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CEREBRAL PALSY ACROSS CANADA

Cerebral Palsy CANADA NETWORK

Survey Analysis Leading the Discussion Toward a National Strategy for Cerebral Palsy

Presented by
Cerebral Palsy
Canada Network &
Organizational
Partners

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Lead Organization

The Cerebral Palsy Canada Network is a national network of cerebral palsy associations, physicians, and researchers. The network acts as a resource for local organizations and community stakeholders and promotes partnerships to collaborate on addressing the issues facing persons with cerebral palsy and other disabilities. Current initiatives include the development of a communications resource hub, recreational and sports promotion, World CP Day, and regional stakeholder focus groups.

The network is actively working on the development of a National Strategy for cerebral palsy to ensure that all Canadians with cerebral palsy and their families have full and equitable access to the resources they need. A national cerebral palsy strategy should be a reflection of Canada's blueprint for the national autism strategy that features federal initiatives to support the community [19].

TRUSTED PARTNERS

The CP Canada Network survey was designed and developed with input and support from provincial CP organizations, researchers and network partners.

Specifically, we would like to thank Kids Brain Health Network, CanChild, ChildBright, McGill University, the University of Calgary and the University of Alberta for the efforts and support.

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FUNDERS

Making our work possible

The survey was funded in part by the Government of Canada.
The federal government recognizes a need to expand diagnostic capabilities and introduce new therapeutic options for those with Cerebral Palsy [20]. Researchers and partners aim to investigate and improve our understanding of brain development to provide health care professionals and caregivers with the information they need to support persons with cerebral palsy and their families.

The survey was also funded in part by Nestle Health Science Inc. Eating, feeding and swallowing services are vital for the health and wellbeing of persons with cerebral palsy. Nestle provides tube feeding products that are nutrition driven. Nestle's mission is to ensure the improvement and successful integration of tube feeding into the lives of families to make mealtime routines healthy, safe and easy. Nestle funded a follow-up interview session with 12 survey respondents to better understand the various quality of life impacts (see Appendix 3).

FORWARD

Over 75 000 Canadians have cerebral palsy (CP), and it is the most common physical disability in childhood. The number of people with the condition is expected to increase to more than 94 000 people by 2031.

Direct health care costs are a concern for those with CP. Direct annual costs in constant 2010 Canadian dollars were about $11 700 for children with CP aged 1-4 years compared to roughly $600 for those without the condition. In addition, people with CP often experience longer periods in poorer health-related quality of life. Persons with CP face challenges related to their ongoing need for specialized medical care and supportive services [1].

CP refers to a group of disorders in the development of motor control and posture, occurring due to a non-progressive impairment of the developing central nervous system. The motor disorders of CP can be accompanied by disturbances of sensation, cognition, communication, perception, and/or seizure disorder.

Motor disability can range from minimal to profound, depending on the individual. Side effects of CP can range from weakness in one hand to an almost complete lack of voluntary movement requiring 24-hour care [2].

While cerebral palsy is not curable, management of the side effects such as training and therapy can significantly improve functioning. Moreover, management often aids in children and adults gaining the ability to achieve their maximum potential in growth and development.

Although much stigma exists surrounding independence for persons with CP, they go to school, have jobs, get married, raise families and live in their own homes [3]. However, many people with CP face multiple and complex barriers to social and institutional inclusion due to lack of services, educational and job opportunities, limited research and funding, and stigma [4].

CP is a life-long disability. While those with CP and their families learn new ways to cope with and manage symptoms, many require long-term physical, psychological and emotional support. In fact, adults with CP often encounter new challenges; thus, receiving relevant and high-quality supports and management tools helps them increase their participation in all aspects of life. Currently, the complex and lifelong physical, medical, educational and social needs associated with CP are unmet in Canada. Relative to the condition's prevalence, CP is under-recognised within the political arena. Being under-recognized has led to significant negative implications for people with CP and their families in terms of social, health, and economic factors. For people with CP to develop and thrive, they must be provided with critical supports and opportunities [4].

“I have problems with access to services because of my combined intellectual disability and health issues. I have difficulty finding physicians willing or comfortable with treating me, (they) dismiss me as unworthy of the same access to care as others would receive”.

- *Respondent & Self Advocate*

EXECUTIVE SUMMARY

Aim & Objective of Leading the Discussion Toward a National Strategy

The vision of the Cerebral Palsy Canada Network, the contributing partners and the entire CP community is to live in a society where the entire CP community can enjoy a high quality of life. We envision a Canada that supports and empowers people with CP to control their own life choices by promoting changes that foster inclusion.

The mission of this report is to lead the discussion toward supporting a CP National Strategy that can improve the health, function, participation and quality of life of individuals with CP and their families. Our fundamental belief is that advocating for provisions of optimal health, disability support, inclusive research, and enhanced community knowledge will help achieve a more accessible Canada for the CP community. The overarching goal for disseminating the Canada Network survey was to gather quantitative and qualitative data to reflect the lived experiences of persons with CP and their family members and care providers. As such, the survey was delivered through an online platform to a representative sample size of 181 respondents. This sample represents some of the needs, opinions and priorities of people with CP and their families. However, a considerable focus of the report is to highlight the robust future research and analysis considerations for the diverse populations outside of the sample captured in the survey.

Method

The data collection method featured a survey where demographic and open-ended questions were asked to understand the participants' lived experiences. The 33-question survey was presented to the sample population in both French and English. The questions consisted of mostly check all that apply style questions, which helped develop variations in the responses and allow for comparisons between gathered data. Some survey participants chose to skip some of the questions, meaning that the number of respondents who answered each question is varied. To view the total respondents for each question, see the tables featured in appendices 1 and 2.

The survey was designed to capture two main groups: families/care providers and persons with CP. The survey was delivered through Survey Monkey, which allowed us to post the survey link on various social media platforms such as Twitter and Facebook. Question topics revolved around the participant's quality of life, overall health, access to services and demographic information such as gender, age, geographic area, type of community, and place of residence.

Using a mixed-methods approach, the survey data were analysed both quantitively and qualitatively. Specifically, the survey analysis was gathered by employing two research methodologies; firstly, a phenomenological research method was used to investigate the phenomena or life events of persons with CP and their families by describing and interpreting the participants' lived experiences. Secondly, the data were analysed using a thematic analysis approach to identify and interpret patterns and themes within the responses to find connections between the respondents lived experiences. Using both methods, three sections are highlight within the report:

- First, we analysed the survey respondents' access to services based on their self-identified demographic information. For example, we looked at the type of community persons with CP and their families reside concerning their access to services and found that both rural and urban communities have challenges when accessing supports. This theme helps support advocates to make specific recommendations around increasing supports for all communities.

- Then we analysed the linkage between quality-of-life self-reporting symptoms of CP amongst the survey respondents given their Motor type or severity of CP they experience. Quality-of-life outcomes linked to CP types is common knowledge amongst the CP community. However, it is a key consideration to highlight within the report. It provides education around how various types of CP contribute to the quality-of-life outcomes for individuals with CP, their families/care providers.

- In the final section of the report, we look at the respondents' research interests. Here, we utilize the concept of inclusive research, which steers away from research on people to research with people. By incorporating inclusive research, the data is analyzed examined within the broader context by bringing a clear picture into how research projects and partnerships are enacted.

> *"We are committed to an environment of dignity, integrity and respect. We put people first and promote diversity, independence and full citizenship"* – Cerebral Palsy Alberta.

Report Structure

Both the survey and report have been structured to garner an in-depth understanding of the nuances surrounding the quality of life for persons with CP and their families. The report has been structured in an inclusive manner and in collaboration to share the findings with institutions, government, advocates, and disability organizations who can promote awareness, acceptance, and understanding for persons with disabilities to live, learn, work, and play in the community. As such, the report highlights discussion points that can lead the way toward a National Strategy.

The survey data will be presented and explained through discussion and visual graphs by displaying the percentages of respondents who answered the survey based on their lived experiences. The data will be displayed in three sections that will highlight various phenomena (life events) and themes mentioned under methods. Additionally, the major themes were enriched by pulling in direct quotes from the survey respondents to expand on their valuable personal lived experiences.

Throughout the report, we discuss some of the limitations of the survey and data analysis while identifying the key considerations and recommendations for future analysis and research. The considerations and recommendations provide insight into the next steps toward a National Strategy that can be taken by the researchers, academics, disability organizations, self-advocates and the CP community as a whole.

Goals & Outcomes

The following goals and outcomes are actions that we would like to see taken as a result of the report's publication. Within the goals and outcomes, there are recommendations for future steps that we believe should be taken to ensure the realization of a CP National Strategy in Canada:

- **Lead the discussion toward a National Strategy for Cerebral Palsy.**
- **Increased knowledge and understanding of disability issues such as access to services in the represented provinces and territories.**
- **Increase effectiveness of programs and services delivered in all provinces and territories in Canada by leading the discussion toward a National Strategy.**
- **Increased partner and organizational capacity to serve and support people with CP and other disabilities in their communities.**
- **Identify barriers to collectively educate the community, government and individuals about CP, barriers to equality as well as inclusive research methods.**
- **Make recommendations for further analysis and research by pointing to opportunities for future analysis and next steps in areas that have been underserved and underrepresented.**
- **Begin to development of a strong and unified network of organizations, academics and self-advocates; and**
- **Additional long-term partnerships with the provincial and federal government in joint recognition that a National Strategy for persons with CP and families will be beneficial for the health and wellbeing of communities as such partnerships can start the dialogue around the necessary steps to mediate challenges.**

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SECTION **PAGES**

1.0
ACCESSIBILITY ANALYSIS

Unpacking the Survey Respondents' Access to Services

The survey garnered 181 respondents from across Canada. When analysing both streams of the survey, we looked at the percentage of respondents who were parents/care providers and adults with CP. We found that 74% of the overall respondents were parents/care providers of a child with CP, and 40% of that group have children between the ages of 5 and 17. Having lower adult persons with CP within the survey population group signals that the analysis has a greater focus on children's lived experiences and needs and families of children with CP. While highlighting the experiences and needs of families and those under the age of 18 is vital for beginning the conversation toward a National Strategy, future analysis and research within the Canadian landscape should consider focusing on the broad range of experiences of adults with CP.

Gender Considerations

Age, gender, language, culture, ethnicity and religion influence a population's health needs, health service usage and health outcomes [1,7]. Across the survey respondent group, there is a marginal difference between gender identity of the survey respondent groups as 47% are female, 49% male, 1% Transgender, with the remainder preferring not to answer. A major consideration to note is that conducting a gender-based analysis plus (GBA+) should be considered for future analysis. The government of Canada is planning a major initiative known as Accessibility Standards Canada made up of a board of individuals who will assess accessibly in various contexts across Canada; however, it does not plan to conduct GBA+ analysis [9]. Gender identity can impact a person's ability to access services, as such sexual health information. Therefore, a GBA+ analysis unpacking Canada's accessibility nuances and challenges must be assessed for those with CP and other persons with disabilities.

Geographic Location

The majority of respondents were from Ontario, Alberta and Saskatchewan, with a significant scarcity in the number of respondents from Quebec at 5%, despite the survey being distributed in both official languages. However, the response from the Atlantic provinces was significant as 24% of the survey population is dispersed across Newfound Land, New Brunswick and Nova Scotia. That said, 0% of the respondents reside in Prince Edward Island (PEI), a province known for having lower accessibility to disability services due to their population size [5]. Future research and analysis should consider recruiting the CP community within Quebec and PEI provinces to better understand the potential accessibility challenges they face.

The survey population had minimal respondents living in the province of Manitoba, with only 4%. Additionally, only 0.5% of the respondents were from Yukon, and the survey did not capture respondents from the Northwest Territories or Nunavut. Again, the lack of responses within these regions presents an opportunity for future analysis. Because the majority of respondents reside in Ontario, Alberta and Saskatchewan, we conclude that the analysis has reflected the life events of the CP communities living in those regions. To embark on a National Strategy for CP, a more rigorous collection of geographic, demographic information from all communities across Canada must be analysed to comprehend differing national complexities.

Comparing Urban & Rural Communities

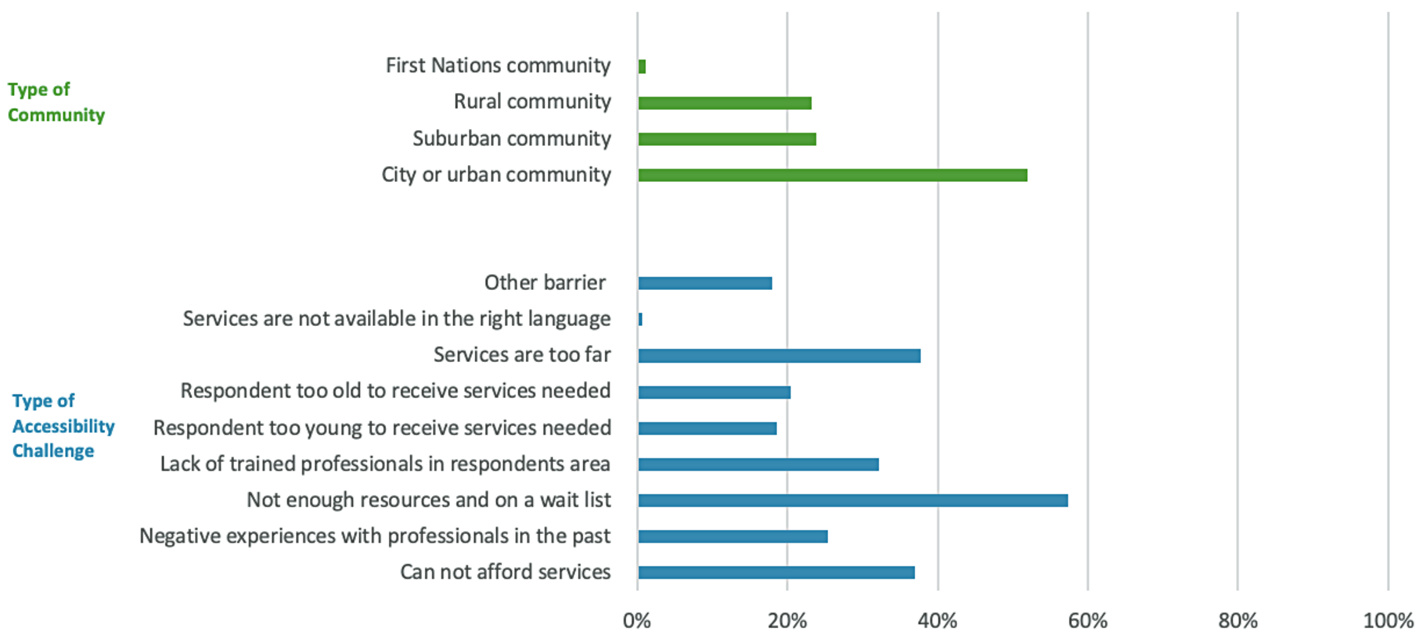
Both residents of rural and urban communities face accessibility challenges [6]. To understand challenges to accessing supports within the context of where people live, we analysed the survey questions related to accessibility and rural vs urban respondents. Conventional wisdom and research show that rural and remote areas have less equitable access to high-quality, evidence-based interventions and services than urban and suburban areas; this is true within other commonwealth countries such as Australia and New Zealand [4,6,7].

The survey data and analysis did highlight accessible equity concerns located in rural communities. For example, one survey respondent noted that “because we reside on a First Nation, our resources are almost nothing. And all services are over an hour away, at a minimum”. Factors like travel time, transportation costs, and population fluctuations can differ among rural communities, influencing a population’s needs, such as social and health services and outcomes. Although many rural communities face unique challenges, a high percentage of healthcare accessibility issues were flagged across both urban and rural communities.

When analysing the demographic data of the survey population sample concerning urban and rural dweller percentages and their accessibility to healthcare-related services, a theme arose, signalling that both communities face similar challenges. Of the survey population group, 76% of the respondents live in urban and suburban areas, whereas only 23% reside in rural communities. Overall, 65% of the respondents reported facing challenges when trying to access appropriate therapies and/or medications. Further, 57% reported facing challenges when trying to access speciality physicians/therapists. When explicitly asked about the barriers they face to accessing services, 57% of respondents reported that there are not enough resources. One respondent stated that they "can't find the service we need", with another explaining that "services are not available in our area". Another expressed that "services are not in our direct community".

Challenges to accessing disability services include barriers such as respondents not qualifying for services due to their age. Barriers noted across participant groups included having a lack of trained professionals and having past negative experiences with professionals. For example, one of the respondents stated that "Doctors blame everything on CP while not understanding it at all. My concerns are dismissed". The most common challenge experienced across respondent communities was that they simply did have access to resources (see Table.1)

Table 1 - Percentage of Respondents Facing Accessibility Challenges and Types of Communities



The challenges faced by urban and rural communities alike conclude that the type of community where persons with CP and their families live may not be a large factor in their ability to access relevant and critical services. Overall, healthcare accessibility is traditionally limited in rural and remote areas, especially in First Nation communities; however, the data underlines that urban and rural dwellers struggle to access equitable, high-quality supports and services.

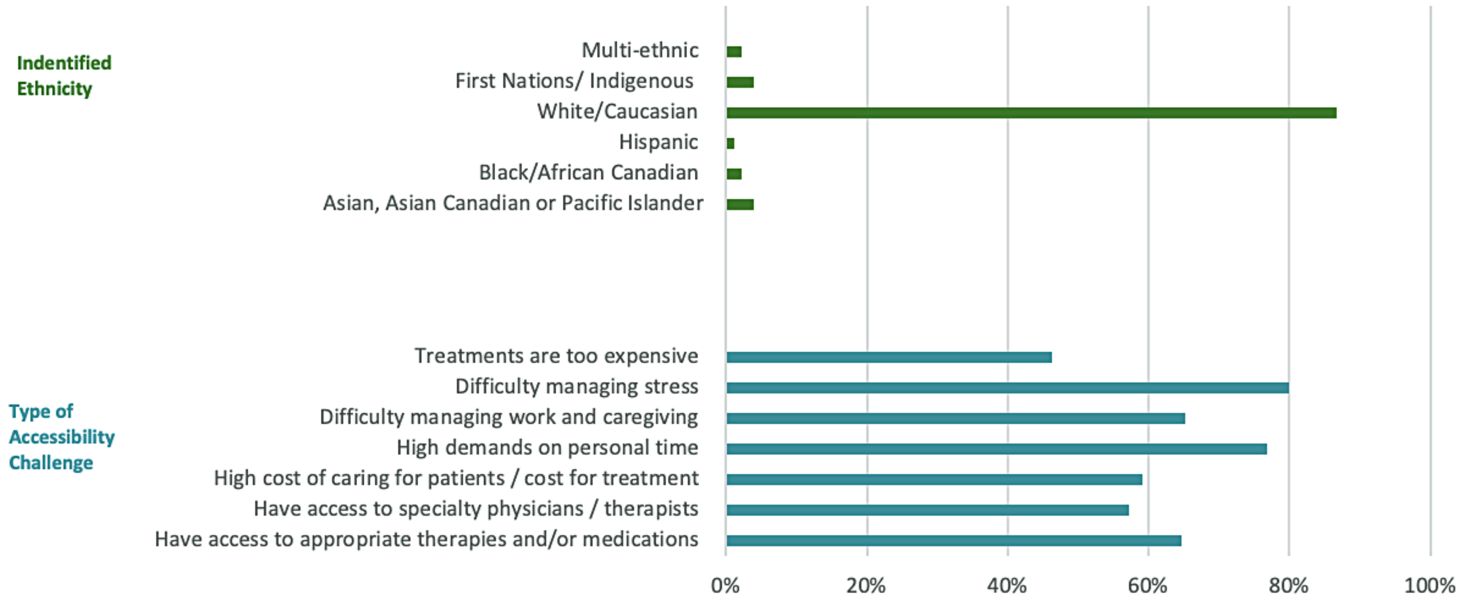
The high percentage of survey respondents living in urban centres provides critical insight into their overall experiences; that being said, having fewer online survey respondents from rural areas points out that rural communities may have less access to the internet or technology or that they may not be as connected with the disability organization as compared to urban dwellers.

Ethnicity Considerations

There are major differences between the ethnic identities of the respondents as a significant majority (over 86%) of respondents identified as white/Caucasian. A key consideration to highlight is that the ethnic identity data for persons with disabilities in Canada is not divided by race/ethnicity; this means that it is not possible to know if the ethnicity of the respondents is a true representation of the ethnic diversity demographics of Canada, nor the CP community [8].

However, the overall incidence of disability is roughly 13.7% in the general population and 27% in Indigenous populations [9]; thus, the lack of Indigenous and non-Caucasian representation within the survey population leads to the assumption that these communities may not have the same level of access to disability networks that Caucasian families of children and adults with disabilities have. We note that roughly 60% of respondents stated that they have a connection to their "local" specialists and attend local therapies; however, about 80% have difficulty managing stress (see Table 2).

Table 2 - Percentage of Accessibility Challenges to Local Services and Respondent Ethnicity Indentity.



When considering the linkages between ethicality and accessibility for persons with CP, a key consideration to recognize is that Indigenous and persons of colour with disabilities face discrimination on multiple intersecting grounds. For example, compared to non-Indigenous communities, Indigenous communities experience higher unemployment rates, lower rates of education, and socio-economic marginalization in general. Differences in funding and provision of services for First Nations people under the Indian Act has caused many Indigenous people with disabilities to lack access to critical supports and programs that advance the quality of life.

In addition, limited funding is available in Indigenous communities for education, social services, and healthcare, meaning that services are often completely unavailable or of poor quality, perpetuating the cycle of poverty within these communities [4].

Future research around access to disability services for specific ethnic communities concerning their access to specific supports is required to capture the full picture of how communities cope with issues such as stress. The goal of this survey was to gather the diverse national experiences of persons and families with CP. That said, we recognize and highlight that there are limitations in the demographic information that was captured. The above considerations are key components when analysing access to services and quality of life.

As a result of not having a profoundly diverse sample population, some of the data may not fully represent all CP communities, such as those living in some provinces and territories and adults with CP. Those located outside of the high survey respondent areas provide multiple robust opportunities for future analysis, leading to a Canadian National Strategy for CP.

To view the full demographic and access to services survey results, please see Appendix 1.

2.0

QUALITY OF LIFE ANALYSIS

Unpacking the Survey Respondents' Quality of Life

Integral to understanding the nuances pertaining to how CP can impact the quality of life for both the person with CP and their loved ones, it is necessary to distinguish between the various types of CP. As such, we describe the four types and some of the common side effects associated with each type.

Types of Cerebral Palsy

There are four main types of CP, also known as Motor Types. The first and most common is Spastic Cerebral Palsy. Those who have spastic CP have increased muscle tone meaning their muscles and movements can become stiff. Spastic CP is usually described by what parts of the body are affected:

Spastic diplegia/diparesis - muscle stiffness mainly in the legs, with the arms less affected or not affected at all. Those with spastic diplegia might experience difficulty walking as their stiff hip and leg muscles cause their legs to pull together, turn inward, and cross at the knees.

Spastic hemiplegia/hemiparesis - affects one side of a person's body; usually, the arm is more affected than the leg.

Spastic quadriplegia/quadriparesis—most severe form of spastic CP. It affects all four limbs, the trunk, and the face, severely impacting a person's ability to walk.

The second type is Dyskinetic Cerebral Palsy (includes athetoid, choreoathetosis and dystonic cerebral palsies). People with dyskinetic CP can experience difficulty walking and functions of daily life as they can have problems controlling their hands, arms, feet, and legs. They often have uncontrollable movements that can be either slow and writhing or rapid and jerky that sometimes affect their face and tongue.

The third type is Ataxic Cerebral Palsy. People with ataxic CP can experience problems with balance and coordination, which often results in unsteady walking. Also, some people have a hard time controlling their hands or arms when they reach for something making quick movements or movements that need much control, like writing, problematic.

Lastly is Mixed Cerebral Palsy. Those with mixed CP experience symptoms of more than one type of CP - the most common symptoms of mixed CP being within the spastic-dyskinetic CP types [2,4]

Reported Motor Types

The prevalence of survey respondents' types of CP matches the CP Motor type national prevalence rates as the majority (74%) reported having the most common type of CP – Spastic. 52% of respondents reported having Spastic quadriplegia, 19% reported having Mixed Motor type, while much lower percentages of the survey respondents reported having Ataxic and Dyskinetic Motor types. Given that the vast majority of the survey respondents had the Spastic Motor type, it is key to consider how this particular type can impact the quality of life for both the person with Spastic CP and their families/care providers. As mentioned above, sub-types within the Spastic Motor type have various side effects ranging from minor to severe depending on the unique individual. Some of the most common side effects of Spastic and Mixed Motor types that impact the quality of life include challenges with mobility, vision, hearing and communication, problems with chewing, swallowing, speaking, and seizures.

"It is emotionally draining watching her suffer".

Due to the profound side effects, families often become the primary care provider to their loved ones, which can substantially impact their lives in multiple ways [10]. Two themes were identified through analysing the high number of respondents reported to have spastic motor types and their quality-of-life phenomena; first, we identified a higher impact on quality of life for families who cared for those with spastic types versus non-spastic types, and second, a higher impact on the quality of life for the person with CP who experience severe symptoms such as seizures (see tables 3 and 4).

Impact on Family/Care Provider Quality of Life

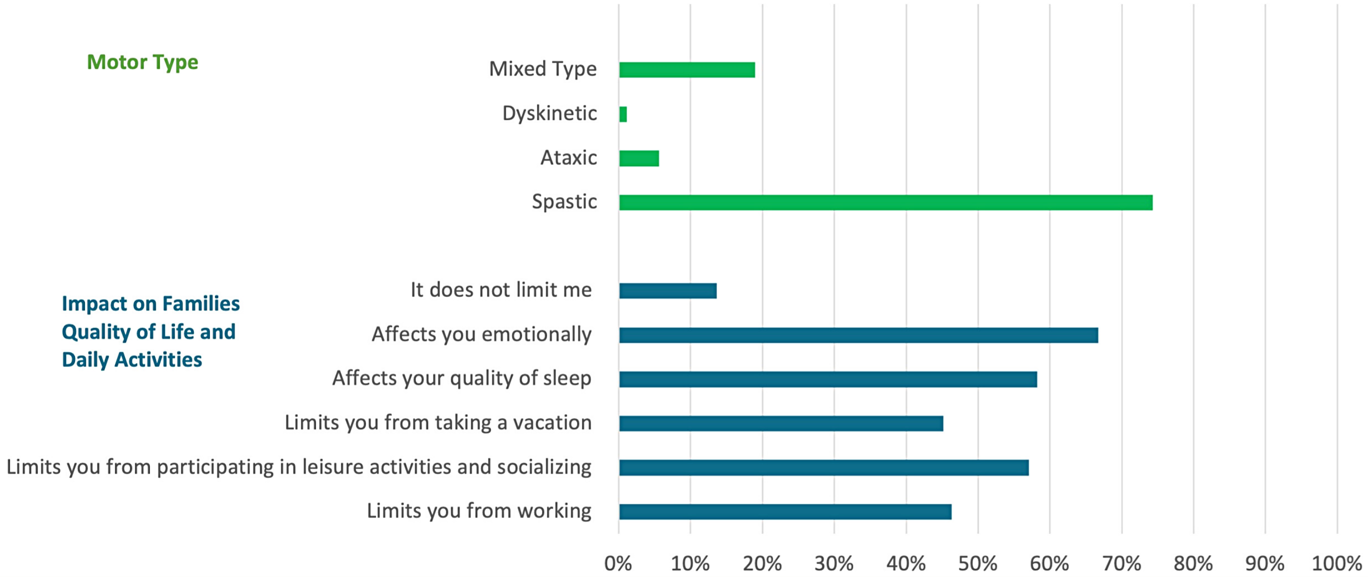
The first of two themes identified are related to families/care providers. Due to the severity of side effects linked to CP, especially spastic motor types, many family members are the primary care providers to their loved ones. When discussing the quality of life, it is important to recognize that a significant factor in a person's quality of life is their overall health. Health is viewed as a multidimensional construct that includes physical, emotional, spiritual, mental, and social domains [11]. Family members who also care, providers face multiple additional challenges when they care for their loved one with CP.
The most significant challenges identified in the survey were related to access to therapies and medications, stress management, self-care, and demands on personal time. Balancing work and caregiving can be difficult, and many care providers find that they cannot find support staff or services to help. Financial burdens exist regarding the costs of treatments and access to appropriate therapies. Further, the survey respondents who are providers noted that inconsistent provincial funding had created difficulties accessing expensive equipment that can help provide better care for their loved ones.

Another quality of life aspects to consider is the mental and emotional side effects such as feelings of loneliness, isolation and depression. One parent respondent with a daughter with CP stated that "It's emotionally draining watching her suffer".

While some families reported that their overall health and quality of life was not impacted or that their daily activities have only been marginally impacted, others stated that providing care to their loved ones lead to conflicts that reduced their quality of life. Of those families who experience impacts on their daily activities, studies have shown that they have higher levels of depression than families without disability. Conflicts can arise between care providers own personal healthcare needs, including the amount and quality of sleep they can get. Also, families have reported that other areas of their lives are impacted by caring for a loved one, such as work, socialization and caring for other family members [12]. T

The types of impacts on daily activities and quality of life were expressed by a survey respondent who stated that they have “extreme exhaustion, fear of the future, fear for our own health declines (which is) caused by caregiving”. Additionally, most families reported that their leisure time, including vacations, had been significantly impacted (see Table 3).

Table 3 - Percentage of Respondents with varying Cerebral Palsy Motor Types and Impact on Families Daily Activities.



We identify that there may be a link between Motor type severity, particularly spastic types and low family/care provider quality of life. The impacts on health, leisure, work and social support are consistently related to low quality of life and higher levels of stress and depression. Researchers have concluded family-centred approaches should be employed for families who report having poor quality of life outcomes related to CP [13].

A family-centred approach can occur when healthcare professionals and other support staff work in partnership with families to help them make their own decisions. This approach is based on the idea that all families are unique and that there is no right way to do things. This is said to create the best environment for the entire family’s health, development and wellbeing.

Core aspects of family-centred care models can be applied to all populations and care contexts when professionals work with families by listening and engaging with them. Professionals can then provide direct assistance with challenges that they face, including counselling and coaching. This often requires both parties to understand the family's strengths, needs, and progress. The family-centred approach will be different for each family depending on the local resources that are available to them [14].

Although the family-centred approach is recognized as ideal for combatting quality of life issues, we recognize that this type of approach may not be accessible for all. Further research specifically related to the relationship between family-centred care access should be considered to understand how well this approach is being implemented in Canada. Findings could inform movement towards a universal family-centred care model for all populations while adding valuable quality of life insights for a National Strategy.

Impact on Quality of Life for Persons with CP

The second theme related to quality-of-life reporting came from those with CP. As mentioned, a significant factor in a person's quality of life is their overall health, including physical, emotional, spiritual, mental, and social domains. We analysed the reported symptoms of CP and the side effects on the quality of life of the percentage of respondents who experienced poor outcomes in education and leisure activities, relationship building and aspects of health such as pain and sleep. Looking at the survey respondents' reported symptoms, we highlight that the majority stated that they have deficits related to stiff or "floppy" muscle tone and delays in milestone development such as neuro diversities related to developmental, cognitive and behavioural aspects.

Almost 65% of the respondents said that they experience pain. Pain is cited as the number determinant in studies assessing the quality of life for both children and adults with CP. In fact, children who report pain tend to have a lower quality of life in all areas. Commonly, the pain will affect every part of children's bodies with CP, especially their hips and back. People with CP also express that pain interferes with their sleep quality and notes that they have frequent sleep disturbances when experiencing pain. 55% of respondents expressed that CP impacted their speech and motor abilities, and they explained how such symptoms directly affect their mental health. One respondent stated that "(My) speech difficulty, in particular, prevents me from building relationships". Another respondent said that "(I) can't play many sports with my friends. In tag I'm always it".

Over 30% of respondents reported experiencing seizures. Seizure symptoms differ depending on what part of the brain is impacted by electrical activity; however, common symptoms include auditory hallucinations, sensory problems, unorganized behaviour, and uncontrollable body movements. Seizure side effects negatively impact a person's overall quality of life, particularly social aspects. They may not feel safe participating in various activities for fear of having a seizure and getting hurt or feeling embarrassed [15]. Mental health, participation and socialization are key considerations for young persons with CP. When young people feel isolated due to factors such as low participation, they are at a high risk of developing depression [12]. We interpret that the CP symptoms reported by the survey respondents impact their quality of life, particularly related to domains including physical, mental, emotional and spiritual well-being, self-perception, autonomy, socialization, communication, and participation (see Table 4).

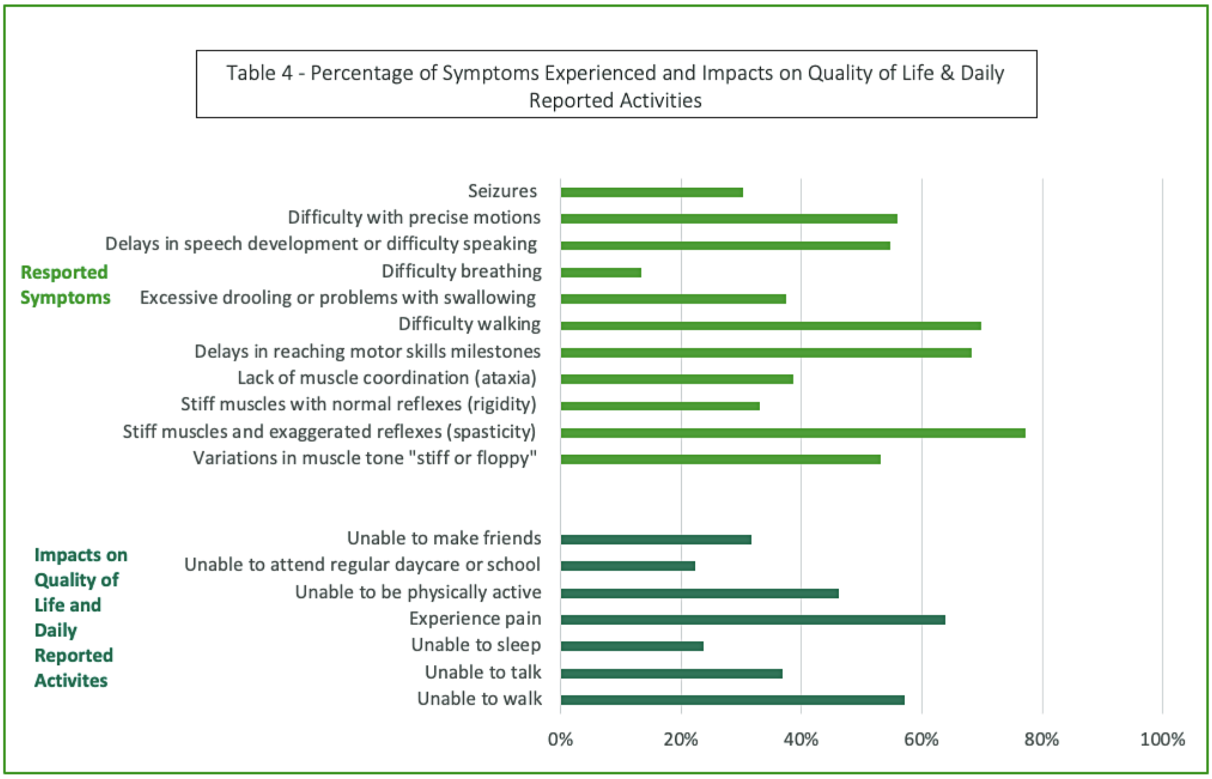


Table 4 - Percentage of Symptoms Experienced and Impacts on Quality of Life & Daily Reported Activities

To view the full demographic results related to Motor types, symptoms and quality of life for individuals and families, please see Appendix 2.

Future Quality of Life Considerations

We recognize that it is essential to understand the quality-of-life impacts on persons with CP based on their Motor types and symptoms experienced. However, equally important is their level of access to critical services such as therapies and peer support. Also, the quality of the healthcare they receive and family/supportive environments also play an integral role in the quality of life people experience. A fundamental obstacle to maintaining a high quality of life for those with CP is their lack of access to equitable health and social outcomes, which can lead to limited opportunities to fully participate in decision-making outcomes; meaning that supports and services may not reflect what is most important to them, nor be provided in accessible places or meaningful ways. Inaccessibility can lead to invisibility where there is little investment and inflexible or inadequate supports that create obstacles to social, educational and community participation affecting the overall quality of life [16].

In addition, there are some areas of the survey connected to quality-of-life considerations that should be more deeply explored, such as mobility device usage. Given some of the symptoms that people with CP experience, they often use mobility equipment to navigate their communities, such as wheelchairs, walkers and crutches. Wheelchairs make up an overwhelmingly high percentage of equipment used by the respondents, with over 92% reporting that they use this type of device (see Appendix 2, Table 17). The high percentage of survey respondents who use wheelchairs signals a need for robust future analysis to uncover accessibility and quality of life factors relating to mobility devices.

Due to the lower percentage of responses from people who experience Mixed, Ataxic and Dyskinetic Motor types of CP, the above analyses may not accurately represent symptoms they experience or the quality-of-life impacts for those individuals. Additionally, we conclude that a National Strategy for CP in Canada must reflect the experiences of all persons with CP regardless of the Motor type they have; as such, there may be ample space for future analysis to unpack the various quality of life considerations.

3.0

RESPONDENTS RESEARCH INTERESTS

Analysing Interests through an Inclusive Research Lens

This section of analysis was completed in the spirit of inclusive research. Inclusive research is the transformation away from “research on people”, to research with them, meaning that the respondents play an active role in the process. By using inclusive research, we are driven to involve the people who were part of the survey in the design by representing their lived experiences while respecting them and valuing their unique ways of knowing [17].

By highlighting the respondents' ideas about what types of research they want to consume and be a part of, we hope that bridges will be built between academics, disability organizations and policymakers. When inclusive research partnerships are employed using collaborative mechanisms, we believe that the community will be closer to achieving a CP National Strategy.

CP Community’s Interests

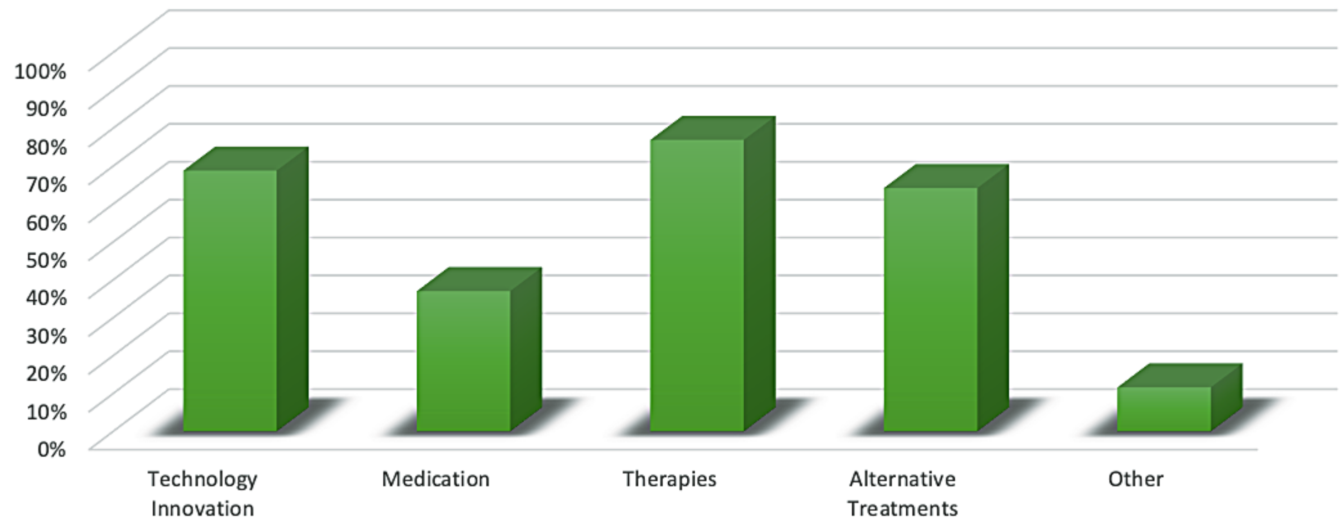
Understanding areas of CP research is important as the CP communities’ interests may not line up with the medical model or the professional medical community’s agenda. For example, scientists and researchers are continuously working on a cure for cerebral palsy [18]. However, the respondents stated that they are interested in research that focuses on better access to services, technologies, and therapies to assist them with their daily needs.

One respondent stated that they are interested in research that underlines “adequate home support”. Another respondent explained that they are interested in learning more about persons with CP and “issues like ageing and sexuality”.

When analysing the responses about research interests, we found that 85% of respondents were interested in research and development. In fact, the top three research interests were identified as therapies, alternative treatments and technology innovation. Other interests included CP and ageing, pain management, sleep, and effectiveness of supports. Ageing was a recurrent area of research that came up in the qualitative analysis. One family member noted that research into therapies is a key consideration as "physical therapies as they get older…seem to become less important to physicians". Moreover, a self-advocate respondent noted that "advances in research" are important as "most information, treatment, services, and research is primarily geared towards children with CP. Children with CP grow up to be adults with CP, and once you age out of children hospital services, (you) often end up forgotten or left behind".

Another key consideration pulled out from the analysis was that the respondents are interested in understanding CP research through online platforms. In fact, 65% of the survey respondents stated that they would like to learn about current CP research through online communities; one respondent stated that they felt a need for "online parent support groups in Yukon, AB, and BC". While another expressed that research information should be provided to the CP community through "conferences (located) in Ontario and areas like maybe Hamilton or Toronto". Through both the quantitative data results (the percentages of respondents) and the qualitative (the respondent's quotes), it is clear that the CP community has the desire to see and engage with various research initiatives (see table 5).

Table 5 - Percentage of Respondents Interested in Various Research Initiatives



Much of the current CP research being conducted focuses on developing a better understanding of the disorder by identifying genetic risk factors and causes. Although such research areas are important, the vast amount of the survey respondents highlighted that they would like to engage with research that supports efforts toward improving technology innovation, therapies and alternative treatments.

While this analysis highlights some of the key considerations regarding the types of research initiatives the CP community is interested in exploring, we recognize many more areas that people with CP their families might be interested in. As mentioned throughout the report, to materialize a National CP Strategy, significant areas of study require more in-depth consideration, including the CP community's research interests.

A Path Toward Inclusive Research

The research interests captured in the survey features the perspectives of a small portion of the persons with CP and their families and, therefore, may be lacking the perspectives of the broader CP community; however, this limitation provides an opportunity for future analysis to better understand the lived experiences of the groups outside of this cohort. Furthermore, inclusive research methods were not included as an option within the survey questions around what types of research the sample population would like to engage with – this leaves room for providing education to both the CP community and researchers alike about inclusive methodologies.

Conducting inclusive research requires far more than qualitative analysis; it requires participant-led research where those being studied become fully immersed in the process. This method instructs that knowledge about the community should be generated from working with the community. When working in inclusive spaces, the community becomes an equal partner who helps to develop research by coming together with the "professionals" in dialogue. This would involve designing the research questions, survey, analysis and report together. As we advance, future researchers should consider developing ways to incorporate inclusive methods within the discussion toward a National Strategy to acknowledge the autonomy and practical wisdom of the CP community.

CONCLUSION & REFLECTIONS

The report and survey were designed to start the conversation toward creating a National CP Strategy in Canada. The survey had two streams: one for families/care providers and one for persons with CP. The analysis featured in the report was person-centred to supports individuals with CP and their families. As noted, the majority of the demographic sample population represented Caucasian parents or care providers of children with CP (see Appendix 1). Having limited population groups based on various factors leaves room for future analysis to include diverse age and ethnic groups as well as CP communities living in low participation geographic areas of Canada such as Quebec, PEI, Manitoba, Yukon, and North West Territories

The survey data analysis was explained by presenting the percentage of respondents who answered the survey questions based on their personal lived experiences, which highlighted two major themes: quality of life based on CP Motor type and urban versus rural access to services. The two major themes were enriched by analysing the nuances around issues related to the themes, highlighting key considerations for future analysis, and pulling in direct quotes from the survey respondents to heighten their voices and lived experiences. This was done using a mixed-methods approach and two research methodologies: Phenomenological and Thematic based analysis.

Throughout the report, we discussed many of the survey and analysis limitations which aided our ability to identify the key considerations and recommendations for future analysis and research. Some of the considerations and recommendations included consultation with diverse age groups and ethnic communities such as Indigenous nations and leaders to understand better the accessibility and quality of life nuances around diverse CP populations. We also recommended family-centred care models to assist in relieving the challenges that families and care providers face. Furthermore, we recommended that future CP research focus on conducting a GBA+ to provide insight into how deferring genders are impacted.

Lastly, we underlined the research initiatives that the CP community is interested in exploring. We also future considerations around doing inclusive research with participants by working with them on the research design process. We believe that a National Strategy should be inclusive, which requires people with disabilities and their allies to conduct research together by engaging with the critical and multidimensional complex issues related to CP. When academics, disability organizations and the CP community come together, we can build bridges between liberating the voices of the CP community and transformative research. Practising inclusivity brings us closer to achieving the goals, outcomes and actions taken to realise a Cerebral Palsy National Strategy in Canada.

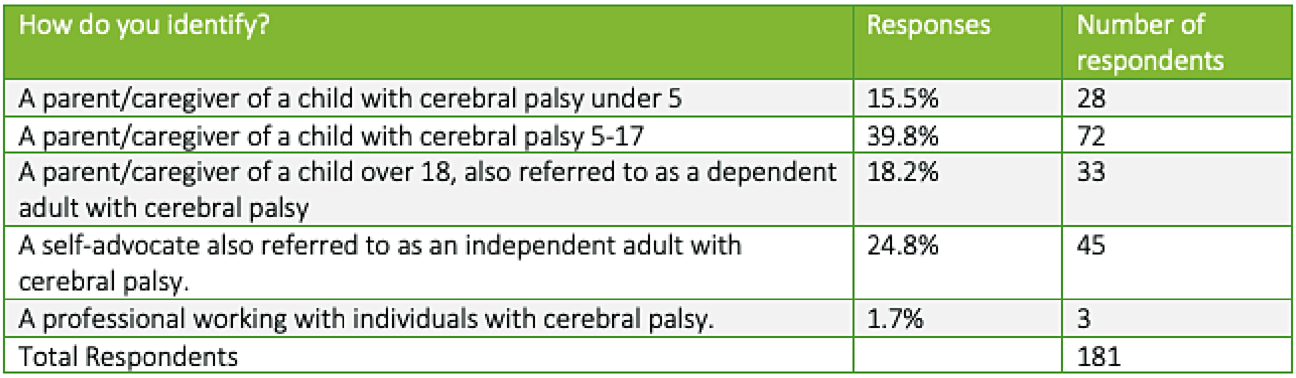
APPENDIX 1

Demographics & Accessibility

The following tables highlight the demographic and self-identities collected from the survey respondents, such as their age groups, the geographic areas where they live, types of residence and community they reside in, and their gender and ethnicity identities. Additionally, the tables below show the percentages of respondents who accessed certain services and tables featuring the accessibility challenges.

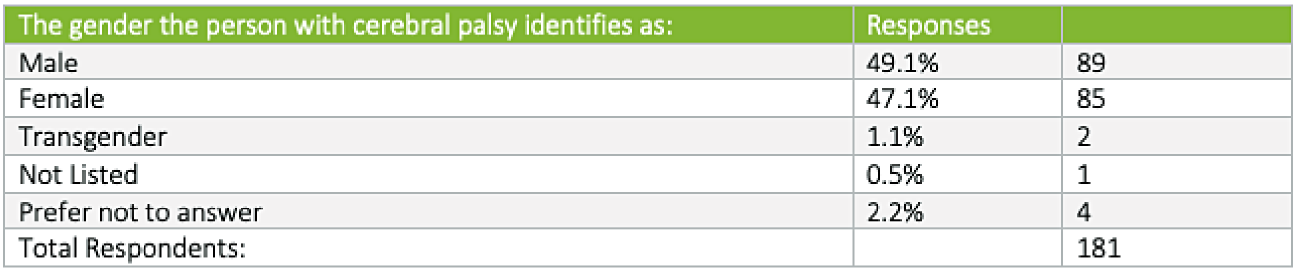
The below tables represent the demographic information collected:

Table 1



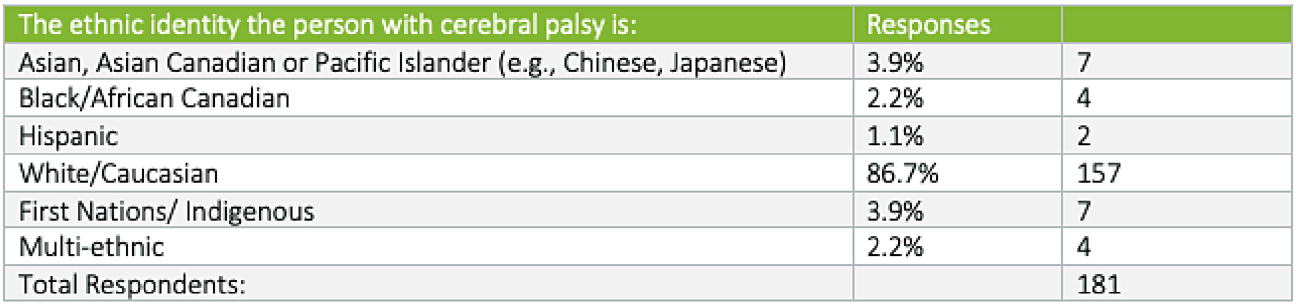
How do you identify?	Responses	Number of respondents
A parent/caregiver of a child with cerebral palsy under 5	15.5%	28
A parent/caregiver of a child with cerebral palsy 5-17	39.8%	72
A parent/caregiver of a child over 18, also referred to as a dependent adult with cerebral palsy	18.2%	33
A self-advocate also referred to as an independent adult with cerebral palsy.	24.8%	45
A professional working with individuals with cerebral palsy.	1.7%	3
Total Respondents		181

Table 2



The gender the person with cerebral palsy identifies as:	Responses	
Male	49.1%	89
Female	47.1%	85
Transgender	1.1%	2
Not Listed	0.5%	1
Prefer not to answer	2.2%	4
Total Respondents:		181

Table 3



The ethnic identity the person with cerebral palsy is:	Responses	
Asian, Asian Canadian or Pacific Islander (e.g., Chinese, Japanese)	3.9%	7
Black/African Canadian	2.2%	4
Hispanic	1.1%	2
White/Caucasian	86.7%	157
First Nations/ Indigenous	3.9%	7
Multi-ethnic	2.2%	4
Total Respondents:		181

Table 4

The province they live in is:	Responses	
Alberta	18.8%	34
British Colombia	11.1%	20
Manitoba	4.4%	8
New Brunswick	10.5%	19
Nova Scotia	8.8%	16
Newfoundland	5.0%	9
Northwest Territories	0.00%	0
Nunavut	0.00%	0
Ontario	22.1%	40
Quebec	5.0%	9
Prince Edward Island	0.00%	0
Saskatchewan	13.8%	25
Yukon	0.5%	1
Total		181

Table 5

The type of community they live in is:	Responses	
City or urban community	51.9%	94
Suburban community	23.8%	43
Rural community	23.2%	42
First Nations Reserve	1.1%	2
Total Respondents:		181

Table 6

The type of residence they live in is:	Responses	
At home	76.2%	138
In residential care	2.8%	5
Own apartment/condo	20.4%	37
Shared arrangement	0.6%	1
Homeless	0.00%	0
Total Respondents:		181

Table 7

Challenges that Care Providers face in caring for someone with cerebral palsy	Responses	
Access to appropriate therapies and/or medications	64.6%	106
Access to specialty physicians / therapists	57.3%	94
Cost of caring for patients / cost for treatment	59.2%	97
Demands on personal time	76.8%	126
Managing work and caregiving	65.2%	107
Managing stress	79.9%	131
Treatments are expensive	46.3%	76
Other (please specify)	14.0%	23
Total Respondents:		164

Table 8

Information related to CP and resources sought	Responses	
Financial assistance	61.11%	99
Government programs	67.28%	109
Transportation	27.16%	44
Housing	39.51%	64
Therapies	61.73%	100
Mental Health Resources	33.95%	55
Other (please specify)	12.96%	21
Total Respondents:		162

Table 9

Programs and services sought	Responses	
Social skills programs	35.9%	61
Activity-based programs	52.4%	89
Specialized summer programs	36.5%	62
Life skills training	30.0%	51
Vocation and employment services	21.8%	37
Recreation/leisure programs	68.8%	117
Support services	60.0%	102
Mental health services	24.1%	41
Total Respondents:		170

Table 10

Barriers faced to accessing services	Responses	
Can't afford services	37.0%	60
Negative experiences with professionals in the past	25.3%	41
Not enough resources – on a wait list	57.4%	93
Lack of trained professionals	32.1%	52
Too young to receive services needed	18.5%	30
Too old to receive services needed	20.4%	33
Services are too far	37.7%	61
Services are not available in the right language	0.6%	1
Other (please specify)	17.9%	29
Total Respondents:		162

Table 11

Information related to CP and resources sought	Responses	
Financial assistance	61.11%	99
Government programs	67.28%	109
Transportation	27.16%	44
Housing	39.51%	64
Therapies	61.73%	100
Mental Health Resources	33.95%	55
Other (please specify)	12.96%	21
Total Respondents:		162

Table 12

Types of Health Services accessed	Responses	
Had a flu shot	58.3%	102
Had a physical exam	72.0%	126
Had an annual dentist appointment	74.9%	131
Access at least one medical specialist	80.6%	141
Physiotherapy	4.6%	8
Been hospitalized	22.9%	40
Other	4.6%	8
Total Respondents:		175

Table 13

Future Accessibility Considerations	Responses	
Research	56.8%	100
Representation for global initiatives	21.0%	37
Support for local organizations	67.6%	119
Annual conference	27.8%	49
Access to information and support	72.2%	127
National strategy for cerebral palsy	40.9%	72
Other (please specify)	7.4%	13
Total Respondents:		176

Table 14

Types of Research Interests	Responses	
Technology Innovation	68.8%	119
Medication	37.0%	64
Therapies	76.9%	133
Alternative Treatments	64.2%	111
Other (please specify)	11.6%	20
Total Respondents:		173

APPENDIX 2
Quality of Life

Motor Types, Symptoms & Quality of Life

The following tables highlight the percentages of the survey respondents who reported their diagnosed CP Motor types, symptoms experienced, and impacts on quality of life such as impacts on daily activities, ability to work, socialize and go to school. The impacts on quality of life were also reported by families/care providers.

Table 15

Type of Cerebral Palsy	Responses	
Spastic	74.30%	133
Ataxic	5.59%	10
Dyskinetic	1.12%	2
Mixed Type	18.99%	34
Total Respondents:		179

Table 16

Parts of the body affected	Responses	
Monoplegia	1.1%	2
Hemiplegia	22.9%	40
Diplegia	25.1%	44
Quadriplegia	52.0%	91
Total Respondents:		175

Table 17

Symptoms of cerebral palsy experienced	Responses	
Variations in muscle tone, such as being either too stiff or too floppy	53.1%	95
Stiff muscles and exaggerated reflexes (spasticity)	77.1%	138
Stiff muscles with normal reflexes (rigidity)	33.0%	59
Lack of muscle coordination (ataxia)	38.6%	69
Delays in reaching motor skills milestones, such as pushing up on arms, sitting up alone or crawling	68.2%	122
Difficulty walking, such as walking on toes, a crouched gait, a scissors-like gait with knees crossing, a wide gait or an asymmetrical gait	69.8%	125
Excessive drooling or problems with swallowing	37.4%	67
Difficulty breathing	13.4%	24
Delays in speech development or difficulty speaking	54.8%	98
Difficulty with precise motions, such as picking up a crayon or spoon	55.9%	100
Seizures	30.2%	54
Total Respondents:		179

Table 18

Types of mobility devices used	Responses	
Cane	9.85%	13
Crutches	7.58%	10
Gait trainers	15.91%	21
Manual wheelchair	67.42%	89
Power or electric wheelchair	25.00%	33
Walker/Rollators	40.91%	54
Scooter	5.30%	7
Total Respondents:		132

Table 19

Due to cerebral palsy, individuals that are:	Responses	
Unable to walk	57.2%	87
Unable to talk	36.8%	56
Unable to sleep	23.7%	36
Experience pain	63.8%	97
Unable to be physically active	46.1%	70
Unable to attend regular daycare or school	22.4%	34
Unable to make friends	31.6%	48
Unable to participate in leisure activities	42.8%	65
Total Respondents:		152

Table 20

How cerebral palsy affects a family's day to day life	Responses	
Limits you from working	46.3%	82
Limits you from participating in leisure activities and socializing	57.1%	101
Limits you from taking a vacation	45.2%	80
Affects your quality of sleep	58.2%	103
Affects you emotionally	66.7%	118
It does not limit me	13.6%	24
Other (please specify)	10.2%	18
Total Respondents:		177

Table 21

How cerebral palsy affects a family's day to day life	Responses	
Limits you from working	46.3%	82
Limits you from participating in leisure activities and socializing	57.1%	101
Limits you from taking a vacation	45.2%	80
Affects your quality of sleep	58.2%	103
Affects you emotionally	66.7%	118
It does not limit me	13.6%	24
Other (please specify)	10.2%	18
Total Respondents:		177

Table 22

Types of mobility devices used	Responses	
Cane	9.85%	13
Crutches	7.58%	10
Gait trainers	15.91%	21
Manual wheelchair	67.42%	89
Power or electric wheelchair	25.00%	33
Walker/Rollators	40.91%	54
Scooter	5.30%	7
Total Respondents:		132

APPENDIX 3
Follow up survey conducted in partnership with Nestlè

The following 15 questions were intended to delve deep into the personal lived experiences of 12 respondents. Featured below is the written accounts of "Respondent 1". Please note that a care provider filled out the follow-up survey for Respondent 1. To view the full follow-up survey, please follow the link provided at the bottom of page 33.

#1: Are you an individual, caregiver, or parent living with cerebral palsy?

(I am a care provider filling out the survey for a) 29-year-old living with Spastic-Quad CP.

#2: How has the diagnosis of CP affected your life?

Limited her choices because of the society we live in. With the government saying we have nowhere for you to live, it's sad as she is forced to live in a nursing home. Her childhood was hard, she knew she was different, she couldn't go to sleepovers, they weren't accessible. If she was invited somewhere, she could only go if accessible. Friendships were hard. She did not date in high school, no one was interested, was difficult. She would be naïve to say the disability wasn't a factor. Growing up in the world and seeing again and again, through policies that were designed to not want her here. Every time she goes to a store she can't get in, they are saying to her we don't want you here, you don't deserve to be here. That is what they are saying with their actions.

#3: What type of community do you live in?

Halifax wanted to live in Halifax because it has more resources. Grew up in a small town, where there were no opportunities, so moved to Halifax. If she wanted to have a future, she felt she had to move to the city.

#4: Do you feel there are barriers to accessing services based on your individual needs? If so, what type of services are you lacking?

Absolutely services are lacking – has to book a bus a week ahead if she wants to go out. Her life is very structured. Her dad has a wheelchair accessible van. Was just allowed to leave her facility for the first time in 7 months. Though she was not allowed to go on the bus, because it's a rule of her nursing home. They don't look at her as individuals. According to Nova Scotia Health 18 -64 is considered a Young Adult (so there is a lack of understanding there). Halifax is a really old city, most of the buildings are not wheelchair friendly. Her best friend just got a wheelchair accessible apartment.

#5: Do you feel you have enough support in your community? What kind of support is available to you and which supports do you feel you are missing?

Her parents are very supportive, because she lives in a nursing home she is disqualified from provincial supports. For example respite funding, she doesn't have access to. Has a social worker.
She is forced to live in a nursing home, so yes it is accessible.

#6: Is your housing accessible based on your individual needs? What barriers are you experiencing?

She is forced to live in a nursing home, so yes it is accessible.
Yes and not, she gets $300 per month from the govt but it is for personal expenses. Her dad helps support her. She sometimes does speaking engagements at $50 per hour, but this is not consistent.

#7: Do you have access to financial supports? If not, what barriers do you encounter when you try to access financial resources?

Yes and no, she gets $300 per month from the govt but it is for personal expenses. Her dad helps support her. She sometimes does speaking engagements at $50 per hour, but this is not consistent.

#8: Regarding nutrition, do you have any concerns? If so, where have you gone or whom have you spoken with regarding the concern? Do you have access to financial supports for your nutritional needs?

Meals are provided by the nursing home, the meals are not good nor tasty, but they do follow the Canada food guide. (Respondent) is able to eat by mouth.

#9: Regarding nutrition & swallowing, how often do you cough, choke, or have pain when eating or drinking?

Has a lot of choking issues, for the past three to four years, has had to change her diet, fruit is very difficult unless pureed. Anything that is very juicy, soups needs to be separated. Is able to cough up on her own, if it is a high risk, eats in front of someone. Her dad brings her food too.

#10: Which of the following statements best describes meal preparation and cooking for you?

Her meals are provided to her by the nursing home.

#11: Regarding your nutrition and acid reflux/heartburn, do you experience any of the following?

No. She did suffer from anorexia for about a year.....it was a way of trying to heal herself.

#12: Do you find the pandemic has affected your individual or family way of living? How so?

Wasn't able to leave her home for 7 months, only doctors appts though. The pandemic made her really depressed, scared about living in a nursing home. Feels sorry for everyone involved. Spoke to a human rights lawyer yesterday, she is putting in a human rights complaint that she is being forced into a nursing home. Pro Bono, a very strong woman is fighting for her.

#13: What types of programs, resources, and supports would you be interested in receiving from a provincial cp association?

Speech therapy offering at a very young age, her young age therapy helped. Funding for equipment regardless of age, respite or day program. Employment agency and education support. Peer support group. Access to different sort of treatments, alternative therapies, if interested. A program that will pay for medications. She uses marijuana oil that her dad pays for that is very helpful for her pain and sleep.

#14: What initiatives would you like to see a national organization like the CP Canada Network focusing on?

Legal defence team to take on cases of injustice, using her example as a Human Rights violation. Feels she is being discriminated against, wants someone to reach out to. Wants to see more effort in putting children in more classrooms, classes are still very segregated, when she was a kid she was taken out to a resource room for additional support, why couldn't support be provided in class, she was teased because she was in a special class. Couldn't eat in the cafeteria, had to eat in the resource room.

#15: What services do you think are most important for the government to focus on in relation to CP?

Flexible care hours for those that need care. Approve more medicines, a review on medicine, look into marijuana oil. Additional funding for living, she only makes $300 a year.

Extra Notes:

Respondent 1 is an amazing advocate for herself and others. She is currently starting the process of a human rights complaint with the government of NS for forcing her to live in a nursing home. She has a strong voice. She is very interested in being a part of a provincial CP association for Nova Scotia.

To view the entire Nestle Follow-Up Survey please use the link:
https://docs.google.com/spreadsheets/d/1LtomtijQOltI8xJffFwQYgvyTWbe1ChH/edit#gid=1545757505

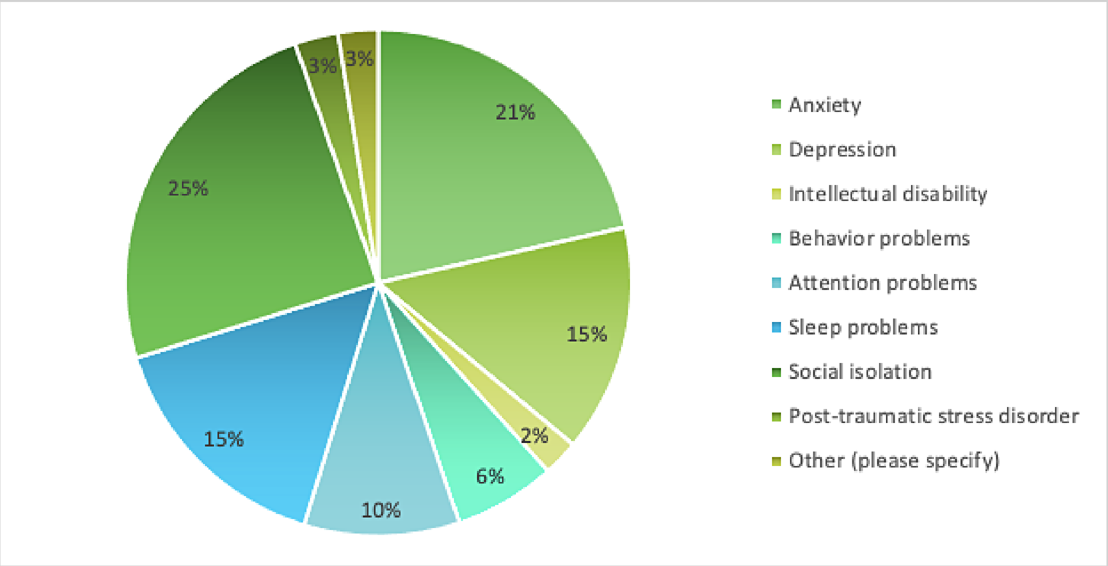
APPENDIX 4

COVID-19 Survey Questions

COVID-19 has disproportionately impacted the disability community. As such, the COVID-19 related questions were asked in the survey and are featured below. To depict the pre and post-pandemic reality, the COVID-19 questions were not assessed in this analysis. During the analysis process, we noted that the pandemic-related questions exasperated the issues that persons with CP and their families face, such as accessibility and social isolation. This signals that COVID-19 has an impact on the CP community; thus, impacts should be thoroughly explored.

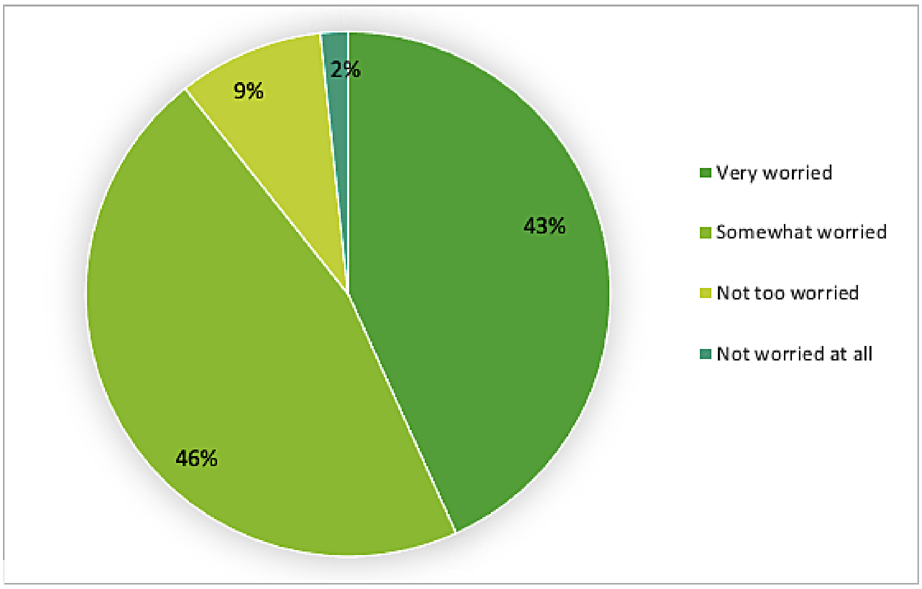
A final consideration is that this survey was disseminated at the beginning of the pandemic in 2020, which may have impacted some of the respondent's answers related to their perception of the pandemic.

Question: *Are you experiencing any mental health challenges due to the isolation of COVID-19 restrictions?* Check all the apply:



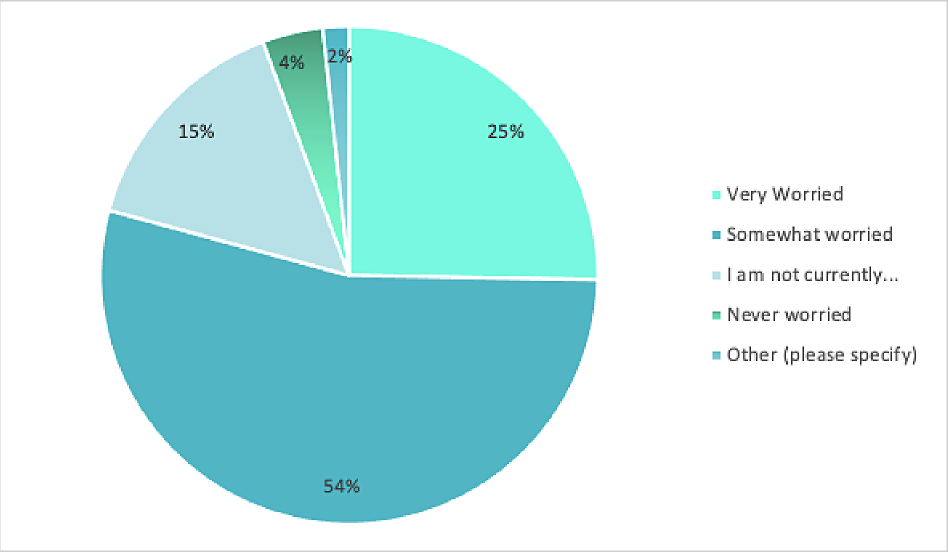
Answer Choices	Responses	
Anxiety	60.78%	93
Depression	41.18%	63
Intellectual disability	6.54%	10
Behavior problems	18.30%	28
Attention problems	28.10%	43
Sleep problems	43.79%	67
Social isolation	69.28%	106
Post-traumatic stress disorder	7.84%	12

Question: *How worried are you about the effect the outbreak will have on Canada's economy?*



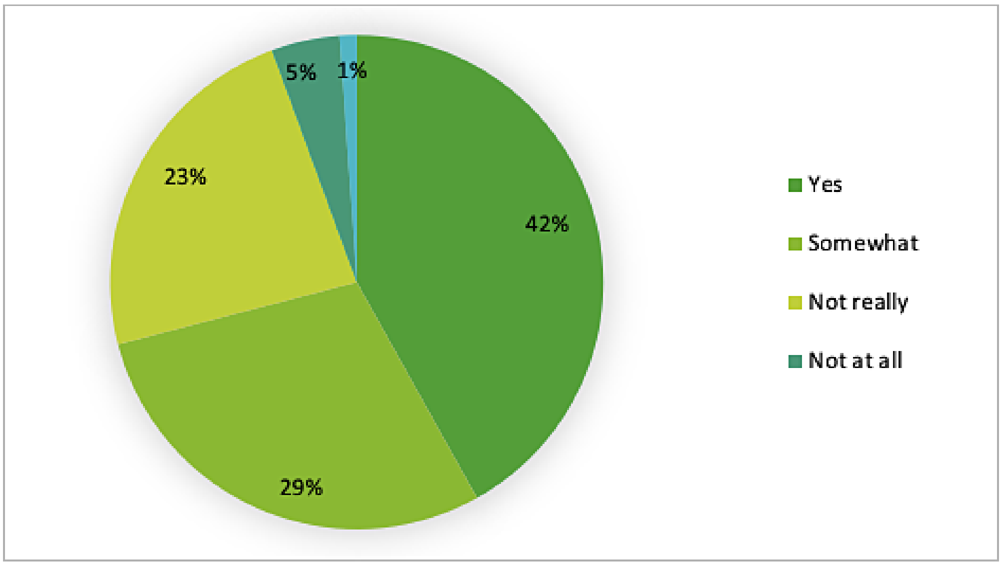
Answer Choices	Responses	
Very worried	43.26%	77
Somewhat worried	46.07%	82
Not too worried	8.99%	16
Not worried at all	1.69%	3
Total Respondents:		178

Question: *How worried are you about the outbreak of the Coronavirus in Canada?*



Answer Choices	Responses	
Very Worried	25.28%	45
Somewhat worried	53.93%	96
I am not currently worried	17.65%	27
Never worried	3.93%	7
Other (please specify)	1.69%	3

Question: Are you concerned that the outbreak would have a negative economic effect on your own household's finances?



Answer Choices	Responses	
Yes	41.90%	75
Somewhat	29.05%	52
Not really	23.46%	42
Not at all	4.47%	8
Other (please specify)	1.12%	2
Total Respondents:		179

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