



# A COVID-19 CONSIDERATION: RESPONDING TO THE EVOLVING NEEDS OF CHILDREN AND FAMILIES AFFECTED BY CEREBRAL PALSY

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## ABSTRACT

Cerebral palsy (CP) refers to a group of disorders in which atypical muscle tone impairs movement, balance, and posture. Resources available to support children and families affected by CP include therapies, assistive technologies, educational supports, and familial and social services. However, the COVID-19 pandemic has disrupted usual access to many of these resources, making it difficult for children with CP and their families to receive necessary support for optimal development. The International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) is a framework used by various stakeholders, such as healthcare workers, caregivers, and educators, to measure health and functioning in children. Additionally, the Ecological Systems Theory, which was created by Urie Bronfenbrenner, provides a powerful lens to examine how a child's development is influenced by their surroundings. This paper provides an overview of the literature about relevant forms of support for those affected by CP and evidence-informed insights about how such supports may be adapted to better fit healthcare needs evolving as a result of the pandemic.

governmental.

The International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) may be used to contextualize the experiences of children with CP, and identify gaps in existing supports.[7] In addition to the ICF-CY, this paper is informed by evidence and Bronfenbrenner's Ecological Systems Theory, which posits that a child's development is influenced by proximal processes and relationships.[8]

This paper provides an overview of the literature for relevant forms of support for children and families affected by CP, and evidence-informed insights about how such supports may be adapted to better fit evolving healthcare needs as a result of the COVID-19 pandemic. The purpose of this paper is to inform decision-making processes pertaining to CP at the clinical and policy level.

## LITERATURE OVERVIEW

### Physical and Occupational Therapy

Physiotherapy supports children with CP by improving motor skill development and gross motor functioning through stretching and strengthening activities.[3] Another main support is Occupational Therapy (OT), which helps children with CP develop the skills required to perform activities in their daily life including play, self-care activities such as grooming, and fine motor tasks such as writing.[9] Additionally, OT modifies equipment and seating to promote functional independence and enhance upper extremity use for children with CP, and also includes parent counselling to help parents support the functional abilities of their child.[9]

With school closures due to COVID-19, access to physiotherapy and OT has been disrupted for children receiving these services at school.[10,11] Additionally, public health authorities in Ontario have recommended that during the COVID-19 pandemic, community based physiotherapy and occupational therapy be delivered virtually where possible.[12-13] Telerehabilitation, rehabilitation supports provided through telemedicine, can be used to deliver care virtually through video conferencing services or by telephone.[14-16] At a telerehabilitation appointment, a physiotherapist could provide support in various ways such as by teaching the child and their caregiver(s) strength, flexibility, and aerobic exercises that assist the child, observing the child to assess their movement, and providing the child and their caregiver(s) feedback on the child's performance.[11]

## INTRODUCTION

Cerebral palsy (CP) refers to a group of permanent disorders in which atypical muscle tone due to non-progressive impairments in the fetal brain cause limitations and/or disturbances in movement, balance and posture.[1] Sensation, perception, cognition, and communication may be impacted as well, due to epilepsy or atypical musculoskeletal development.[1] CP is the most common motor disability in childhood and is approximated to affect one in 500 children born in Ontario.[2]

Resources available to those affected by CP include therapies, assistive technologies and devices, educational supports, and familial and social services. Physiotherapy and speech and language therapies aim to minimize barriers associated with atypical physical development, specifically damage of the cerebral cortex.[3-4] Assistive technologies and devices may be used by individuals with CP to improve or aid in mobility, communication, and daily living.[5] There are federal, provincial, and environmental adaptations that may be used in educational settings to support children with CP.[6] In Ontario, familial and social services may be governmental or

While CP-focused telemedicine poses challenges, such as less physical interaction and the requirement of telephone or video conferencing technology and skills, it provides opportunities for continuous, accessible, and convenient care.[12-16] Children and their families would be able to access the services from the safety and comfort of their home.16 Additionally, telemedicine provides an opportunity for the therapist to assess the child's function in their natural environment.[16] It also has the potential to reduce stress and the financial burden on families affected by CP as traveling and taking time away from work would reduce in necessity with virtual care.[16-17]

### **Speech and Language Therapy**

Language and functional impairments often limit participation in social and physical activities for children with CP.4,18 To overcome some of the challenges brought on by the symptoms of CP, Speech and Language Therapy (SLT) can be performed to improve communication skills and oral, feeding, and swallowing skills.[19-20] SLT employs a variety of exercises that train the brain to pronounce and interpret auditory stimuli, such as having the child mimic sounds and syllables modeled by the therapist, and encourages the use of body language and assistive devices for enhanced communication.[21] Recreational Therapy (RT) minimizes barriers imposed by limited functional ability through adaptations and modifications. Adaptations refer to the use of orthotics, adaptive equipment or assistive technologies, while modifications are alternate methods for a child to perform an activity.[18] Both therapies, SLT and RT, are highly individualized and intend to improve a child's physical, mental and social experiences through participation in activities of their choice.[4,18]

The provision of SLT services during the COVID-19 pandemic has been limited given the necessity of having face-to-face communication.22 The inability to observe the speech articulators of SLPs and establish eye contact during therapy sessions due to Personal Protective Equipment (PPE) often renders this form of therapy ineffective when completed in-person.[22] As a result, SLT services are now accessed only through telemedicine where PPE does not hinder the ability of children to observe speech from others. Although, some barriers to this method include the need for additional licenses and concerns about patient confidentiality, the COVID-19 pandemic provides an opportunity to facilitate the transition to online platforms and educate patients about the confidentiality terms of telemedicine.[22] In addition, the restrictions imposed by the pandemic has shifted the focus of recreational therapy from assisting children in physically demanding activities, as most are not currently available, to finding accessible forms of play/recreation.[23-24] For example, the Jooya app has been created to spread awareness of appropriate leisure activities available in communities across Canada for children with disabilities.[25]

### **Assistive Technology and Devices**

There are a variety of assistive devices and technologies available for individuals with CP, namely mobility devices, communication aids, daily living assistance and even surgical interventions.[5] Mobility devices can range from wheelchairs to orthotic devices including braces, splints and casts

casts to improve movement, balance and posture.5 Additionally, communication ability varies for speaking, writing, and hearing difficulty.[26] Electronic communication boards and eye tracking devices are available which verbally impaired people can use to generate automated speech.[27] For children who are able to write, special pencils with customized grip can be purchased to aid in their use of these writing utensils.[28] One can also attach a small keyboard to the child's hand to assist them in typing and communicating electronically.[28] Additionally, in the realm of communication devices, hearing aids and cochlear implants can help children with hearing impairments better communicate.[26] Moreover, many devices assist with daily living such as modified toilet seats, shower chairs, and dressing aids.5 Furthermore, possible surgical procedures include orthopedic surgery to correct bone abnormalities caused by muscle spasticity and selective dorsal rhizotomy.29 The latter surgical intervention is performed by cutting the nerve that serves the spastic muscle to relax it and reduce pain.[29] Assistive devices and technologies can provide individuals with CP many benefits such as increased independence, a more engaged social life, and more inclusion in activities and recreation.[29]

The accessibility of these assistive devices has changed due to COVID-19, namely by the closure of non-essential medical services.[30] Children with CP are evaluated by physical therapists, occupational therapists, and orthopedic surgeons to determine necessary additional assistance. This process may have been slowed or halted depending on the severity of CP and accessibility of resources during the COVID-19 pandemic. Additionally, receiving an orthotic device requires an in-person consultation with an orthotist to determine the best device, which can bring discomfort to families from the associated infection risk. Moreover, many homes have multiple assistive devices that cannot be found in the community such as modified toilet seats, ramps or customized eating utensils.[5] The shift to an online world could be beneficial as the child would have access to their familiar home environment and ideal adaptive technology reducing challenges with travel.

### **Educational Support**

In considering the changes to support services available for children with CP through the education system, access to these services and programs may be connected to their individualized education plan (IEP) and a combination of other therapies such as occupational therapy and physiotherapy to address muscular needs or speech services for language development.6 For in-person lessons, classrooms can be set up to support wheelchair bound students through use of adaptive equipment for settings such as the science lab or gymnasium for physical education.[29] Students may further require a 1:1 aide for support and/or use assistive technologies for fine motor control such as enlarged keyboard or voice activated programs. Due to the delivery of online learning this year, these adaptations in the classroom may not be prioritized, but students with disabilities rely on the school system for transportation, safety measures, and educational and transitional plans.[31] The opportunities and funding offered by the non-profit organization the Ontario Federation

for Cerebral Palsy (OCFP) can extend to support families and students with CP directly during the pandemic.[32] In addition to the vaccine support fund, covering costs associated with receiving the vaccine, OFCP provides information about support for essential services such as local community support for grocery and medicine delivery.[32] Federal low-cost home internet programs have also been established which is necessary for the increasing reliance on devices for online learning.[31] A gap in support that has been brought to light during the pandemic is support established for post-secondary students. Steps have been taken, including the \$2.2 million provincial investment and the development of the Nova Scotian COVID-19 Response Grant, to provide new career opportunities to disadvantaged and underrepresented youth in the Greater Toronto Area and for post-secondary students with permanent disabilities.[33-34] A study on the impact of the pandemic in nine major Canadian and American universities suggested that “students with physical, neurodevelopmental, or cognitive disabilities and students with all disabilities (physical, learning, neurodevelopmental, or cognitive) are over twice as likely as students without disabilities to experience major depressive disorder.”[35] These results further emphasize that the impact of the pandemic on mental health and wellness also impact the academic outcomes of students.

### Familial and Social Services

There are various support services, both governmental and non-governmental, that are available for families who have children with CP. Different organizations provide different services, so there is a breadth of resources available depending on what a family is looking for specifically. For example, the Government of Ontario provides funding under certain conditions to purchase items or services for children with disabilities, including but not limited to sensory items, technology, items to support home-based recreation and fitness activities, PPE and supplies, and behavioural support plans.[36] Meanwhile, the OFCP supports people with CP through system navigation support, therapies, and financial resources.[37]

At an international level, there are organizations such as United Cerebral Palsy (USA), which assists disabled people and their families through education, employment, assistive technology, resource guides, research and statistics, international resources, housing, and travel and transportation.[38] In Australia, the Cerebral Palsy Support Network helps families find support workers and shares information/advice.[39] There are also support services that are not based in any one country, such as the Cerebral Palsy Family Network, which is the largest online community for families with CP.[40] This organization provides legal advocacy, informational videos, care plans, and resource directories.[40]

During the COVID-19 pandemic, the CP support programs have been somewhat flexible in adapting to the situation. The Government of Ontario and OFCP both have resources available on their websites specifically for COVID-19, such as mental health supports, food delivery, and virtual events.[36-37] However, other organizations either have not

adapted their services for the pandemic specifically, or refer people to other resources outside of their organization for COVID-19 support. Thus, there is an urgent need to adapt some of these programs to meet the needs of the CP community.

	Part 1: Functioning and Disability		Part 2: Contextual Factors	
Components	Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Domains	Body functions Body structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological)  Change in body structures (anatomical)	Capacity Executing tasks in a standard environment  Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities Participation	Facilitates	not applicable
	Functioning			
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers / hindrances	not applicable
	Disability			

Table 1: ICF-CY overview.[7]

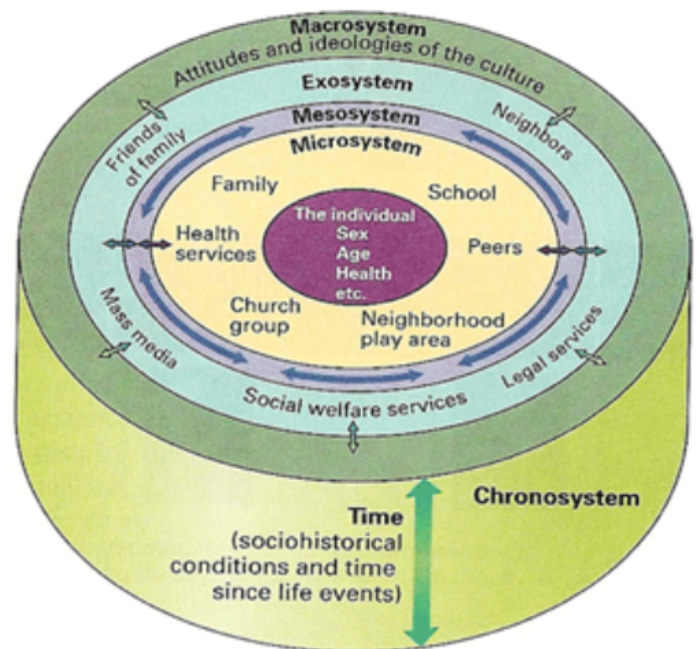


Figure 1: Bronfenbrenner's Ecological Systems Theory[38]

## DISCUSSION

Supports available to children and families affected by CP should reflect evolving healthcare needs as a result of the COVID-19 pandemic. According to Bronfenbrenner's Ecological Systems Theory, a child's development is influenced by proximal relationships and systems.[8] Thus, in proposing adaptations to resources, a child's ecosystem must be taken into account. The ICF-CY framework will be used in tandem with Bronfenbrenner's theory to justify the significance and implications of proposed changes.

### Therapy

Moving forward, schools, physiotherapists, occupational therapists, and other allied health professionals should strive for smoother and more efficient transitions from services being delivered in schools to via telemedicine, so that children and their families can experience less disruptions in care with school closures. Similarly, more reliance can be placed on telemedicine for the delivery of SLT as the demand for this service persists throughout the pandemic. SLT is particularly important for children during critical years of development, when the brain can most easily learn language skills, therefore this therapy is not only needed but also timely.[22] Since this therapy can be offered through telemedicine, the COVID-19 pandemic offers a unique opportunity to research the feasibility and effectiveness of this method; the increased use of this platform over the past decade suggests that this method may be equally as effective as in-person support.[22] Moreover, benefits such as being able to see children in their natural environments, reduced costs, and the increased accessibility offered by the use of telemedicine has been reported by parents of children with disabilities.[41]

Additionally, more research and funding should go towards developing video games and low-cost virtual reality programs to help children with CP improve sensory motor skills from the safety and comfort of their homes.[14,42] Video games and low-cost virtual reality programs have increasingly been shown to be effective as therapeutic interventions for children with physical disabilities and are especially well suited for pediatric populations due to their motivating and playful qualities.[42] For example, novel video games for children with CP have shown promise in improving health outcomes, such as wellbeing, fine-motor skills, and shoulder, elbow, and wrist function, and reducing pain.[43-44] Moreover, although the demand for RT has lessened during the pandemic due to laws that restrict participation in many activities, efforts should continue to be made to include children with CP in social and physical activities that improve their well-being.[22-23]

It is important to continue the support offered through all therapy as they impact the child at each level of the ecological model. All therapies form an important part of the microsystem, as they facilitate interactions between the child and their immediate environment by facilitating movement and play, while SLT most significantly impacts the child's interaction with the larger environment as language forms a fundamental part of perception.[8,45]

Moreover, continuing the delivery of therapy during the COVID-19 pandemic via telemedicine platforms helps children build skills in the body functions and structures, activities, and participation areas of the ICF-CY model.[3,7,18-19,46] While there is overlap, physiotherapy primarily focuses on the body functions and structures component of the ICF-CY by decreasing impairments through stretching and strengthening activities.[3,7] In addition to participation, SLT focuses on the activities component of the ICF-CY, helping the child communicate in ways that may or may not be directly important to them, while OT and RT focus on participation with the aim of helping the child engage in society in ways that are meaningful to them.[3,7,18-19]

### Educational Support and Assistive Devices

Remote learning can allow for an ideal environment mobility wise, though the social restrictions pose a challenge. When in-person classes resume emphasis should be made to make the classroom more accommodating and accessible to children with CP to maximize learning opportunity and ease. Playgrounds, elevators and desk space should be taken into account to help children with CP transition back into the typical education setting. Many of these educational components are designed with typical developmental children in mind and often neglect to include those with physical limitations.

Assistive technology and devices would be considered part of the microsystem when put in the context of Bronfenbrenner's ecological model as they directly impact the child.[8] These devices have implicit consequences for the mobility, functionality and daily life of children with CP. Additionally, adapting classrooms to be more accommodating or consist of assistive technology and devices is in line with the ICF-CY model, which addresses participation, defined as a person's involvement with life and encompasses functioning, social play and peer relationships.[7]

Assistive technology can make physical activity more accessible and provide children the opportunity to exercise more autonomy and decision making capabilities, by allowing them more functional control over everyday routines.

### Familial and Social Services

One way to bridge this gap in services is to offer a centralized, Ontario wide program that connects families affected by CP. This completely new program would address the gaps that exist within non-family centred approaches to care and would be available to children with CP and their families, through clinician- or self- referral. Upon inputting family data, such as family structure, geographic location, needs, and goals, into the program, at the discretion of the family, the algorithm would match families with similar data. Paired families would be able to connect with each other in the presence of a healthcare professional, who would facilitate discussion and guide the families through a program tailored to address the psychosocial aspects of CP. The goal of the program would be to foster positive and long-term connections among families affected by CP.

With the Ecological Systems framework, family and friends are part of the microsystem and have the most direct influence on an individual.[38] With this knowledge, the proposed program is designed to give families maximum impact through interactions with other families on a personal level. Under the ICF model, our proposed program addresses the participation domain by promoting social and community engagement.[7] This program can be extended in application to provide educational support for students and families. As educators play a large role in developmental monitoring and encouraging socializing, their collaboration with families, healthcare professionals, and community workers within the pairing program can promote sustainability and long-term effectiveness of said initiatives. Their unique ability to connect with many families of children with CP at once can promote the sharing of local programs and resources available and gain the trust of the community.

## CONCLUSION

This paper aims to address the array of supports available to children with CP and their families during the COVID-19 pandemic, and how previous methods of service delivery have changed due to social-distancing requirements. A broad understanding of the impact of the COVID-19 pandemic was provided by examining literature on therapies, assistive technologies, and social, familial, and educational services. Furthermore, this knowledge was used to identify the strengths and weaknesses of current supports to suggest evidence-informed future directions. Methods of service delivery implemented during the pandemic may act as short-term fixes for some types of support, and long-term solutions for others.

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