CADTH

ENVIRONMENTAL SCAN

# Care Coordination and Funding of Pediatric Cerebral Palsy in Canada — Project Report


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**Authors:** Charlotte Wells, Deba Hafizi, Jeff Mason, Danielle MacDougall

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## Abbreviations

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| **AB** | Alberta |
| **BC** | British Columbia |
| **CP** | cerebral palsy |
| **CSHCN** | children and youth with special health care needs |
| **GMFCS** | Gross Motor Function Classification System |
| **LPN** | licensed practical nurse |
| **MB** | Manitoba |
| **NL** | Newfoundland and Labrador |
| **NP** | nurse practitioner |
| **NS** | Nova Scotia |
| **ON** | Ontario |
| **OT** | occupational therapist |
| **PT** | physiotherapist |
| **RN** | Registered Nurse |
| **SK** | Saskatchewan |
| **SLP** | speech language pathologist |
| **SW** | social worker |

## Summary


- The objective of this Environmental Scan was to summarize the current state of care coordination and funding for children with cerebral palsy in Canada.
- The Environmental Scan was informed by two surveys (a care coordination survey and a funding survey) and by an existing literature review conducted by an external stakeholder. There was a 70% response rate for both surveys.
- Nine unique organizations from six provinces including British Columbia (two organizations), Alberta (one organization), Manitoba (one organization), Saskatchewan (one organization), Ontario (three organizations), and Newfoundland and Labrador (one organization) provided data that informed this Environmental Scan.
- Four out of seven organizations who responded to the care coordination survey reported offering a formal care coordination program for children with cerebral palsy. These formal programs each had their own eligibility criteria for recipients, who most likely exited the program once they reached adulthood. Three programs were identified as informal but provided similar activities and services to the formal programs.
- Individuals directing formal care coordination programs were often called “coordinators,” including Clinical Nurse Coordinator, Complex Care Coordinator, Service Coordinator, or Clinical Service Lead. Backgrounds for these positions include nursing, social work, and occupational therapy.
- Programs were typically referred to as pediatric care coordination or pediatric rehabilitation programs and included activities such as needs assessments, shared treatment plans, goal setting, coordinating appointments, identifying community resources and financial support, and providing patient and family education.
- Travelling or outreach clinics were provided by all participating care coordination units — as well as small, rural, remote, and isolated areas where geographic location may be a barrier to accessing care programs — in order to reach priority populations and medically complex children.
- Providers of care coordination received a mix of funding from public, private, charity, and out-of-pocket sources for the delivery of services and resources.
- Perceived gaps in funding were reported by multiple respondents, including gaps in funding for mental health, psychosocial assessments, rehabilitation services, social work, support staff, equipment, and transportation for children with cerebral palsy.


## Context

Cerebral palsy (CP) is considered a group of neurological disorders involving permanent motor dysfunction that affects muscle tone, posture, and/or movement as a result of permanent and irreversible damage to the developing fetal or infantile brain.[1] The overall prevalence of CP is approximately 2 per 1,000 live births[1] and affects approximately 1 in 400 Canadians.[2] Although the signs and symptoms of CP are unique to each individual, typical symptoms include poor coordination, stiff or weak muscles, and tremors, as well as issues with sensation, vision, hearing, swallowing, and verbal communication.[3] Diagnosis is based on the child’s development over time; CP is typically diagnosed between the ages of 12 to 24 months; however, earlier diagnosis is increasingly common.[4] Treatment and therapy are focused on maximizing functional independence and participation in daily activities, while minimizing the extent of disability.[5] Children with CP often have complex health care needs that may need to be managed by a variety of health care professionals.[6] For this reason, caring for children with CP can be physically and psychologically demanding for parents and

caregivers who must navigate the health care system and communicate with multiple providers across different settings and systems to obtain the services and support that they need.[7] Care coordination has been identified as a viable solution to alleviate stress, financial burden, and to identify and meet the needs of families of children with CP to improve medical care.[8-10] Optimal care has been reported to involve multiple components including: a patient- and family-centred approach to goal setting; multidisciplinary care with both virtual and face-to-face communication with providers; coordinated appointments with different multidisciplinary providers together at the same visit; development of a shared treatment plan involving health care providers, caregivers, and community-based supports such as teachers, and therapists; and periodic or ongoing re-evaluation of goals to allow for necessary changes to the care plan.[5]

The purpose of this Environmental Scan was to identify how care coordination services are used and funded across the country, as there is lack of clarity as to what care coordination services and resources exist (and how they compare to evidence-based best practices).

## Objectives

This report summarizes information obtained through a literature search and two surveys of key organizations across Canada. The key objectives of this Environmental Scan are, as follows:

- to determine the current state of care coordination services and resources across Canada for children with CP and contrast this to evidence-based best practices, where possible
- to determine the current state of funding for care coordination services and resources across Canada for children with CP and contrast this to evidence-based best practices, where possible.

This Environmental Scan does not include an assessment of the clinical or cost-effectiveness of care coordination or funding services for children with CP. Conclusions or recommendations about the value or place in therapy of care coordination services for CP therapy are outside of the scope of this report

## Methods

The findings of this Environmental Scan are based on a literature review (Literature review: pediatric care coordination for children with Cerebral Palsy — updated, Sunny Hill Health Centre at BC's Children's Hospital, 2020: internal document, Appendix 1) and responses to two surveys distributed to contacts in jurisdictions across Canada that provide care to children with CP. In consultation with external stakeholders and CADTH Liaison Officers, potential survey respondents were approached to gauge interest in the project. Ten people working in eligible organizations expressed interest, representing six provinces including Alberta (AB), British Columbia (BC [n = 2]), Manitoba (MB), Newfoundland and Labrador (NL), Ontario (ON [n = 4]), and Saskatchewan (SK). Responses were not received from contacts in Nova Scotia, Quebec, or from additional contacts from ON. Identified potential respondents were administrators of their organization's programs or services that support care of children with CP.

## Literature Review

A literature review conducted by a CADTH external stakeholder (Sunny Hill Health Centre at BC's Children's Hospital, Appendix 1) was used to inform the project plan for the Environmental Scan, including the survey components and questions. The literature review aimed to identify, review, and compile published evidence on care coordination concepts, models, and their components for children with CP or other relevant populations (Sunny Hill Health Centre at BC's Children's Hospital, Appendix 1).

Specifically, the research questions for the literature review were (Sunny Hill Health Centre at BC's Children's Hospital, Appendix 1):

1. What are current or emerging best practices or standards to ensure high-quality care coordination in practice for children with CP?
2. What comparable pediatric care coordination models have been implemented? How do their key features of setting, care coordination providers, and program structure vary?
3. If an evaluation has been conducted on relevant pediatric care coordination models, what is their effectiveness on family goals, child, and caregiver's health outcomes? What lessons can we draw from for children with CP?

Given the quality, relevance, and timeliness of this literature review, CADTH did not conduct an independent literature review, instead using information from the already identified literature review to inform this scan. The literature search methods were reviewed by the CADTH Research Information Specialist team. Appendix 1 presents the full literature review (Sunny Hill Health Centre at BC's Children's Hospital, Appendix 1.

## Survey Development and Response

Two surveys were developed to address the two objectives for this scan: one to assess the state of care coordination for children with CP, the other to assess the funding of services and resources for children with CP. The surveys were developed after the completion of the literature review and the results from the literature review were used to inform question development. Draft questionnaires were reviewed by the CADTH team and by a working group consisting of health care professionals and families of children with CP. Edits were made accordingly and once questions were finalized the questionnaire was uploaded to the Survey Monkey platform and sent electronically for pilot testing by external stakeholders and by independent CADTH researchers unrelated to the current project.

Following the completion of the pilot testing phase, questionnaires were electronically distributed to the 10 pre-identified respondents, as previously noted. Respondents were given four weeks to complete each survey, with follow-up reminders sent at 2 weeks post-survey invitation.

Respondents who gave their consent have their information represented in this report. Survey responses were excluded if more than 90% of survey questions were incomplete. Survey respondents were given the opportunity to validate their data following CADTH's summary of the survey responses; at that time, some respondents clarified and added to data collected related to their program.

For the purposes of the survey, populations living in small, rural, remote, or isolated communities were defined using the following definitions from Statistics Canada:[11]

- a small population centre is a community with 1,000 to 29,000 people
- a rural area is any area outside a population centre (an area with a population of at least 1,000 and a density of 400 or more people per square kilometre)
- a remote or isolated community is located more than four hours away from tertiary hospital services by ground transportation, with or without road access.

For the purposes of this survey, priority populations included (but not limited to) are First Nations, Inuit, and Métis; newcomers, and racial and ethic minorities; and English- or French-learning families.

### Care Coordination Survey

The care coordination survey contained 48 questions, with a mix of multiple choice, matrix, yes/no, and open-ended questions. The questions focused on the evidence-based practices for CP care coordination identified in the external stakeholder's literature review. The care coordination survey was sent to respondents on February 6, 2020.

Respondents were asked if they had a formal care coordination program based on the following definition by the Agency for Healthcare Research and Quality: care coordination is the "deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services."[12]

Respondents were asked several questions regarding the activities of their care coordination program (formal and informal), care provider team, program structure, and care coordination activities for rural, remote, and priority populations. Respondents were also asked about the specific formal care coordination activities provided by their site with regard to the following five categories identified through the literature review (Sunny Hill Health Centre at BC's Children's Hospital, Appendix 1: 1) Coordination of Care Needs; 2) Planning and Assessment; 3) Information and Specialist Support; 4) Practical Support; and 5) Mental, Emotional, and Social Support. Appendix 2 details the full list of questions asked in the survey.

### Funding Survey

The funding survey contained 22 questions, with a mix of multiple choice, matrix, yes/no, and open-ended questions. The funding survey was sent to respondents on March 16, 2020. Appendix 2 details the full list of questions asked in the survey.

## Findings

The following findings are based on responses received and collected as of May, 2020, and on the literature review results (Sunny Hill Health Centre at BC's Children's Hospital, Appendix 1). An additional response to the funding survey was received in September 2020 as a result of the stakeholder feedback process and is appropriately included and reported here. Nine organizations participated in one of the two surveys, with five respondents participating in both the care coordination and funding surveys. The results are summarized and presented according to each objective.

## Objective 1: Current State of Care Coordination Services Across Canada

There is a lack of consensus on what defines “care coordination” and what activities broadly constitute care coordination. Despite this inconsistency, the field of care coordination is rapidly evolving and literature appears to show support for the concept in improving pediatric care. Effective care coordination may include patient- and family-centred care, effective communication between different providers and patients, accountability and clarity of roles with one central coordinator, a co-developed shared plan that includes participation of the patient and family, and ongoing evaluation of the care plan. More information on these concepts can be found in Appendix 1.

The following section is an overview of some of the various activities performed in select formal and informal care coordination programs in Canada, the providers involved in care coordination for these programs, specific challenges and strategies in rural and remote care, and care coordination in priority populations.

### Care Coordination Survey Results

Seven responses were received out of 10 sent surveys for the care coordination survey (70%). Responses were received from one organization each in AB, BC, MB, NL, SK, and two organizations in ON. For clarity, the two different ON sites will be distinguished as ON Site 1 and ON Site 2.

Appendix 3 provides more detailed results of the care coordination surveys in tabular form.

#### *Activities of Care Coordination Programs*

**Formal Care Coordination Programs**

Four of the seven organizations that participated in the survey (BC, AB, MB, and NL) reported that they provide a formal care coordination service to pediatric patients with medical complexities such as CP. Three of these four organizations specified that they provided care coordination specifically for children with CP.

Respondents were also asked to describe the definition of care coordination used to design the activities provided by their organization. Respondents from BC and AB both followed the definition used from the Agency for Healthcare Research and Quality (the same definition that guided the development of the survey), while respondents from MB and NL noted that they had developed their own definitions. The respondents from MB and NL noted that their definitions also build on the similar theme of working with the patient and family to facilitate appropriate care. Direct responses are listed in Appendix 3.

Overall, the four formal programs shared many components, including identifying resources close to patients’ homes, identifying support resources, conducting needs assessments, gathering information from the patient and family, goal setting, co-developing a care plan, educating patients and explaining navigation of the health system, and coordinating mental health services.

Appendix 3, Table 1 provides more details on what components are present in the identified formal programs.

The respondent from NL reported providing all the activities related to care coordination identified in the survey, whereas the respondents from BC and MB reported providing all but one identified activity. The NL respondent described that care coordination was delivered via a weekly CP clinic where multiple health care providers would meet to discuss needs and action items such as consultations and referrals. The respondent added that a social assistance worker was available to offer practical as well as financial support by facilitating application processes for various program funding; they have also facilitated a transition group for patients transferring to adult services.

From the potential services identified, the organization from BC does not provide educational, social services, or community support beyond the realm of health care but noted it did offer additional services such as referrals to community supports, advocacy support, and quality improvement projects to improve access and quality of care. In BC, the respondent also described activities related to the surveillance of emerging needs, providing follow-up assessments and providing a road map of the care pathway, as well as developing new care pathways to anticipate future needs. The formal program in BC also carries out additional activities such as collaborating with community partners, sharing information and resources, and developing tools to ensure the continuity of care; this was reportedly completed via participation in committees, working groups, online course development, and conference presentations.

The respondent from MB does not manage acute situations directly, but reported that MB has a specific complex care program carried out by a nurse clinician for children, including those with CP, who have complex care needs, (typically level IV or V on the Gross Motor Function Classification System [GMFCS]). The organization from AB reported providing a comprehensive program addressing planning and assessment (surveillance, follow-up, and addressing urgent needs, in addition to planning treatment and scheduling regular appointments), information and specialist support, connecting patients with community resources and activities, and collaborating with social work and community providers to identify and facilitate the needs of patients. Fewer activities are provided related to coordination of care needs, practical support, and mental, emotional or social support. Additional comments were provided by respondents for each of the five categories, summarized in Table 2.

### *Eligibility Criteria*

The literature noted that components of a care coordination program — such as eligibility — can vary depending on who is defining the service and how it is defined.[13] Mirroring this, the survey found each of the four formal programs had their own set of eligibility criteria, as described by respondents. This typically included a diagnosis from a physician or nurse practitioner (NP) and referral — either through a physician, NP, hospital, or in some cases via self-referral. For example, the NL respondent reported that families of children with CP are eligible to apply for care coordination provided they have appropriate medical documentation (e.g., appropriate diagnosis) and referral from a physician or NP. The respondent in MB described a central intake line at Manitoba Possible that could be used by families of children with a diagnosis of CP to enroll in the care coordination services themselves. The MB respondent also mentioned that, while there is no specific medical clinic for children with CP in MB, there is a care pathway to guide all caregivers to make appropriate referrals for clinical care and support. Certain organizations described more specific eligibility criteria beyond a diagnosis and referral. In AB, it was reported that a child with CP would be eligible for care coordination if they require any of the following:

- screening for associated impairments and functional limitations
- surveillance of musculoskeletal complications
- assessment for adaptive equipment
- planning of goal-focused therapy
- tone management
- orthopedic management in collaboration with orthopedic surgeons
- child and family support
- monitoring outcomes associated with specialty treatments.

The BC respondent reported that children, including those with CP, are eligible for care coordination if they require a referral to three or more neuromotor clinics or if they require clinic support as well as community support such as at home or child day programs. In BC, children are selected into the program via a registered nurse (RN), who is responsible for screening patient files for potential inclusion. Patient's files are subsequently referred to a multidisciplinary complex intake review team that then conducts an initial needs assessment.

### *Case Load*

Three out of four of the respondents who identified having a formal care coordination program reported the approximate case load of their program. At the time of the survey, approximately 800 to 1,000 children, including those with CP, were reported to be accessing the care coordination site in AB, approximately 200 children with CP were reported to be accessing the care coordination site in NL, and approximately 20 children with various conditions including CP were participating in care coordination at the BC site.

### *Exit Criteria*

Respondents were also asked if there was a set of "exit" criteria to determine when a child with CP no longer receives care coordination services. Overall, respondents stated that children with CP "exit" their program when the child no longer requires multidisciplinary follow-up; if they moved out of the province or country; and most commonly, when they turned 18 years of age and require transfer to adult services. However, the BC respondent reported that children with CP may continue within the care coordination program up to the age of 19 and the MB respondent reported that children may continue up to the age of 21 if they are still attending high school.

### *Evaluation of Care Coordination*

According to published literature, a successful care coordination program includes the following key indicators: a patient- and family-centred care coordination service, increased child and family satisfaction of health care services received, increased patient family's knowledge and skills in caregiving and advocacy, decreased caregiver stress and isolation through streamlining appointments and saving money and time, obtaining the appropriate services and supports closer to home, and facilitating the appropriate services and supports to meet family goals and needs.[12]

With respect to formal or informal evaluation of their care coordination programs, two of the four respondents reported that their programs were evaluated. Both respondents were asked for more details regarding the process of evaluation and key outcome measures. The

respondent in BC described an informal evaluation process using outcomes related to improved chart flow, collaborative intake processes, and wait time between referral and first assessment to measure the impact of the quality and timeliness of care. According to the respondent, future evaluations will focus on patient outcomes. In NL, program success was reported to be measured through improvements in functional outcomes and progress of the child, as noted in their patient file. Success was also measured through the verbal satisfaction of patient families with care coordination and outreach services.

**Informal Care Coordination**

Three of the seven organizations that responded to the survey reported that they did not have a formal care coordination program. These three respondents (ON Site 1, ON Site 2, and SK) were also asked what activities of care coordination their site provided for children with CP and all three described providing the following activities:

- identifying and acquiring resources close to the patient's home
- managing consultations, therapies, and/or appointments by coordinating interdisciplinary teams in primary and tertiary settings
- initial needs assessment
- gathering information from the patient and family
- goal setting and co-developing a shared plan
- patient education
- explaining how to navigate the health system
- identifying resources for support
- encouraging communication via email, phone, or videoconference.

In addition to these services, the organization in SK reported providing regular meetings with the family, triaging emergency complaints, and advocating and coordinating mental health services support. None of the organizations reported managing acute situations directly, attending appointments with a patient and their family and interpreting medical information or test results, or coordinating educational or social support services beyond the realm of health care. However, ON Site 1 and ON Site 2 reported providing care coordination services for children with disabilities, not just CP, which included coordination of multiple service providers in the community.

### *Providers of Care Coordination*

To minimize gaps and maximize consistency for families, the literature recommends the use of a "lead coordinator" for greater accountability and ownership of patient care.[14] Despite a "care coordinator" role being seen as "crucial" in the literature, the literature also pointed to the duties of the care coordinator and the structure of the role varying due to the external environment the care occurs in, the internal environment of the health care system, the specific individual receiving care, and the nature of the interactions between care providers and patients.[15] The literature reported that the majority of pediatric children with medical complexity and children and youth with special health care needs (CSHCN) groups (10 of 13) did not have a single care coordinator but used multidisciplinary groups with a nurse lead to coordinate care, as nurses and NPs have clinical skills, interpersonal skills, and educational requirements for the position. Team-based and multi-agency support is also

recommended as best practice for the care of children with medically complex needs, such as those with CP.[14]

This was partially reflected in the survey results, with three of the four formal programs having a designated care coordination role and all of the identified informal programs leveraging other professionals involved in the care to perform overall coordination duties, frequently as a multidisciplinary team. All respondents additionally described providing counselling support and psychosocial assessments, either through a psychologist, social worker, or in some cases the care coordinator who referred individuals to appropriate services as needed. The literature described a consistent role for individuals tasked with care coordination — namely, to provide the coordination of care needs, planning and assessment, information and specialist support, and emotional and practical support.[15] These roles were reflected in the survey questions, as respondents were asked about these specific care coordination activities and how they are integrated into the program.

**Formal Programs**

Three respondents with formal programs (AB, NL, and BC) reported that their service or program had a designated person in a care coordinator role. Two of these programs (AB and NL) noted using multidisciplinary teams led by a designated and consistent contact for pediatric patients with CP, who is also one of the nurses on the team. This is in line with reported models of care coordination in the literature that noted that the nurse on the team was a key driver of care coordination success given the profession's core standard of patient-centred care coordination.[16] This is also in line with the style of care coordination provided by some of the informal care programs and the CMC and CSHCN groups in the literature.

Administrators of formal care coordination programs were often referred to by respondents as "coordinators," with titles including Clinical Nurse Coordinator, Complex Care Coordinator, Service Coordinator, Case Coordinator, or Clinical Service Lead, with professional backgrounds including nurse (RN, nurse manager, licensed practical nurse [LPN]), occupational therapist (OT), and social worker (SW). In NL, the leader of the multidisciplinary care coordination team was a nurse coordinator (a care coordinator with a nursing background) who facilitates care in both the tertiary and local settings through travelling clinics. In MB, while the respondent reported that there is not a designated person in the care coordinator role, they did specify that in MB, most children with CP have an assigned case coordinator through Manitoba Possible (formerly known as the Society for Manitobans with Disabilities) who collaborates with other team members and connects families to services and resources including home care services. According to the MB respondent, children with CP with the most medically complex needs will have a nursing or SW case coordinator from the Integrated Children's Services team.

Two of the formal programs — in AB and NL — reported administrating programs via a coordinated multidisciplinary team. The multidisciplinary team is involved in all aspects of care and care coordination. In AB, the site's care coordination team was reported to consist of a general practitioner, a specialist physician, an NP, a nurse and nurse manager, a physiotherapist (PT) and OT, a speech language pathologist (SLP) and SW, a psychologist and dietitian. The GPs, specialist physicians, and NPs all provided patient education in their formal program, while the triage of emerging medical issues and the conducting of initial needs assessments were the responsibility of GPs and specialist physicians. It was reported that GPs identify and acquire resources close to the patient's home and specialist physicians manage acute situations directly alongside the NP, who also provides information

and specialist support. The AB respondent further clarified that the management of consultations, therapies, and coordination of appointments and teams is carried out in a tertiary care setting but not in a primary care setting. The nurses, PTs, OTs, SLPs, and SWs were all described as being involved in managing consultations, therapies, and/or appointments, planning and assessment, information and specialist support, practical support, and mental and social support activities. (Table 1 contains a full list of these activities). Psychologists were reported to assist with learning needs and mental health, and the dietitians were reported to assist with monitoring nutrition and growth. Furthermore, the respondent reported that patients within the care coordination program receive support from SWs, who identify community resources and activities to address patient needs.

In NL, the site's care coordination program — also known as the Pediatric Rehabilitation Process — consists of GPs (at the community level), specialist pediatricians (neurologist, developmental pediatrician, orthopedics), a nurse, a nurse manager, an LPN), a PT, an OT, an SLP, an SW, a social assistance worker, a recreational therapist, a psychologist, and an orthotist. The GPs, specialist physicians, nurses, and SWs are involved in activities of mental and social support, whereas PTs, OTs, and SLPs are involved in facilitating educational support, social services, or community support beyond the realm of health care. Recreational therapists, orthotists, and music therapists were described as organizing and coordinating recreational services.

According to the AB and NL respondents, the multidisciplinary health care providers collaborate with one another by attending regular team meetings, facilitating appointments, communicating referrals via a written or shared plan, and providing ongoing communication with families and patients.

**Informal Programs**

The respondents for the identified informal programs noted that there was no official care coordination role. In the absence of this, other professionals facilitate care coordination at these sites. ON Site 1 reported that care coordination was the responsibility of the medical director, while ON Site 2 reported it was the role of multiple health care providers such as PTs, OTs, SLPs, and SWs. The SK respondent reported that patients with complex care needs are assigned to a rehabilitation coordinator (OT), who develops a care plan that is then carried out by the multidisciplinary team. The team includes a specialist physician, NP, nurse(s), PT, OT, SLP, and SW. All three sites that reported having formal care coordination programs reported that care coordination was carried out by a multidisciplinary team. This was similar to the CMC and CSHCN groups in the literature, who frequently used nurses together with other support members such as clinical SWs, psychologists, family advocates, project managers, administrative coordinators, and dietitians as a multidisciplinary team to provide care.

### *Referrals to Medical Specialists*

Referrals to medical specialists are handled by different professionals, depending on the jurisdiction. According to the BC respondent, referrals to medical specialists are directed by GPs, specialist physicians, NPs, and nurse clinicians. For multidisciplinary team assessments, the BC respondent reported that a complex intake review committee made up of an experienced RN, OT, PT, and SW reviews each chart and conducts an initial needs assessment. In AB, medical referrals are directed by nurses and PTs; and in MB, referrals are directed by the multidisciplinary team, including the GP, specialist physician, NP, nurse (e.g., RN, LPN, nurse manager), PT, OT, SW, and the service coordinator. In NL, the

respondent reported that each week after the program's CP clinic, the multidisciplinary team has a conference to discuss consultations and referrals, which are then carried out by the care coordinator.

## Care Coordination for Rural, Remote, and Isolated Communities

There were no responses regarding care coordination for small, rural, remote, and isolated communities of informal programs (i.e., ON Site 1 and 2, and SK). Therefore, the following sections refer to formal programs, only.

### *Challenges to Accessing Care Coordination for Formal Programs*

Respondents were asked if the process of accessing care coordination services at their sites differed for those living in small, rural, remote, or isolated communities compared with those living in larger population centres. Two of the respondents (BC and AB) reported that the process did not differ due to strategies in place to improve access for these communities. These strategies are subsequently described. In contrast, the other two respondents (MB and NL) reported that the process did differ for patients in small, rural, remote, or isolated communities. These respondents described that challenges such as accessing care and communicating with staff exist for pediatric populations in small, rural, remote, or isolated communities and that staff and resources are limited in these areas.

### *Strategies to Improve Access for Formal Programs*

All four respondents reported that their program employed strategies to fill in gaps and remove barriers to timely care in small, rural, remote, or isolated settings. In MB, the respondent reported that strategies include phone consultation, virtual care, and coordinating face-to-face visits with medical appointments in Winnipeg at a centre for specialized services for children and youth. The BC respondent described similar measures including phone consults, coordinating community telehealth appointments, and coordinating face-to-face appointments with other medical clinics in the Vancouver area to minimize the number of trips, length, and depth of disruption for families from small, rural, remote, or isolated communities. At the time of the survey, videoconferencing was another strategy being explored by this respondent to break down barriers for children in small, rural, remote, or isolated communities. Shifts in access to technology and leveraging new technology were also noted in the literature as factors in facilitating better access to care for families, with shared IT infrastructure and other technologies being a priority.[14] The NL respondent reported a rehabilitation program referred to as "Day Patient Stay Admissions," whereby children in rehabilitation who require further treatments such physiotherapy or primary care are scheduled, in advance, into daily clinics for various disciplines. Participants may attend the rehabilitation program for one week or more depending on the treatments needed. Program participants travel from anywhere in the province and those travelling into urban areas from a small, rural, or remote area are provided accommodations such as a hotel or Ronald McDonald House located near the clinic site.

All four respondents reported providing outreach or having satellite clinics in small, rural, remote, or isolated communities. Regarding outreach services, members of the health care team travel to outlying communities to administer and plan ongoing care in collaboration with the primary care providers of the children with CP living in these areas. Two respondents provided the frequency of these travelling or outreach clinics: The AB respondent reported that outreach services are provided twice a year and the NL respondent reported that there are three travelling clinics that are provided yearly to the western, central, and Labrador areas of the province. The AB respondent reported that their site has outreach clinics in Red

Deer, Grande Prairie, and Fort McMurray, whereby a physician and RN work with the child's Allied Health Team to provide care. The physician and RN may also visit outlying communities within the city that have a large population of severely complex children (GMFCS Level V), including those with CP who may have difficulty accessing their clinic directly. In NL, members of the travelling clinic vary depending on the location of travel; a CP-specific nurse coordinator facilitates the western travelling clinic and a general nurse coordinator facilitates the central and Labrador travelling clinic. All travelling clinics consist of a nurse coordinator, LPN, SW, psychologist, orthotist, PT and OT; the central and western areas additionally have a pediatric-specific PT and OT.

### Care Coordination for Priority Populations

Respondents were asked if the process of accessing care coordination services at their site differed for families of children with CP who are members of priority populations. Two respondents (MB and NL) reported "yes." The MB respondent reported that children living with CP in First Nations, Métis, and Inuit communities receive care coordination from Jordan's Principle case managers instead of care coordinators at the organization. Jordan's Principle is a child-first legal requirement meant to prevent First Nations children from experiencing inequities or delays in receiving essential public services that are ordinarily available to other children.[17] The MB respondent further reported that OTs, PTs, and SLPs play a significant role in First Nations communities by assisting in providing care coordination services to children with CP on and off the reserve. The NL respondent reported that children living with CP on the reserve may receive care coordination from Jordan's Principle case managers and their care is also coordinated, as needed, by nurse coordinators at the hospital, either as an inpatient or outpatient. The NL respondent further reported that their team's Labrador travelling clinic visits participants of their care coordination program (also known as the pediatric rehabilitation program) living on reserve to provide better access to care services.

The two respondents (BC and AB) reported that there was no difference in care for the children of priority populations described and that their organizations take multiple measures to ensure equitable access to services for all clients and are mindful of geographic location and barriers that priority populations face.

## Objective 2: Current State of Funding for Care Coordination Services and Resources Across Canada

Seven responses out of ten sent surveys (70%) were received. Respondents were from BC (two organizations), ON (three organizations), MB (one organization) and NL (one organization). For clarity, the BC sites are distinguished by BC Site 1 and BC Site 2, and the ON sites are distinguished by ON Site 1, ON Site 2, and ON Site 3.

The literature suggests that social care costs, especially during childhood, are a main health care expenditure associated with caring for someone with CP.[18] One study found that households with a child living with CP as compared to a child living with another special health care need had significantly higher out-of-pocket expenses, financial burden, time spent caring for the child, and greater impact on family work life.[19]

In response to questions about how various services and resources were funded, most services and resources were reported to be funded by a mix of public, private, charity, and out-of-pocket sources. Funding frequently comes from multiple sources for equipment, supplies, medication, home renovations, rehabilitation, counselling, respite care, nursing

support, and education support. All of the respondents reported using public funding for equipment and rehabilitation therapies, whereby public funding was less common than out-of-pocket sources for home renovations. A summary of survey responses is presented in Table 3.

BC Site 1 reported that there were several different additional funding services provided by public payors including the At Home Program, Fair PharmaCare, and the Healthy Kids Program. However, the respondent noted that these are not specific to CP. The At Home Program in BC is a function-based assessment rather than a diagnosis-based model[20] and is designed to support children and teens with a severe disability or with complex health care needs.[20] The respondent further elaborated that families who are not eligible for public funding due to level of function or income status rely on private insurance, charities, or out-of-pocket sources in order to access equipment, services, medications, and therapies. Additional funding from charities are used to pay for sports and recreation programs, art and music therapy, van modifications, and time-limited private therapy to work on specific skills. The respondent from BC Site 1 reported that there are two charity funders specific to CP in BC: the Jason & Rand Fund and the JGL Foundation. The Jason & Rand fund provides an equipment subsidy through the Cerebral Palsy Association of BC.[21] The JGL Foundation is a private charity that provides grants to individuals with CP to improve access to equipment, assistive devices, and therapies such as traditional physiotherapy or therapeutic horseback riding in order to enhance mobility and independence.[22] Additional out-of-pocket funding is used for alternative therapies such as naturopathy, homeopathy, and cannabidiol oil.

The ON sites reported that additional funding from public payors is used in medical expenses, some recreational expenses, and some counselling expenses. Additional funds from charity are used for camps and vehicle modifications, and additional funds from out-of-pocket sources are used for private therapy such as OT, PT, SLP, and SW.

The respondent from MB noted that additional funds were used from public payors but did not elaborate what the funds are used for, and additional funds from charity are used for day camps and family support programs.

## Funding Allocation Across Various Age Groups

Three out of seven respondents from BC Site 2, and ON Site 2 and 3, reported that age does not determine how funding is allocated. The other four respondents reported that funding was allocated to children aged zero to 18 years (MB, NL, and ON Site 1) or zero to 19 years (BC Site 1), aligning with the age eligibility for care coordination services, as well.

## Funding Allocation Across Various Levels of Function

Three respondents from MB, NL, and ON Site 1 reported that the GMFCS level was utilized to determine how funding is allocated. The MB respondent reported that children with GMFCS Levels I and II do not receive the same level of funding for equipment and may not be eligible for therapy services in the school compared to children with GMFCS Levels III to V. The respondent from ON Site 1 reported that children with CP receive funded services if they require complex care generally associated with a higher GMFCS level. In addition, the ON Site 1 respondent reported that children with GMFCS Levels of IV and V are eligible to receive funding from the Make-a-Wish Foundation and can apply for this funding with the assistance of the social work department at their hospital site. The NL respondent described that the provision of resources and services is dependent on the care that is needed and the level of function, as well as the family's financial needs. The NL respondent reported that

families of children with CP may apply to a number of programs to access support such as the Special Child Welfare Allowance, NL Prescription Drug Program (NLPDP) or Direct Home Services Program. [23] Typically, respondents reported that children who have medically complex needs (i.e., requiring assistive devices) receive more services to meet these needs.

### Gaps in Funding

When prompted, all respondents reported perceived gaps in funding for children with CP. For example:

- One site reported a gap in funding for transportation.
- One site reported a gap in funding for social work staff and support, which creates a gap in access for counselling and mental health support.
- Two sites reported a gap in funding for higher-functioning children and middle-income families.
- One site reported a gap in funding to meet the needs and demands for rehabilitation and therapy services.
- One site reported a gap in public funding for equipment costs.
- One site reported limited funding for recreational services, such as health and fitness maintenance, camps, art, and music therapy.

Three respondents (ON site 1, BC site 1, and BC site 2) expressed concerns that families will often narrowly miss eligibility for public programs because the cut-offs for funding are set at a lower functioning level (e.g., the GMFCS level is too low) or the family income is considered middle instead of low income. Given such gaps in public funding, families often pay out-of-pocket or apply for charity funding to obtain needed equipment, care, and support to empower the development of their child with CP. Moreover, the equipment needs and out-of-pocket expenses of children with complex disability, such as CP, are widespread and parental time to support caring for the child is extensive.[24]

### Funding Services for Families in Small, Rural, and Remote or Isolated Areas

One respondent in NL specified that patients in small, rural, and remote or isolated areas are eligible to receive travel funding. The respondent reported that travel funding for these areas may be accessed by completing an application form via the social assistance worker at this site. The other six respondents reported that there is no specific funding available for patients living in small, rural, and remote or isolated communities.

### Funding for Priority Populations

Six out of seven respondents indicated that there is funding available specifically for priority populations. Three respondents specified that patients with CP from First Nations, Métis, and Inuit communities are eligible to receive funding for medical equipment or therapy through Jordan's Principle. The respondent from BC Site 2 reported that children with CP can also access equipment through the Aboriginal Infant Development Program and the Aboriginal Supported Child Development program. It was further specified that families of children with CP from priority populations would typically need to apply directly for the population-specific funding resources, such as those at the provincial and federal levels. The respondent from BC Site 1 also added that there is funding available for First Nations, Métis,

and Inuit children with CP living on reserves through their respective communities. For example, children with CP of First Nations status are eligible to receive funding through the First Nations Health Benefits program and/or the federal Non-Insured Health Benefits program. Refugees new to Canada within the past year are eligible to apply for the Interim Federal Health Program, which can cover supplemental costs such as rehabilitation therapy and equipment provided there is appropriate medical documentation.[13]

The respondent from ON Site 1 specified that certain First Nations charity groups donate to the care coordination facility for patients with CP or to patient families directly; however, this is not a consistent source of funding.

## Limitations

Although the survey respondents provided invaluable information, not all relevant agencies and provinces were represented. Providers in other jurisdictions and provinces or territories, as well as members of First Nations, Métis, and Inuit communities were not represented. A further limitation was that surveys were only available in English, limiting the inclusion of primarily French speaking facilities and respondents. Another limitation of the survey was the participation rate of 70% for both surveys. A potential factor for the lower response rate was the COVID-19 pandemic, which overlapped with the survey time-period and likely took precedence over time and resources at the participating facilities.

## Conclusions and Implications for Decision- or Policy-Making

The overall objective of this Environmental Scan was to determine the current state of care coordination services and resources, and their funding, across Canada for children with CP. The survey responses from administrators of care coordination programs for children with CP, together with a previously conducted literature review by an external stakeholder, were the primary sources of information for this Environmental Scan. Responses came from six provinces including AB, BC, ON, MB, SK, and NL. However, due to the lack of representation from all Canadian jurisdictions and the small sample size, conclusions from the survey data should be interpreted with the limitations in mind.

Based on feedback from the care coordination survey, four out of seven respondents reported providing a formal care coordination program. Activities of care coordination included gathering information about the patient's and their family's needs, triaging acute and emerging medical needs, planning and assessment, specialist support, practical support, mental/social support, and patient education and advocacy skills. Activities consistent among all programs were identifying resources for the patient, initial needs assessment, gathering information from the patient, goal setting, co-developing a shared plan, patient education, health care navigation support, and advocating and coordinating mental health services. Providers of informal care coordination provided similar activities for children with CP. These activities were in line with those described in the literature.

Team-based, multidisciplinary, and multi-agency support are considered best practice care for children with medical complexities such as those with CP. Two respondents reported providing formal care coordination via a multidisciplinary team; however, all seven programs that responded to the care coordination survey stated that at least one or more disciplines were involved in the care coordination of children with CP. The primary and consistent

contact for the formal multidisciplinary programs was a nurse coordinator, which was in line with successful models of care coordination in the literature.[14] The number and types of disciplines were generally the same between these sites (with few exceptions) and typically included a general practitioner, specialist physicians, NP, nurses, OT, PT, SLP, SW, and psychologist.

Children were eligible for care coordination programs if they had a medical diagnosis such as CP; referral to the program through a doctor, NP, hospital, or self-referral; and in some cases medical documentation that the child is accessing multiple care services such as community or multidisciplinary support. Self-referral was described by one site in MB, which reported that case coordinators are assigned via a service known as Manitoba Possible. Most sites had a specific complex care program for children with complex care needs. Caseloads were reported and included up to 1,000 children currently accessing services. Typically, children exited a care coordination program when transitioning to adult services or they no longer required the service. All of the formal care coordination programs conducted outreach clinics for outlying communities to improve access to care for priority populations and medically complex children. Evaluations of formal care coordination programs are needed to assess the impact of these services on patient outcomes and these are ongoing in many programs.

Based on feedback from seven responses from the funding survey, respondents identified that resources and services for their site were funded by a mix of public, private, charity, and out-of-pocket sources. Although public funding was reported to be available for most services and resources, respondents described that families often had to pay out of pocket or seek charity funding in order to acquire the resources and services necessary for the improved development of their child's functional independence. Respondents further identified several perceived gaps in funding for children with CP and their families. Some of these gaps included funding for transportation, mental health support, psychosocial assessments, limited staff and resources, limited recreational funding, respite care, and lastly, gaps in funding for children with CP who are higher functioning or from middle-income families who may be struggling to pay for services and equipment without government assistance. Certain jurisdictions, such as NL, have a more comprehensive list of public funding programs to assist families of children with CP, including travel funding, and to obtain necessary services and resources. Eligibility of these NL programs, such as the Special Child Welfare Allowance program, are typically based on a medical diagnosis of CP, the child's functioning, and family income.

Overall, this report provides an overview and description of some care coordination models and programs that exist across various jurisdictions in Canada. Certain programs reported a more comprehensive list of care coordination activities compared to others. This document may be used to identify areas for development in order to make improvements to the care of children with CP and their families.

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# Appendix 1: Literature Review

## Literature Review: Pediatric Care Coordination for Children with Cerebral Palsy, September 2019

Sunny Hill Health Centre for Children;
Child Development & Rehabilitation Evidence Centre
BC Cerebral Palsy Project
Updated: September 30, 2020

## Introduction

Sunny Hill Health Centre for Children is embarking on a multi-year project to improve evidence-informed care for children living with cerebral palsy (CP) in BC. This initiative was formed to address the reality that children with CP in BC are underserved and have many unmet needs. This project is led by the BC CP Advisory Committee, comprised of family advocates, physicians, nurses, social workers, therapists, and other community partners. One of the three identified priorities for the BC Advisory Committee is care coordination.

Caring for children with CP involves managing complex health care needs and the burden is physically and psychologically demanding for parents and caregivers (1). Most families must navigate alone between disconnected providers across different settings and systems to obtain the services and support that they need. (2) The lack of family-centered care coordination is further complicated if a child has a dual diagnosis of a neurodevelopmental disorder like CP and one or more mental health disorders (3) Informed by a literature review, environmental scan and interviews with families, the BC CP Advisory Committee will develop and propose a new model of care coordination that fits the BC context and lived-experience of families of children with CP.

The intention and purpose of proposing a new care coordination model is to reduce caregiver burden and enhance health outcomes and quality of life for children with CP and their families. The BC CP Advisory Committee's subsequent work is grounded in the following definition of high-performing pediatric care coordination developed by Antonelli et al. in 2009:

> "A patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families.

The defining characteristics of high performing pediatric care coordination are:

1. Patient- and family- centered (PFC)
2. Proactive, planned, and comprehensive
3. Promotes self-care skills and independence
4. Emphasizes cross-organizational relationships." (4)

At this first stage, this literature review aims to identify, review, and compile published evidence on care coordination concepts, models, and their components for children with CP, and will consider comparable models that exist for other relevant populations.

## Review Questions

1. What are current or emerging best practices or standards to ensure high-quality care coordination in practice for children with CP?
2. What comparable pediatric care coordination models have been implemented? How do their key features of setting, care coordination providers, and program structure vary?
3. If evaluation has been conducted on relevant pediatric care coordination models, what is their effectiveness on family goals, child, and caregiver's health outcomes? What lessons can we draw from for children with CP?

## Literature Review — Key Messages

- In essence, care coordination is the "non-face-to-face" communication activities and time spent between medical appointments to improve quality of care and reduce the financial, time, and emotional burden for caregivers.
- Care coordination is a viable solution to alleviate the unmet needs, stress and financial burden of families affected by children with CP and decrease the risk of medical errors. It has the ability to address services and functions among families and professionals spanning multiple organizations and sectors.
- A care coordination service or program must be well defined and understood, with functions and responsibilities explicitly detailed.
- The literature search yielded virtually no studies that involved children with cerebral palsy. Instead the search scope was expanded to include two distinct populations: children with special healthcare needs and children with medical complexity.
- There is no single recommended patient- and family-centered care coordination model. Adapting applicable critical attributes and elements from existing successful care coordination services is suggested. This will allow a custom-tailored care coordination model which ideally considers resources available in BC's health care system, patient and family needs and preferences, increased integration of primary care providers (PCPs) and tertiary care services, and ensure access equity of care coordination availability across the province.
- Key success indicators of patient- and family-centred care coordination service:
  - increase child and family satisfaction of health care services received and caregivers feeling less alone in managing all the required needs of CP;
  - effectively acquire and facilitate the appropriate services and supports to meet goals and needs, as specifically identified by families in their care plan;
  - decrease caregiver stress through streamlining appointments, money and time saved, obtaining the appropriate services and supports closer to home;
  - and empower the family's knowledge and skills in caregiving and advocacy.
- Critical to effective communication within a care coordination team and its activities will be to develop documentation in the form of a care plan, co-developed with the child and family. At the most ideal level, it will
  - incorporate multiple electronic health record (EHR) components (e.g., medication lists, hospitalization summaries)
  - be easy to update by all care team members involved across agencies and systems
  - and accessible to providers and families across care settings.

## Literature Review – Findings

### Target Population

Children with CP can have a wide spectrum of physical, cognitive, communication and behavioural issues requiring regular and ongoing rehabilitation services including different types of therapy as well as physician, psychology and nursing services (5). In the initial literature search, only one study related to care coordination specifically involving children with cerebral palsy was found. Therefore the target population was broadened to include care coordination models for: Children and Youth with Special Health Care Needs (CSHCN), and Children with Medical Complexity (CMC). The CSHCN population includes children who have or are at increased risk of a chronic physical, developmental, behavioral, or emotional condition and require health care and related services of a type or amount beyond that required by children generally (6). CMC represents a small subset of CSHCN who have "high family-identified needs; complex chronic disease necessitating specialized care; functional disability; and high health care utilization" (7). Children with CP can be included in both these broader populations. The search for care coordination models for CSHCN and CMC yielded 24 relevant articles.

### The Health Care Environment in British Columbia

In BC, programs and services that children with CP require from health, social, and education sectors are fragmented as a result of the number of separate provincial Ministries and Health Authorities responsible for delivering them. This delivery design fails to ensure a continuum of care due to the uncoordinated nature between these entities and their services. (3) CMC require frequent hospitalizations and are at greater risk of medical errors caused at least in part by poor communication between hospital and community providers (2). Care coordination is not consistently available or delivered to address the myriad of issues families face. Inequity arises especially for families living in remote communities away from pediatric tertiary centres that offer care coordination services. Without sufficient resources and support to overcome the barriers of travel, the child's care is constrained by local primary care providers' capacity. At the most ideal level, the impact of high quality care coordination for CMC including CP would alleviate the families' financial, time, and emotional burden, and increase tangible support for caregivers. (8)

### Care Coordination Definitions, Best Practices and Standards

There is a lack of consensus on the definition and use of the term 'care coordination' (Appendix 1), and this issue was raised in 5 of the 24 full-text articles reviewed. (8–13) For this review, special attention was given to studies that applied all or part of the high performing pediatric care coordination characteristics as specified for the project above. An interchangeable concept closely examined was the "medical home" approach for CSHCN and CMC in the United States, as its principles matches closely the specified high quality care coordination characteristics. The medical home is defined as:

> "Providing comprehensive and high-quality primary care. A medical home is not a building or place; it extends beyond the walls of a clinical practice. A medical home builds partnerships with clinical specialists, families, and community resources. The medical home recognizes the family as a constant in a child's life and emphasizes partnership between health care professionals and families." (14)

Adding to the landscape of complex care for CMC and CSHCN, there are similar job titles used such as case or care management, care coordination counselor, nurse coordinator, key worker, family support or patient navigation (11,12). It is worth pointing out the relationship between care integration and care coordination. Care integration is defined as:

> "The seamless provision of health care services, from the perspective of the patient and family, across the entire care continuum. It results from coordinating the efforts of all providers, irrespective of institutional, departmental, or community-based organizational boundaries."

This term describes a long-term vision of system transformation and theoretically requires quality care coordination in order to achieve it.(12)

Despite the lack of a consistent definition and an absence of any definition at all in some studies, pediatric care coordination is an area that continues to evolve. Results from studies support the efficacy of this approach for improving the family and child's quality of life, and cost savings for the health care system (9,11,15,16).

The most promising literature for unifying key elements for quality pediatric care coordination comes from reports and research on care coordination for CMC by researchers affiliated with the Lucile Packard Foundation for Children's Health (8,12,17,18) and the U.S. Department of Health & Human Services' Agency for Healthcare Research and Quality.(19)

Within the definitions used in reviewed literature, several frequently cited attributes emerge that are especially relevant for vulnerable and at-risk populations like CSHCN and CMC. The development of a pediatric care coordination model for children with CP can draw upon these as guiding principles for best practices:

- *Patient and Family-centered*: The child and family are at the centre of a collaborative partnership of both concepts of care coordination and medical home. As participants in decision-making, their assessed needs, priorities, goals, values, culture and traditions are considered to be guiding principles for a care plan.
- *Effective communication*: Members of the child's care team including primary care providers, clinical specialists, the family and any associated support members rely on each other for exchange of information in order to manage the child's health care activities. Routine, reciprocal, and timely communication establishes trust between all participating members of the child's care team and empowers caregivers to optimally manage their child's care through education and skill-building.
- *Accountability and clarity*: Each member requires knowledge about their and others' own roles and responsibilities as participants of the care team, clearly delineated – with one central care coordinator who has the ability to facilitate care across departments, organizations, and locales.
- *A co-developed shared plan*: Development of a team-based care plan enables family and patient participation. The child and family's needs and goals collected during an initial assessment forms the core of the plan. The plan needs to be easily accessible and usable, and referenced as the main blueprint to guide treatment, therapies and any decision-making by all involved.
- *Ongoing evaluation*: Ensure regular monitoring and a feedback loop about the ongoing services amongst clinical service providers and family is in place, allowing necessary changes to be modified to the care plan.

*Pediatric Care Coordination for CSHCN and CMC: Implementation*

Components of a pediatric care coordination service's design such as purpose, scope of delivery, operational structure, and eligibility are all dependent on how it is defined and who defined it. As discussed above, the different definitions of care coordination used reflect how broad the concept is and results in a wide array of models implemented. Contributing to the diversity is also a lack of consensus on what constitutes best practices within the field. (8) There is no singular ideal model for all CSHCN and CMC. Components of the models can be adapted to a particular system's capacity in terms of resources, personnel, and patient needs to construct a model that will best fit a given environment (8,15).

A total of 13 pediatric care coordination programs for CSHCN or CMC were examined in the full-text review. The studies were mostly based in the U.S. and Canada, and one each in Italy and Australia. Even though the term care coordination was not explicitly defined in each study, some services' descriptions included achieving a goal of either better care integration or a medical home model (12). This allowed the assumption made that core elements of care coordination were considered for the program's design. Each program varied greatly in its setting, scope of service, length, resources and personnel involved, and evaluation focus.

**1. From where is care coordination performed?**

The programs examined included a range of environments where care coordination is performed. These included:

a. Local community, by PCPs
b. At a tertiary pediatric hospital, as an outpatient service
c. At a tertiary pediatric hospital, as an inpatient service
d. At the family home remotely via telehealth services (phone and videoconference)
e. A combination of the above settings

Every service model's structure had its distinct benefits and disadvantages for the families involved. For example, care coordination available only through tertiary care facility-based programs aren't feasible for families that live far away from those sites, traveling repeatedly for care can be disruptive and costly.(20) In addition, tertiary care coordination providers may lack knowledge of community-based services, limiting their ability to provide tailored and comprehensive care coordination. PCPs such as family physicians also experience barriers to providing quality care coordination; including the extra time required during visits, unfamiliarity on conditions of CSHCN and CMC, complexity of coding and billing, and limited reimbursement (2,21–23). This is particularly evident in the United States where the reimbursement system is complicated and fractured between the private insurance and government sectors. On the other end of the spectrum, advantages of a structured care program in the tertiary care setting include proximity to specialists and dedicated medical expertise in complex care. (24,25)

Models that featured collaboration between care coordinators based at a tertiary care centre and local PCPs showed the most promise and potential in creating a comprehensive service that was accessible to most families.

**2. Who performs care coordination?**

One systematic review examined the nature and composition of the care coordinator role for CMC during a critical phase, as they transitioned from hospital home. This review reported the role was crucial to providing sustainability and continuity of care for families. (11) But the

scope of a care coordination program is subject to infinite variations due to its design, inherently meaning the intended and actual duties for a care coordinator role can vary too according to four key factors:

- The external environment – the economic, political, socio-cultural, legal and technological environment in which the health care service provider operates
- The internal environment – the structure, size and funding of the health care system
- The individual – specific skills and experience of the care coordinator brings
- The interaction – the nature of the relationship and interaction between the care coordinator, the child and the family. (11)

A majority of pediatric care coordination programs for CMC or CSHCN, 10 out of 13, were comprised of multidisciplinary teams with nurses leading as the central care coordinator role. The variety of the nurses' designation included registered nurse, pediatric nurse practitioner, nurse clinician, complex care nurse, and advanced practice registered nurse. After nurses, clinical social workers were the preferred choice of care coordinators for the examined programs. Other supporting members on care coordination teams included physicians in hospitals, local primary care providers, psychologists, family advocates, project managers, administrative or appointment coordinators, and dietitians. There was one study that examined the role of community family physicians in Italy exclusively providing and documenting time spent on care coordination services.

To minimize gaps and maximize consistency for families, accountability and ownership over a child's care coordination, a "lead" care coordinator or a member who is "most responsible" was identified and emphasized for some programs. (26)

The advantage of a larger comprehensive care coordination team was having the right personnel that can perform the care coordination duties and deliver clinical care together under one setting. In addition, diverse teams that comprised of members across different specialities meant higher efficiency of "matching skill set with tasks". Some care coordination models used non-physicians to perform many of the more administrative services, such as direct communicating between care teams or streamlining appointments for families. (26)

**3. What are the core tasks of care coordination?**

In the 2016 systematic review of the care coordinator role for CMC internationally, the core expectations of the care coordinator service were found to be consistent. The intentions of care coordination for CMC are to provide: coordination of care needs, planning and assessment, information and specialist support, and emotional and practical support. (11)

The AHRQ (US Agency for Healthcare Research and Quality) and National Quality Forum (NQF) also recommend that effective care coordination should help in the management of information and communication, development of a plan of care/goals, establishment of accountability, and facilitation of transitions (27).

Of the 13 care coordination models examined, these tasks performed by a care coordinator or the care coordination team matched the aforementioned expected responsibilities:

a. Coordination of care needs

- Identifying and acquiring care and support services closer to the child's home community

- Managing consultations, therapies and other health care appointments by organizing and collaborating with various care teams in both primary and tertiary settings
- Advising and managing emergent or acute situations directly

b. Planning and assessment

- Initial needs assessment, gathering of the child and family's profile and goal setting
- Developing a type of shared care plan that co-developed with the family and regularly updated by the family and health care providers

c. Information and specialist support

- Providing patient education
- Explaining how the tertiary care system operates
- Identifying community resources and supports in the family's local area

d. Practical support

- Maintaining regular meetings and encouraging families to get in touch through email, phone or videoconference whenever needed proactively
- Triaging emerging medical issues when contacted by families

None of the models mentioned provision of emotional support at all, let alone as a priority. Only one pediatric care coordination program listed advocacy and coordinating mental health service support as part of the service (28).

## Pediatric Care Coordination for CSHCN and CMC: Evaluation

Every study measured the value and impact of the service differently. A lack of a shared definition for care coordination, the CMC population, and standardized outcomes made comparing real life care coordination services and their effectiveness on family outcomes difficult. (8)

Success in care coordination will always be perceived in different ways depending on the perspective: whether it is the child/family, health care professional, or system representative. As such, measuring care coordination comprehensively will depend on these three different distinct groups of stakeholders and their experiences and how they define measures of effectiveness. "The data source is a function of who is asked or what is assessed." (27)

Twelve of the 13 pediatric care coordination programs for CMC or CSHCN had measured different outcomes from the above perspectives or evaluated just the specific tools developed as part of the care coordination program. (Excluded was the study of local family physicians documenting time spent on care coordination services) The types of results below were most commonly reported among the studies examined:

### *System Perspective*

- In a few of the studies conducted in the US, researchers especially focused on the economic impact of care coordination in terms of cost reductions for the hospital and health care system. This was measured by calculating the dollars saved from service utilization of "hospital encounters" including emergency department visits, in-patient admission and length of stay, etc. (29,30)
- Optimization of care coordination team structure and workflow processes through continuous quality improvement

Of most interest to us though is the impact on child health outcomes and child/family experience.

*Child and Family Perspective*

- Increased access to and satisfaction with coordination of care; feeling less abandoned and alone
- Increased linkage with services or resources closer to home community
- Decreased confusion or hassle – one central person to contact and coordinate needs
- Money and time saved as a result of streamlining appointments together for families who need to travel to a tertiary centre – this included calculation of time, money saved on gas and loss of employment days for caregivers
- Decreased of unmet needs and improved perception of provider through better communication and education of child's health condition
- Increased empowerment of family's advocacy and caregiving skills
- Decreased levels of caregiver stress

## Critical Elements Contributing to Positive Child/Family outcomes

### 1. Leadership and fostering genuine collaborations

Team-based, multi-agency support is advocated as best practice for CMC, and this approach is favoured by families. (31) This matches the assumption of how care coordination's success is contingent on interdisciplinary and inter- and intra-system collaboration as well as truly empowering the child and family as full participants.

Ten out of 13 examined studies appointed nurses or nurse practitioners with expertise with CMC as the most appropriate designated lead care coordinator. The rationale for this is they have the clinical skills, interpersonal skills, and education in caring for CMC, allowing them to streamline and troubleshoot issues families face as the care coordinator and the central point of contact with families. Nurses as care coordinators have also nurtured the development of clinical partnerships among multiple clinical teams involved in the care of CMC (31). A principal clinician can also be added to the team working with a care coordinator if the person in the role does not have the specialized clinical expertise with complex pediatric conditions. In both the ProSPer and TeleFamilies models, it was noted that the nurse was a key driver of care coordination success. Underlying the success of these models was the nursing profession's core standard and competency of patient-centered care coordination.(21)

Particularly, the efficacy of "agency-based" or "centre-based" care coordinators improved when they were integrated into primary care practices. (8) This allowed the advantage of combining strengths from tertiary care expertise with local community services. Several models examined had nurse practitioners who were based in a hospital partner with local PCPs or other community service providers to work with families in-person or online and in order to coordinate needs between both settings.

### 2. Harnessing technology to improve communication and shared plans

Effective communication between providers and family was a common theme in many of the care coordination program results that led to higher family satisfaction. Successful care coordination models recognized and acknowledged parents as equal stakeholders because they knew their child best (2). Having a dedicated care coordination team in place meant

parents could rely on getting the information and support they needed. One program's parents cited numerous examples of how with "just one call" or "email" their questions about their child's health were answered, and/or an appointment with a specialist was organized that could help resolve their concerns (20). In addition to provider-family communication, bridging the communication gap between providers was equally important. The care coordinator's individual capabilities and skills could contribute to leadership that values the importance of interpersonal relationships between key providers (11).

Technology is playing an increasingly important role to facilitate care coordination and provide immense potential to optimization. A few of the pediatric care coordination programs are incorporating and taking advantage of technology for two primary communication purposes:

1. To facilitate better access to providers for families
2. To provide a better way of sharing information. In addition to traditional in-person visits or phone calls, families and providers used email to proactively reach out to one another (13,21,25,32,33). In two other models, care coordinators added web-based videoconferencing to supplement phone calls and emails. (21,34)

Shared IT infrastructure, e-health records and shared care plans are identified in the literature as priorities for improving quality and safety of health care and patient and care giver experiences. (31) A popular tool found in a majority of the studies was a care plan, jointly-developed by families and care coordinators. This critical document is a point of reference, and relies on families and providers using and sharing accurate, up-to-date health information. It becomes even more important during times of transition such as a child is being discharged from inpatient care back into home and supported by health services in the community. One care coordination pilot study developed a completely paperless, mobile complex care plan that was integrated within its electronical health record (EHR) system. This allowed any care providers and parents of CMC to make updates, view the plan at any time on the computer or mobile device, parents can directly receive messages and contact care team instantly. Results reported higher parental engagement and improved understanding their child's medical condition, leading closer to an ideal and dynamic patient-centred blueprint for CMC, caregivers and providers (33) However, caution is advised when designing and implementing EHR-based communication tools. Given the volume of health information and frequent transitions within and across systems of care by CMC, there is the potential for "information chaos". Studies have also shown inconsistent adoption of these tools in practice. (21)

## Knowledge Gaps

A majority of the care coordination studies did not address how care coordination can link the disconnected and health, community, social, and education sectors operating in silos to meet CMC needs comprehensively. Only one study touched upon the links between health and education domains. The study found that family-centred care is associated with fewer absences in school and improved care coordination for CSHCN in the US (10). Connecting CMC, CSHCN or caregivers with the appropriate mental health care is another important area not addressed in the studies examined. They still encounter significant challenges to acquire mental or behavioural health services and supports, smooth transitions to adult care, and inadequate support for caregivers (3,8). This leaves families with CMC or CSHCN more vulnerable to the risks of unmet mental health needs.

In addition, of note here is that none of studies reported on either direct health outcomes of neither the participants nor their quality of life after care coordination in the long term. Instead, some studies focused on indirect measures such as emergency department visits and number of days spent as an inpatient.

The sustainability of a health care system providing pediatric care coordination was not explored in any Canadian settings. Even though studies have shown cost reduction as a benefit for the health care system (28,29) and families (19,24), the service still requires a considerable amount of dedicated personnel and resources. What are the true costs of care coordination and how should it be budgeted?

## Emerging Questions for E-Scan

- Because multiple sources have indicated there is no consistent definition of care coordination and its implementation is also quite varied: How does each of the centres define care coordination that their service or program is based on?
- If the surveyed site does operate a pediatric care coordination program that children with CP are eligible for, does the scope of care include supporting families beyond health care? (i.e. facilitating educational, social services or community support) Or how familiar are the care coordinators with accessing such services?

## Abbreviations

| | |
|---|---|
| **AHRQ** | Agency for Healthcare Research and Quality |
| **CP** | Cerebral palsy |
| **CMC** | Children with medical complexity |
| **CSHCN** | Children with special health care needs |
| **HER** | Electronic Health Record |
| **PCP** | Primary care provider |
| **PFC** | Patient- and family-centered |
| NQF | National Quality Forum |

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## Authors

Vivian Wong
Research Coordinator, BC Cerebral Palsy Project
Sunny Hill Health Centre for Children
Department of Pediatrics, University of British Columbia

Kimberly Miller, PT PhD
Senior Leader of Clinical Education and Special Projects, Sunny Hill Health Centre for Children
Investigator, Evidence to Innovation, BC Children's Hospital Research Institute

With support from Andrea Ryce, MLIS
Information Specialist, Clinical Librarian
BC Children's Hospital, Sunny Hill Health Centre for Children
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# Appendix 2: Environmental Scan Surveys

## Care Coordination for Children With Cerebral Palsy Survey

### Section 1: Demographics

To begin, please tell us a bit about yourself and where you work.

1. What is your name? **[text box answer]**
2. What is your professional background? (Select one.) **[select one]**
   - ○ Family physician or general practitioner
   - ○ Specialist physician (e.g., neurologist, orthopedic surgeon, developmental pediatrician)
   - ○ Nurse (e.g., RN, LPN, nurse manager)
   - ○ Nurse practitioner
   - ○ Physiotherapist
   - ○ Occupational therapist
   - ○ Counsellor or psychologist
   - ○ Speech language pathologist
   - ○ Social worker
   - ○ Other:
3. What is your position or title? **[text box answer]**
4. Please provide an email address and/or phone number where you can be reached should we require clarification of any of your answers. **[short answer]**
5. In what jurisdiction is your organization located? (Select one.) **[select one]**
   - ○ Alberta
   - ○ British Columbia
   - ○ Manitoba
   - ○ New Brunswick
   - ○ Newfoundland and Labrador
   - ○ Northwest Territories
   - ○ Nova Scotia
   - ○ Nunavut
   - ○ Ontario
   - ○ Prince Edward Island
   - ○ Quebec
   - ○ Saskatchewan

- ○ Yukon
- ○ Federal

6. What is the name of your organization? **[text box answer]**

7. What is the name of the site you work at? **[text box answer]**

## Section 2: Main Features of Care Coordination Services or Programs

For the purposes of this survey we will define care coordination as "a cross-cutting system intervention that is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services." Care coordination may involve a number of activities, including needs assessment, goal setting, managing or coordinating appointments and services, patient education, or triaging emergent medical issues.

8. Based on the previously provided description, does your site offer a formal care coordination service or program to pediatric patients with medical complexities, including those with cerebral palsy? **[Yes/No] [If no, Go to question 11]**

9. Does your site offer a care coordination program or service specifically for pediatric patients with cerebral palsy? **[Yes/No]**

10. What definition of care coordination does your site, service, or program utilize to design its activities? As mentioned previously, we have defined care coordination as "a cross-cutting system intervention that is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services." **[short answer] [Go to question 13]**

11. In the absence of a formal care coordination program or service, who follows the progress of pediatric patients with cerebral palsy? (Select one.) **[select one]**

    - ○ Family physician or general practitioner
    - ○ Specialist physician (e.g., neurologist, orthopedic surgeon, developmental pediatrician)
    - ○ Nurse (e.g., RN, LPN, nurse manager)
    - ○ Nurse practitioner
    - ○ Physiotherapist
    - ○ Occupational therapist
    - ○ Counsellor or psychologist
    - ○ Speech language pathologist
    - ○ Social worker
    - ○ Other:

12. In the absence of a formal care coordination program or service, some sites may undertake activities similar to care coordination. Does your site offer any of the following to pediatric patients with cerebral palsy? **[select all that apply] [Go to Section 7, question 47 when complete]**

    - ○ Identifying and acquiring resources close to the patient's home
    - ○ Managing consults, therapies, and/or appointments by coordinating interdisciplinary teams in primary and tertiary settings
    - ○ Managing acute situations directly
    - ○ Initial needs assessment
    - ○ Gathering information from a patient and their family
    - ○ Goal setting
    - ○ Co-developing a shared plan with family and communicating updates to family and health care providers
    - ○ Patient education
    - ○ Explaining how to navigate the health system
    - ○ Identifying resources for support
    - ○ Regular meetings and encouraging families to proactively get in touch via email, phone, or videoconference whenever needed
    - ○ Attending appointments with a patient and their family and interpreting medical information or test results
    - ○ Triaging emerging medical issues when contacted by family
    - ○ Advocating and coordinating mental health service support (i.e., referral to psychologist, counsellor, or respite care programs; other community support groups or forums)
    - ○ Other support (e.g., facilitating educational, social services or community support beyond the realm of health care):

13. What specific **Coordination of Care Needs** activities does your care coordination service or program provide to pediatric patients with cerebral palsy? **[select all that apply]**

    - ○ Identifying and acquiring resources close to the patient's home
    - ○ Managing consults, therapies, and/or appointments by coordinating interdisciplinary teams in primary and tertiary settings
    - ○ Managing acute situations directly
    - ○ Other:

14. What specific **Planning and Assessment** activities does your care coordination service or program provide to pediatric patients with cerebral palsy? **[select all that apply]**

    - ○ Initial needs assessment
    - ○ Gathering information from a patient and their family
    - ○ Goal setting
    - ○ Co-developing a shared plan with family and communicating updates to family and health care providers
    - ○ Other:

15. What specific **Information and Specialist Support** activities does your care coordination service or program provide to pediatric patients with cerebral palsy? **[select all that apply]**

    - ○ Patient education
    - ○ Explaining how to navigate the health system
    - ○ Identifying resources for support
    - ○ Other:

16. What specific **Practical Support** activities does your care coordination service or program provide to pediatric patients with cerebral palsy? **[select all that apply]**

    - ○ Regular meetings and encouraging families to proactively get in touch via email, phone, or videoconference whenever needed
    - ○ Attending appointments with a patient and their family and interpreting medical information or test results
    - ○ Triaging emerging medical issues when contacted by family
    - ○ Other:

17. What specific **Mental, Emotional, or Social Support** activities does your service or program provide to pediatric patients with cerebral palsy? **[select all that apply]**

    - ○ Advocating and coordinating mental health service support (i.e., referral to psychologist, counsellor, or respite care programs; other community support groups or forums)
    - ○ Other:

18. What **Other Support** activities (e.g., facilitating educational, social services or community support beyond the realm of health care) does your care coordination service or program provide to pediatric patients with cerebral palsy? **[short answer]**

## Section 3: Providers of Care Coordination

In this section we would like to know more about the health care providers and staff involved in your care coordination service or program for pediatric patients with cerebral palsy.

19. Does your service or program have a designated person in a care coordinator role? **[Yes/No/Other, comment]**
    **[Comment/Other]** If yes, what is the professional background and/or title of your service or program's care coordinator? **[short answer]**

20. Is care coordination at your site provided by a multidisciplinary team? **[Yes/No]**
    **[If no, proceed to Question 34]**

21. What role(s) (if any) does each of the following health care providers play in **Coordination of Care Needs** within your care coordination service or program team? **[matrix with comment]**

| | Identifying and Acquiring Resources Close to the Patient's Home | Managing Consults, Therapies, and/or Appointments by Coordinating Interdisciplinary Teams in Primary and Tertiary Settings | Managing Acute Situations Directly |
|---|---|---|---|
| **Family Physician or General Practitioner** | | | |
| **Specialist Physician (E.g., Neurologist, Orthopedic Surgeon, Developmental Pediatrician)** | | | |
| **Nurse (RN, LPN, Nurse Manager)** | | | |
| **Nurse Practitioner** | | | |
| **Physiotherapist** | | | |
| **Occupational Therapist** | | | |
| **Speech Language Pathologist** | | | |
| **Social Worker** | | | |

**[Comment box tied to Matrix]**

Do the health care providers listed here play other roles you consider to be part of **Coordination of Care Needs**? Please list the role and the corresponding provider.

22. Are there other health care providers who play a role in **Coordination of Care Needs** who are not named in the previous question? **[Yes/No/Other, comment]**
    **[Other, comment]** If yes, please list the provider(s) and their role(s).

23. What role(s) (if any) does each of the following health care providers play in **Planning and Assessment** within your care coordination service or program team? **[matrix, comment box]**

| | Initial Needs Assessment | Gathering Information From a Patient and Their Family | Goal Setting | Co-developing a Shared Plan With Family and Communicating Updates to Family and Health Care Providers |
|---|---|---|---|---|
| **Family Physician or General Practitioner** | | | | |
| **Specialist Physician (E.g., Neurologist, Orthopedic Surgeon, Developmental Pediatrician)** | | | | |
| **Nurse (E.g., RN, LPN, Nurse Manager)** | | | | |
| **Nurse Practitioner** | | | | |
| **Physiotherapist** | | | | |
| **Occupational Therapist** | | | | |
| **Speech Language Pathologist** | | | | |
| **Social Worker** | | | | |

**[Comment box tied to matrix]**

Do the health care providers listed here play other roles you consider to be part of **Planning and Assessment**? Please list the role and the corresponding provider.

24. Are there other health care providers who play a role in **Planning and Assessment** who are not named in the previous question? **[Yes/No/Other, comment]** **[Other, comment]** If yes, please list the provider(s) and their role(s).

25. What role(s) (if any) does each of the following health care providers play in **Information and Specialist Support** within your care coordination service or program team? **[matrix]**

| | Patient Education | Explaining How to Navigate the Health System | Identifying Resources for Support |
|---|---|---|---|
| **Family Physician or General Practitioner** | | | |
| **Specialist Physician (E.g., Neurologist, Orthopedic Surgeon, Developmental Pediatrician)** | | | |
| **Nurse (E.g., RN, LPN, Nurse Manager)** | | | |
| **Nurse Practitioner** | | | |
| **Physiotherapist** | | | |
| **Occupational Therapist** | | | |
| **Speech Language Pathologist** | | | |
| **Social Worker** | | | |

**[Comment box tied to matrix]**

Do the health care providers listed here play other roles you consider to be part of **Information and Specialist Support**? Please list the role and the corresponding provider.

26. Are there other health care providers who play a role in **Information and Specialist Support** who are not named in the previous question? **[Yes/No/Other, comment] [Other, comment]** If yes, please list the provider(s) and their role(s).

27. What role(s) (if any) does each of the following health care providers play in **Practical Support** within your care coordination service or program team? **[matrix]**

| | Regular Meetings and Encouraging Families to Proactively Get in Touch Via Email, Phone, or Videoconference Whenever Needed | Attending Appointments With a Patient and Their Family and Interpreting Medical Information or Test Results | Triaging Emerging Medical Issues When Contacted by Family |
|---|---|---|---|
| **Family Physician or General Practitioner** | | | |
| **Specialist Physician (E.g., Neurologist, Orthopedic Surgeon, Developmental Pediatrician)** | | | |
| **Nurse (E.g., RN, LPN, Nurse Manager)** | | | |
| **Nurse Practitioner** | | | |
| **Physiotherapist** | | | |
| **Occupational Therapist** | | | |
| **Speech Language Pathologist** | | | |
| **Social Worker** | | | |

**[Comment box tied to matrix]**

Do the health care providers listed here play other roles you consider to be part of **Practical Support**? Please list the role and the corresponding provider.

28. Are there other health care providers who play a role in **Practical Support** who are not named in the previous question? **[Yes/No/Other, comment] [Other, comment]** If yes, please list the provider(s) and their role(s).

29. What role(s) (if any) does each of the following health care providers play in **Mental, Emotional, or Social Support** within your care coordination service or program team? **[matrix]**

| | Advocating and Coordinating Mental Health Service Support (I.e., Referral to Psychologist, Counsellor, or Respite Care Programs; Other Community Support Groups or Forums) | Facilitating Educational, Social Services, or Community Support Beyond the Realm of Health Care |
|---|---|---|
| **Family Physician or General Practitioner** | | |
| **Specialist Physician (E.g., Neurologist, Orthopedic Surgeon, Developmental Pediatrician)** | | |
| **Nurse (E.g., RN, LPN, Nurse Manager)** | | |
| **Nurse Practitioner** | | |
| **Physiotherapist** | | |
| **Occupational Therapist** | | |
| **Speech Language Pathologist** | | |
| **Social Worker** | | |

**[Comment box tied to matrix]**

Do the health care providers listed here play other roles you consider to be part of **Mental, Emotional, or Social Support**? Please list the role and the corresponding provider.

30. Are there other health care providers who play a role in **Mental, Emotional, or Social Support** who are not named in the previous question? **[Yes/No/Other, comment]**
**[Other, comment]** If yes, please list the provider(s) and their role(s).

31. What is the interplay of different specialty roles and providers, if any? **[select all that apply]**

    - ○ A form of written or shared plan
    - ○ Regular team meetings
    - ○ Communication with referrals and facilitating appointments
    - ○ Interprofessional and inter-system collaboration
    - ○ Other:

32. Does your multidisciplinary care coordination team have a single service provider who is the main and consistent contact with pediatric patients with cerebral palsy (i.e., facilitates care coordination for these patients?) **[Yes/No]**

33. Which service provider(s) on your multidisciplinary care coordination team act as the main and consistent contact of pediatric patients with cerebral palsy (i.e., who facilitates care coordination for these families)? **[Select all that apply]**

    - ○ No one
    - ○ Family physician or general practitioner

- ○ Specialist physician (e.g., neurologist, orthopedic surgeon, developmental pediatrician)
- ○ Nurse (e.g., RN, LPN, Nurse Manager)
- ○ Nurse practitioner
- ○ Physiotherapist
- ○ Occupational therapist
- ○ Counsellor or psychologist
- ○ Speech language pathologist
- ○ Social worker
- ○ Other:

34. Who decides what specialists the patient should see to meet their medical needs? **[Select all that apply]**

- ○ Family physician or general practitioner
- ○ Specialist physician (e.g., neurologist, orthopedic surgeon, developmental pediatrician)
- ○ Nurse (e.g., RN, LPN, nurse manager)
- ○ Nurse practitioner
- ○ Physiotherapist
- ○ Occupational therapist
- ○ Counsellor or psychologist
- ○ Speech language pathologist
- ○ Social worker
- ○ Other:

## Section 4: Program Structure

In this section we would like to know more about the structure of your care coordination service or program for pediatric patients with cerebral palsy.

35. How do pediatric patients with cerebral palsy access your care coordination program or service? **[select all that apply]**

- ○ Family physician or general practitioner referral
- ○ Nurse practitioner referral
- ○ In-patient hospital referral by another staff member
- ○ Self referral or self enrolment
- ○ Other:

36. How do you communicate with patients between services or appointments? **[select all that apply]**

    - ○ By phone
    - ○ By text messaging or instant messaging
    - ○ By email
    - ○ By videoconference
    - ○ No communication; must schedule an appointment
    - ○ Other:

37. Are there eligibility criteria for which pediatric patients with cerebral palsy can access your care coordination service or program? **[yes/no/Other, comment]**
    **[Other, comment]** If yes, what are the eligibility criteria for accessing your care coordination service or program?

38. How many children with cerebral palsy are currently accessing your care coordination service or program? **[short answer]**

39. Does your site have "exit" criteria to determine whether a patient is no longer enrolled in your care coordination program or service? **[Yes/No/Other, comment]**
    **[Other, comment]** If yes, please describe the criteria used to determine the exit of a patient from your care coordination program or service.

40. Has your site ever formally or informally evaluated your care coordination service or program? **[Yes/No]**

## Section 5: Care Coordination in Small Population Centres, Rural, and Remote or Isolated Areas

We would now like to ask you about care coordination for pediatric patients with cerebral palsy for patients living in small population centres, rural areas, and remote or isolated communities. For the purposes of this survey:

- ○ A population centre is a community with at least 1,000 people and a population density of 400 persons per square kilometre or more.
- ○ A rural area is any area outside of a population centre.
- ○ A small population centre is a community with 1,000 to 29,000 people.
- ○ A remote or isolated community is located more than four hours away from tertiary hospital services by ground transportation, with or without road access.

41. Does the process of accessing care coordination services at your site differ for patients living in small population centres, rural areas, and remote or isolated communities compared with those living in larger population centres? **[Yes/No/Other, comment]**
    **[Other, comment]** If yes, please describe the difference in accessing or obtaining care coordination for patients living in small population centres, rural areas, and remote or isolated communities compared with those living in larger population centres.

42. Does your care coordination program or service have strategies to facilitate services in a timely manner for pediatric patients with cerebral palsy living in small population centres, rural areas, and remote or isolated communities (e.g., grouping appointments together all at once; optimizing care between service providers)? **[Yes/ No/Other, comment]**
    **[Other, comment]** If yes, please describe the strategies your care coordination program or services uses to facilitate optimally timed appointments or services for pediatric patients with cerebral palsy living in small population centres, rural areas, and remote or isolated communities (e.g., grouping appointments with different specialists in one visit; facilitating travel accommodations; satellite clinics in the community; physician or nurse visits).

43. Are there outreach or satellite clinics in small population centres, rural areas, and remote or isolated communities to fill the gaps in care between service (i.e., when a child's health changes, is there somewhere in their community — such as a family physician's office — where they can be referred to other than the hospital or your site)? **[Yes/No]**

44. Do care coordinators or other care coordinator team members travel to perform outreach services or collaborate and support primary care providers in those areas? **[Yes/No]**

## Section 6: Care Coordination for Priority Populations

Some groups of people living in Canada experience challenges or difficulty accessing health care. We would like to ask you about care coordination for pediatric patients with cerebral palsy for patients who are members of priority populations (which, for the purposes of this survey, include but are not limited to First Nations, Inuit, Métis, newcomers, racial and ethic minorities, and English- or French-learning families).

45. Does the process of accessing care coordination services at your site differ for families of pediatric patients with cerebral palsy who are members of priority populations? **[Yes/No/Other, comment]**
    **[Other, comment]** If yes, please describe the difference(s) in accessing care coordination for patients who are members of priority populations.

46. Is your care coordination service or program different for patients who are members of priority populations? **[Yes/No/Other, comment]**
    **[Other, comment]** If yes, please describe how your care coordination service or program is different for patients who are members of priority populations.

### Section 7: Further Discussion

47. Is there someone in your organization other than yourself who we can contact to further discuss these responses?

    - ○ Yes (please provide their name and email):
    - ○ No, I am the main contact

48. Is there anything you would like to tell us that has not been covered in this survey? **[short answer]**

## Funding Survey

### Section 1: Demographics

To begin, please tell us a bit about yourself and where you work.

1. What is your name? **[text box answer]**
2. What is your professional background? **[select one]**

    - ○ Family physician or general practitioner
    - ○ Specialist physician (e.g., neurologist, orthopedic surgeon, developmental pediatrician)
    - ○ Nurse (e.g., RN, LPN, nurse manager)
    - ○ Nurse practitioner
    - ○ Physiotherapist
    - ○ Occupational therapist
    - ○ Counsellor or psychologist
    - ○ Speech language pathologist
    - ○ Social worker
    - ○ Other:

3. What is your position or title? **[text box answer]**
4. Please provide an email address and/or phone number where you can be reached should we require clarification of any of your answers. **[short answer]**
5. In what jurisdiction is your organization located? **[Select One]**

    - ○ Alberta
    - ○ British Columbia
    - ○ Manitoba
    - ○ New Brunswick
    - ○ Newfoundland and Labrador
    - ○ Northwest Territories
    - ○ Nova Scotia

- ○ Nunavut
- ○ Ontario
- ○ Prince Edward Island
- ○ Quebec
- ○ Saskatchewan
- ○ Yukon
- ○ Federal

6. What is the name of your organization? **[text box answer]**

7. What is the name of the site you work at? **[text box answer]**

## Section 2: Funded Services

Please tell us how support services and resources (e.g., respite care, nursing support, home care) for pediatric patients with cerebral palsy are funded at your site.

8. What support services and resources are funded by the following stakeholders in your jurisdiction? (Select all that apply.) **[matrix]**

| | Public (E.g., Health Authority, Hospital, Ministry) | Private (E.g., Third-Party Organizations, Private Insurance) | Charity | Out-of-Pocket | Do Not Know |
|---|---|---|---|---|---|
| **Equipment (E.g., Power Mobility, Wheelchair, Assistive Devices, Orthotics, Communication and Safety Equipment)** | | | | | |
| **Supplies (E.g., Biomedical — Catheter, Underpads)** | | | | | |
| **Medication** | | | | | |
| **Home Renovations** | | | | | |
| **Rehabilitation/Therapy (E.g., PT, OT, Speech Language Pathologist)** | | | | | |
| **Counselling** | | | | | |
| **Respite Care** | | | | | |
| **Nursing Support** | | | | | |
| **Education Support** | | | | | |

9. Are there additional services that are funded by public payors? **[Yes/No/Other, comment]**
   **[Other, comment]** If yes, please describe the additional services that are funded by public payors.

10. Are there additional services that are funded by private payors? **[Yes/No/Other, comment]**
    **[Other, comment]** If yes, please describe the additional services that are funded by private payors.

11. Are there additional services that are funded by charities? **[Yes/No/Other, comment]** **[Other, comment]** If yes, please describe the additional services that are funded by charities.

12. Are there additional services that are funded out-of-pocket? **[Yes/No/Other, comment]**
**[Other, comment]** If yes, please describe the additional services that are funded out-of-pocket.

13. Across what age groups is funding allocated? (Select all that apply.) **[Select all that apply]**

    - ○ Patient age does not determine how funding is allocated
    - ○ Under 3 years old (Infant or toddler)
    - ○ 3 to 5 years old (Pre-school)
    - ○ 6 to 11 years old (Elementary school)
    - ○ 12 to 15 years old (High school transition)
    - ○ 16 to 19 years old (Adult transition)

14. Across what levels of the Gross Motor Function Classification System (GMFCS) is funding available or allocated? **Select all that apply]**

    - ○ GMFCS does not factor into how funding is allocated
    - ○ Level I (Walks without limitations)
    - ○ Level II (Walks with limitations)
    - ○ Level III (Walks using a hand-held mobility device)
    - ○ Level IV (Self-mobility with limitations; may use powered mobility)
    - ○ Level V (Transported in a manual wheelchair)

15. In your opinion, are there any gaps in funding for children with cerebral palsy (e.g., services, resources, age, cultural group, or mobility or impairment level)? **[short answer]**

## Section 3: Funding Services for Families in Small Population Centres, Rural, and Remote or Isolated Areas

We would now like to ask you about how services for pediatric patients with cerebral palsy are funded for patients living in small population centres, rural areas, and remote or isolated communities. For the purposes of this survey:

- ○ A population centre is a community with at least 1,000 people and a population density of 400 persons per square kilometre or more.
- ○ A rural area is any area outside of a population centre.
- ○ A small population centre is a community with 1,000 to 29,000 people.
- ○ A remote or isolated community is located more than four hours away from hospital services by ground transportation, with or without road access.

16. Is there specific funding available for pediatric patients with cerebral palsy who live in small population centres, rural areas, or remote or isolated communities? **[Yes/No] [if No, Go to Section 4, question 20]**

17. What types of funding programs are available for pediatric patients with cerebral palsy living in small population centres, rural areas, or remote or isolated communities? **[select all that apply]**

    - ○ Travel funding
    - ○ Grants
    - ○ Bursaries
    - ○ Other:

18. Please describe the process for accessing these funding programs. **[short answer]**

19. Is there assistance available to apply to these funding programs (e.g., patient handout, pamphlet, program, assigned staff)? **[Yes/No]**

## Section 4: Care Coordination for Priority Populations

Some groups of people living in Canada experience challenges or difficulty accessing health care. We would like to ask you about funding for pediatric patients with cerebral palsy for patients who are members of priority populations (which, for the purposes of this survey, include but are not limited to First Nations, Inuit, Métis, newcomers, racial and ethic minorities, and English- or French-learning families).

20. Is there special funding available for those who are members of priority populations? **[Yes/No/Other, comment]**
    **[Other, comment]** If yes, please describe the special funding available to those who are members of priority populations.

## Section 5: Further Discussion

21. Is there someone in your organization other than yourself who we can contact to further discuss these responses?

    - ○ Yes (please provide their name and email):
    - ○ No, I am the main contact

22. Is there anything you would like to tell us that has not been covered in this survey? **[short answer]**

# Appendix 3: Data Tables

## Table 1: Components of Formal Care Coordination Programs Across Respondent Organizations in Their Jurisdictions

| Care coordination activity | British Columbia | Alberta | Manitoba | Newfoundland and Labrador |
|---|---|---|---|---|
| **Coordination of care needs** | | | | |
| Identifying and acquiring resources close to the patient's home | X | X | X | X |
| Managing consultations, therapies, and/or appointments by coordinating interdisciplinary teams in primary and/or tertiary settings | X | | X | X |
| Managing acute situations directly | X | | | X |
| **Planning and assessment** | | | | |
| Initial needs assessment | X | X | X | X |
| Gathering information from the patient and family | X | X | X | X |
| Goal setting | X | X | X | X |
| Co-developing a shared plan and communicating updates to family and health care providers | X | X | X | X |
| **Information and specialist support** | | | | |
| Patient education | X | X | X | X |
| Explaining how to navigate the health care system | X | X | X | X |
| Identifying resources for support | X | X | X | X |
| **Practical support** | | | | |
| Regular meetings | X | | X | X |
| Encouraging families to get in touch via email, phone, or videoconference proactively, whenever needed | X | | X | X |
| Attending appointments with family and patient, and interpreting medical information or test results | X | | X | X |
| Triaging emerging medical issues when contacted by family | X | | X | X |
| **Mental, emotional, or social support** | | | | |
| Advocating and coordinating mental health service support; i.e., referral to psychologist, counsellor, or respite care programs; other community support groups or forums | X | X | X | X |
| Facilitating educational, social services, or community support beyond the realm of health care | | | X | X |

## Table 2: Summary of Care Coordination Activities Across Respondent Jurisdictions Without a Formal Program

| Care coordination activity[a] | Ontario (Site 1) | Ontario (Site 2) | Saskatchewan |
|---|---|---|---|
| **Coordination of care needs** | | | |
| Identifying and acquiring resources close to the patient's home | X | X | X |
| Managing consults, therapies, and/or appointments by coordinating interdisciplinary teams in primary and tertiary settings | X | X | X |
| Managing acute situations directly | | | |
| **Planning and assessment** | | | |
| Initial needs assessment | X | X | X |
| Gathering information from the patient and family | X | X | X |
| Goal setting | X | X | X |
| Co-developing a shared plan and communicating updates to family and health care providers | X | X | X |
| **Information and specialist support** | | | |
| Patient education | X | X | X |
| Explaining how to navigate the health system | X | X | X |
| Identifying resources for support | X | X | X |
| **Practical support** | | | |
| Regular meetings | | | X |
| Encouraging families to get in touch via email, phone, or videoconference proactively, whenever needed | X | X | X |
| Attending appointments with a patient and their family, and interpreting medical information or test results | | | |
| Triaging emerging medical issues when contacted by family | | X | X |
| **Mental, emotional, or social support** | | | |
| Advocating and coordinating mental health service support (i.e., referral to psychologist, counsellor, or respite care programs; other community support groups or forums) | | | X |
| Facilitating social services or community support beyond the realm of health care | | | |

## Table 3: Support Services and Resources by Funding Type

| Service or resource | Funding sources | | | | |
|---|---|---|---|---|---|
| | Public funding:[a] 7 respondents (%) | Private funding:[b] 7 respondents (%) | Charity: 7 respondents (%) | Out of pocket: 7 respondents (%) | Do not know: 7 respondents (%) |
| **Equipment (e.g., power mobility, wheelchair, assistive devices, orthotics, communication, and safety equipment)** | 7 (100%) | 7 (100%) | 7 (100%) | 6 (86%) | 0 |
| **Supplies (e.g., biomedical — catheter, underpads)** | 5 (71%) | 4 (57%) | 4 (57%) | 4 (57%) | 1 (14%) |
| **Medication** | 5 (71%) | 3 (43%) | 2 (29%) | 3 (43%) | 2 (29%) |
| **Home renovations** | 3 (43%) | 4 (57%) | 5 (71%) | 6 (86%) | 1 (14%) |
| **Rehabilitation/ therapy (e.g., PT, OT, SLP)** | 7 (100%) | 5 (71%) | 2 (29%) | 5 (71%) | 0 |
| **Counselling** | 6 (86%) | 6 (86%) | 1 (14%) | 5 (71%) | 1 (14%) |
| **Respite care** | 6 (86%) | 4 (57%) | 2 (29%) | 6 (86%) | 0 |
| **Nursing support** | 6 (86%) | 2 (29%) | 0 | 3 (43%) | 1 (14%) |
| **Education support** | 7 (100%) | 1 (14%) | 0 | 3 (43%) | 0 |

OT = occupational therapy; PT = physiotherapy; SLP = speech language pathologist.

Note: Support services and resources could be funded by multiple different sources; hence, respondents may have selected more than one funding source for each category.

Note: Jurisdictions represented in these results include British Columbia (two responses), Ontario (three responses), Manitoba (one response), and Newfoundland and Labrador (one response).

[a] Public funding includes but is not limited to funding from the health authority, hospital, and government.

[b] Private funding includes but is not limited to funding from third-party organizations and private insurance of the patient's family.

## Table 4: Definitions of Care Coordination Reported By Each Participating Jurisdiction

| Province | Approach to care coordination as described by respondents |
|---|---|
| Alberta | The deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services |
| British Columbia | The organization of patient care activities between two or more participants including the patient and family involved in a patient's care to facilitate the appropriate delivery of health services, and collaboration with community services; this involves the exchange of information among participants responsible for different aspects of care.[7] |
| Manitoba | Works with families to find the best ways to meet the child's and family's specific needs by helping families to identify strengths, needs, and goals, and direct them to appropriate services and resources |
| Newfoundland and Labrador | Offers a multidisciplinary team approach to health care for patients with cerebral palsy |