Please check all that apply.
  - a. Youth with a disability or mental health diagnosis
  - b. Parent/caregiver of a youth with a disability or mental health diagnosis
  - c. Individuals from non-profit and community organizations with experience providing services to or working with youth with disabilities during the COVID-19 pandemic.
  - d. None of the above  If this is selected, participants will see the following message: "Unfortunately, based on your response, you are not eligible for our study. Thank you again for your interest."

### IF A IN Q4

7. Are you between the ages of 18 and 30 years (inclusive)?
  - a. Yes
  - b. No  If this is selected, participants will see the following message:  
"Unfortunately, based on your response, you are not eligible for our study. Thank you again for your interest."
8. What age are you?
9. What disability or mental health diagnosis/diagnoses have you received?

### IF B IN Q4

5. Is the child under your care under the age of 31 years?
  - a. Yes

- b. No  If this is selected, participants will see the following message:  
“Unfortunately, based on your response, you are not eligible for our study. Thank you again for your interest.”

- 6. What age is your child?
- 7. What disability or mental health diagnosis/diagnoses has the child in your care received?
- 8. How would you describe your relationship to youth with a disability in your care?  
(Examples include parent, grandparent, aunt/uncle, etc.)

IF C IN Q4

- 5. Which of the following best describes you?
  - a. Service provider
  - b. Representative from a non-profit or charity organization
  - c. Representative from a community organization
  - d. Other: \_\_\_\_\_
- 6. What is your job title?
- 7. How many years of experience do you have in your current profession?
- 8. For which organization do you currently work? Please let us know if you worked for a different organization at any point during the COVID-19 pandemic.
- 9. Please briefly describe your experience with youth with disabilities and their families:

ALL PARTICIPANTS

- 10. In the focus groups, we will be discussing potential policy solutions for COVID-19 recovery and future emergency planning. **We ask that you please briefly share any previous policy or advocacy-related personal or professional experience that you may have.** This will help us to assess what kind of background information we will need to provide to ensure a productive discussion during the focus groups.
- 11. Which province or territory do you live in?
  - a. Alberta
  - b. British Columbia
  - c. Manitoba
  - d. Newfoundland and Labrador

- e. New Brunswick
- f. Nova Scotia
- g. Ontario
- h. Prince Edward Island
- i. Quebec
- j. Saskatchewan
- k. Northwest Territories
- l. Nunavut
- m. Yukon

12. Did you live in this province or territory for the duration of the COVID-19 pandemic?

- a. Yes
- b. No  If no, please explain:

13. What gender do you identify with?

- a. Male
- b. Female
- c. You do not have an option that applies to me. I identify as:
- d. Prefer not to answer

14. Which of the following best describes your community size?

- a. Rural (less than 1,000 people)
- b. Small (1,000 to 29,999 people)
- c. Medium (30,000 to 99,999 people)
- d. Large urban (100,000 people or more)
- e. Prefer not to answer

15. Please select the option that best aligns with your Indigenous identity:

- a. Non-Indigenous
- b. First Nations
- c. Metis
- d. Inuit
- e. Other: \_\_\_\_\_
- f. Prefer not to answer

16. If selected to participate in the focus group, do you have any accessibility requirements we should know about? For example, do you need a sign language interpreter, captioning, etc.

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