University of Manitoba

SPINAL CORD INJURY ONTARIO
LÉSIONS MÉDULLAIRES ONTARIO

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Identifying Jurisdictional Gaps in Providing Essential Attendant Services, Medical Supplies, and Assistive Devices Needed by Canadians Living with Spinal Cord Injury

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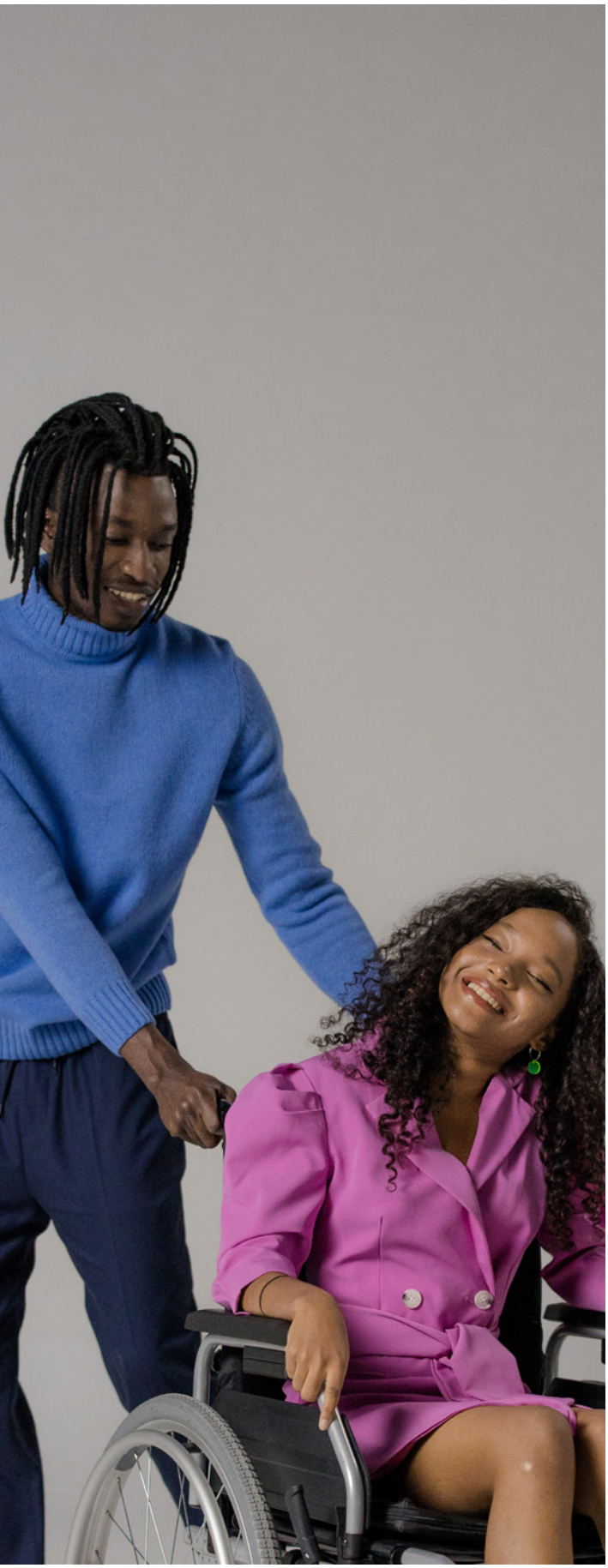

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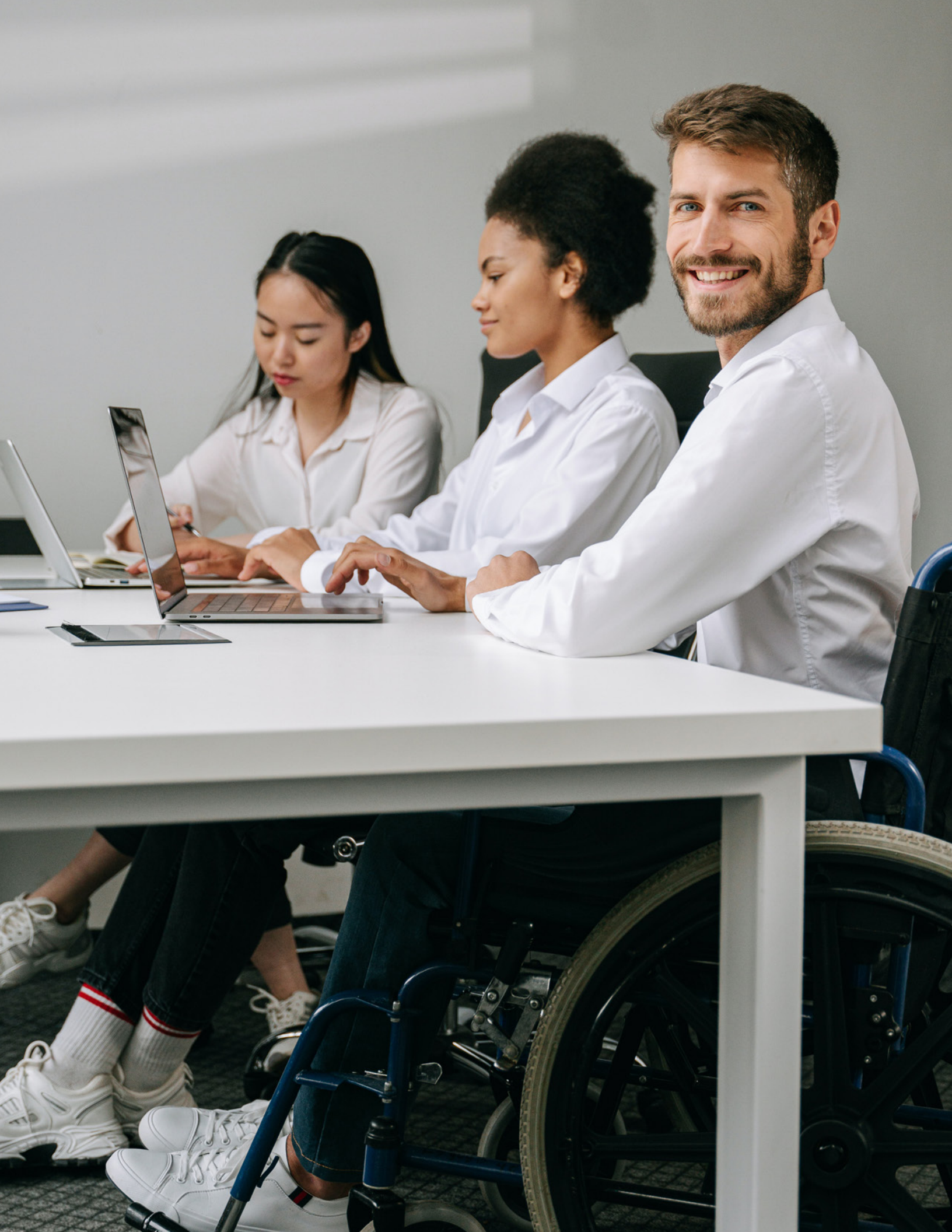

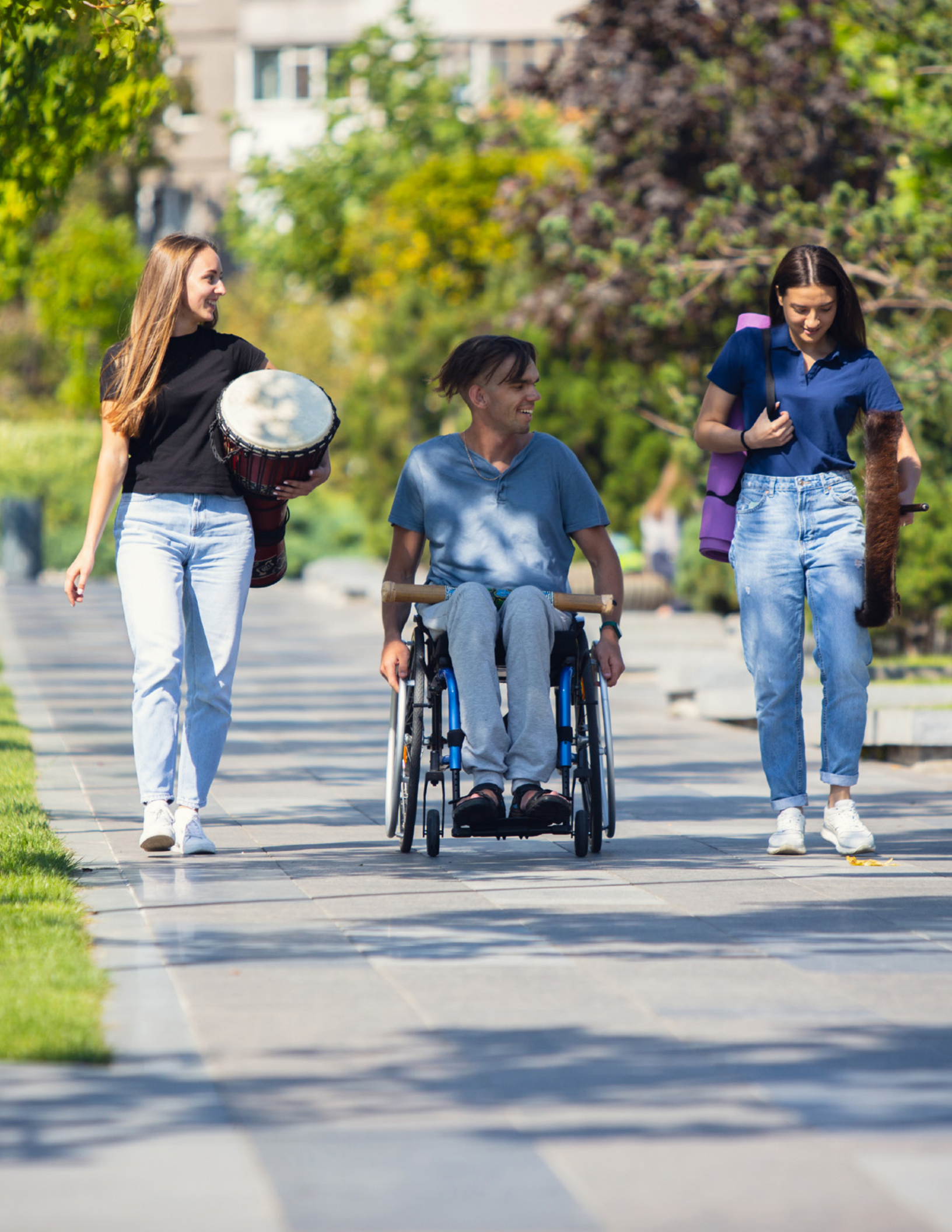

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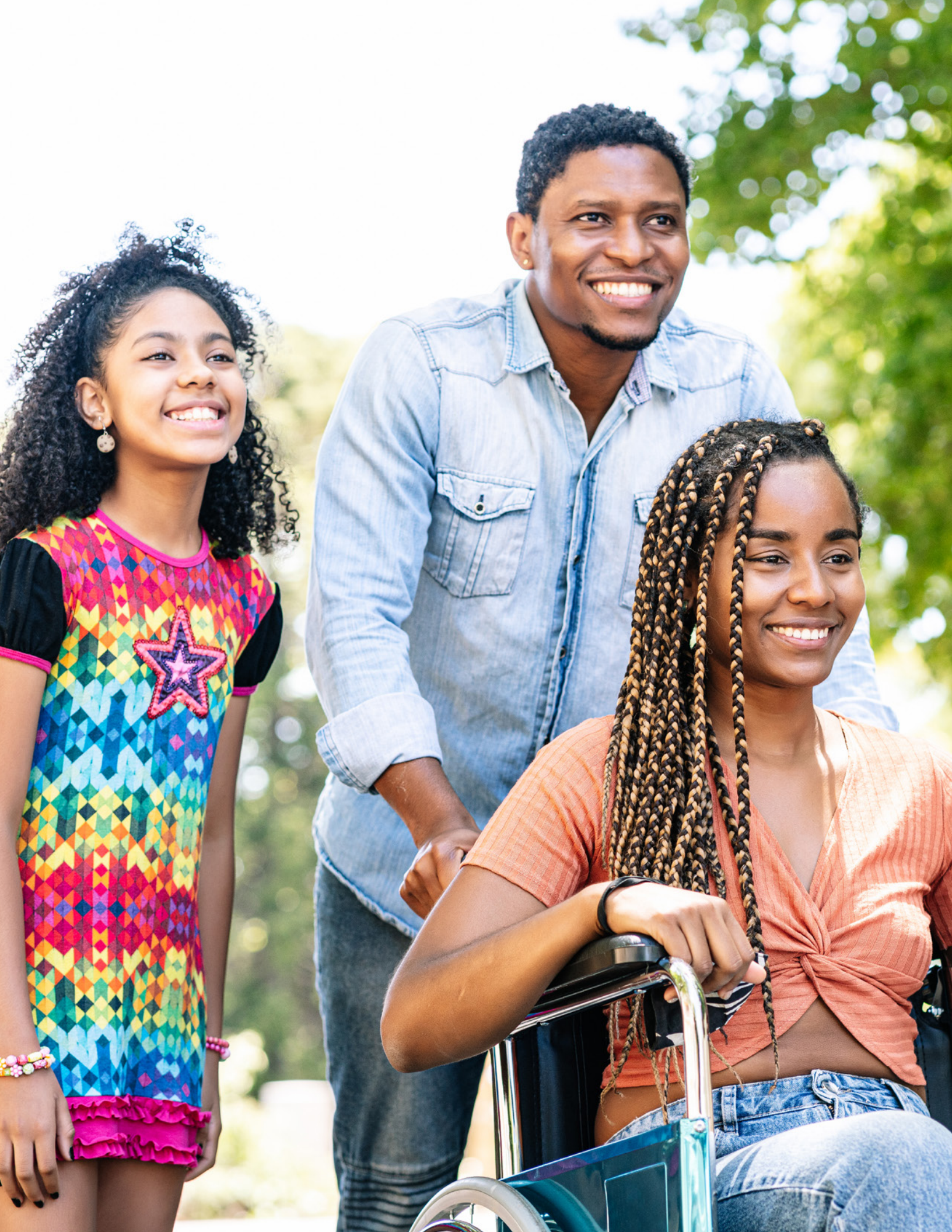


Executive Summary

Canada adopted a universal health care system through legislation passed in 1957 and 1966, bringing in a new era of public coverage for essential medical needs. This included items such as prenatal maternal health care, childbirth delivery, access to free vaccines, cancer treatments and many more life sustaining services. Significant advances in life quality and increased wealth of the general Canadian population followed. Today however, there are limited processes in place to systematically identify 'essential, publicly-fundable' services and supplies between provinces/territories. Thus, although universal health care is federally mandated and transfer payments are provided to each province/territory, there is quite a bit of autonomy in determining health care delivery levels and financial coverage of medical services and supplies within each jurisdiction. This report examines the delivery of essential health care services and supplies essential for life after spinal cord injury (SCI) in Canada.

In this report, essential needs are defined as medical services, supplies or equipment that, if withheld, could result in death of a person with SCI within days or weeks. These needs encompass three domains: i) attendant services for activities of daily living; ii) medical supplies for neurogenic bladder and bowel management; and iii) essential wheelchair, seating, and lift and transfer devices for those unable to ambulate.

Overall findings

1. There are significant disparities and inequalities between provinces for each domain of essential need. These disparities include lack of access in rural areas and abrogation or failure of the public payor to meet their responsibility within some Indigenous domains.
2. Essential services and supplies are often difficult to access or request, involving complicated financial and functional assessments performed only by designated personnel. Differences in terminology for the same services or supplies in different jurisdictions makes navigating access more difficult (e.g., home care vs. attendant services, incontinence supplies vs. medical supplies for draining the bladder). Wait times for referral, assessment, analysis, and provision of essential services, supplies and equipment are often considered exorbitant (e.g., 6-12 months for assessment and to receive a power wheelchair).
3. Despite having a great deal of expertise regarding their needs and a time horizon of decades of continual need for these services and supplies, those with SCI are relegated to passive recipient roles and subjected to repeat assessments of financial and functional status to receive minimal and often inadequate essential health care services, supplies or equipment. Furthermore, the allowance for earned income is too low to be able to afford these essential services, supplies and equipment. This leads to inappropriate reuse of supplies and creates strong disincentives to leave income assistance realms and enter the paid workforce.
4. ATTENDANT SERVICES FOR ACTIVITIES OF DAILY LIVING. There are substantial inequities and shortages in essential attendant services. Means testing exists for attendant services/home care for activities of daily living (ADL) in 5/10 provinces (BC,

NB, NL, NS & SK), with many charging an individual with SCI thousands of dollars per year once the person earns income above the poverty line (e.g., a person with SCI in NL pays 24% of earned income for home care for any income between $13,000 and $18,000, and pays a higher percentage for earnings beyond this level). Generally, provinces restrict services to 'in home only' or have severe scheduling restrictions that make outside employment or training difficult or impossible to maintain. Also, substantial shortages in health care workers are reported. While the titles/qualifications and scope of practice change between provinces/territories, there are insufficient nurses, personal attendant care workers for ADL and care coordinators. Scheduling and lack of access to services is exacerbated for those living in rural or Indigenous settings, which is further complicated by a lack of accessible housing. This often forces those with SCI to relocate to urban locations to obtain needed attendant services for ADL. Failure of community health care workers to make scheduled appointments in private home care provision settings places those with SCI at risk and puts unreasonable pressure on family and friends. Alternate delivery models exist (e.g., self-managed attendant care) which may alleviate scheduling or service location issues, but payment levels are inadequate, forcing service limitations that impair the health of those with SCI. Once care needs exceed a certain undefined 'threshold', those with SCI are often encouraged to seek life in institutions rather than remain active members of their communities.

5. BLADDER AND BOWEL MANAGEMENT SUPPLIES. Means testing exists for essential bladder and bowel management supplies in 9/10 provinces (all but SK). Supplies are often severely limited such that recommendations of the Canadian Urological Society (CUA) cannot be achieved. The CUA recommends single-use hydrophilic coated catheters for all person with neurogenic bladder dysfunction, necessitating 6-8 catheters per day (Campeau et al., 2020). In contrast, provinces limit catheters to 1-4 per day of 'the most inexpensive option available'. Further, public provision of these essential supplies in many provinces are limited to those living under the poverty line or receiving some form of social assistance.
6. POWER AND MANUAL WHEELCHAIRS. Means testing exists for provision of essential wheelchair, seating, and lift and transfer devices in 4/10 provinces (BC, NL, ON & PEI) or is based on providing a piece of equipment from a loans inventory program in 6/10 provinces. Programs are administered by health authorities in 3/10 provinces (AB, SK & QC) or relegated to charities in 3/10 provinces (MB, NB & NS). Wording in policy documents "most inexpensive suitable option" does not address the concept of a customized, functionally adequate wheelchair that considers the person's *pre-injury* level of activity, employment and education interests and functional status. Provision of wheelchairs appears to be determined by contracts negotiated with national suppliers or availability of items in a loaned equipment pool that do not meet the individualized functional needs of each person with SCI. Most programs provide only one or a few models of wheelchairs and do not appear to have mechanisms in place to update available technology based on medical advances. The most functionally diverse list of approved wheelchairs exists in Ontario's program.

Conclusions and recommendations

1. Overall, because of the lack of clarity and discrepancies across and within provincial jurisdictions regarding these three domains, a nonpartisan, objective scientific review committee/body should determine definitions of *essential* health care in Canada and identify minimal acceptable standards of care and treatment options. Recommendations for an acceptable standard of care/service should be determined by research-based evidence and reflect evolving changes in technology and medical advances. This will help to l*evel the playing field* across the country such that a person living with SCI in one province/territory will have the same access to essential medical supplies and services regardless of income.
2. ATTENDANT SERVICES FOR ADL are an

essential health need and means testing-based provision of service in certain jurisdictions contravenes concepts of universality of health care in Canada. Current levels of attendant services are inadequate in many jurisdictions. Lack of access leaves those with SCI (and other disabilities) at significant risk and extremely limits their ability to remain active contributing members in Canadian society. Levels and quality of care need to increase.

3. Means testing and limitations to the availability and coverage of medically necessary BLADDER AND BOWEL MANAGEMENT SUPPLIES is dangerously shortsighted and can lead to substantial increases in long-term costs to society through secondary complications such as urinary tract infections (UTIs), pressure injuries, and skin tears. More importantly, it leads to increased related morbidities, negative health outcomes and a reduced quality of life for individuals living with SCI.
4. POWER AND MANUAL WHEELCHAIRS for those unable to ambulate due to SCI are an essential need. Means testing and a lack of access to functionally appropriate equipment in a timely fashion exacerbates wait times for hospital discharge, and limits employment and educational opportunities and community participation of those with SCI. Provision of functionally appropriate wheelchairs should be introduced or improved in jurisdictions across Canada to meet the concept of universality of health care.
5. A basic minimum allowance for essential medical supplies and services should be considered for those living with SCI, and these persons should be given greater autonomy in determining the characteristics of the services and supplies that meet their needs. In other words, essential health care services and supplies should be defined by functional need rather than earned income.

Context

The Convention on the Rights of Persons with Disabilities in Canada was adopted in 2006 (A/RES/61/106). The United Nations Disability Inclusion Strategy (2019) notes that "organizations of the United Nations system reaffirm that the full and complete realization of the human rights of all persons with disabilities is an inalienable, integral and indivisible part of all human rights and fundamental freedoms." The purpose of the Convention is to "is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1). The principles of the convention include "respect for inherent dignity, individual autonomy, including the freedoms to make one's own choices; full and effective participation and inclusion in society; equality of opportunity and accessibility."

According to Noonan et al. (2012), it is estimated there are over 80,000 Canadians living with SCI (51% traumatic and 49% nontraumatic in origin). Our report analyzes provision of essential health care needs of those living with SCI in Canada. We defined an essential need as a service or medical device or equipment that, if withheld, could result in death of a person with SCI within days or weeks. We limited these to: i) attendant services for ADL (without attendant services to facilitate bladder and bowel emptying, death can result within a few days or weeks); ii) neurogenic bladder and bowel management supplies such as catheters (without catheterization, a person with SCI can die within days/weeks); and iii) wheelchairs, seating/positioning components for pressure relief, and lifting/transfer devices.

A comprehensive policy and practice review of these supplies and services across Canada has not been performed to date. Reviews of current public support programs in place for intermittent catheters and related supplies has been performed in certain jurisdictions, such as *A Path to Modernize Public Coverage in Ontario for Intermittent Catheters and Related Supplies* (Spinal Cord Injury Ontario, 2021), which demonstrated inadequacies in provision of these supplies. Surveys to date examining provision

of provincial assistive technology or medical supply programs across the country such as AGE-WELL NCE (2017), LeBlanc et al. (2019), and Wang et al. (2019) provide overviews of programs within each province, but details regarding the three SCI-specific areas examined here are lacking. A recent survey of direct delivery (self-managed) care programs across Canada demonstrated wide discrepancies in levels of funding and support for self-managed attendant care (Kelly et al., 2020).

Our focus was to examine delivery of these essential needs from the perspective of a person living with SCI. As such, multiple factors determine payor, including cause of injury, age, Indigenous status, or employer. Cause of traumatic SCI also varies widely, ranging from motor vehicle accidents to falls to work-related injuries. The public is often *payor of last resort*, with insurance-based coverage mandated to be used first. Levels of insurance-based coverage vary widely across jurisdictions, such that tort systems are in place in certain provinces or no-fault insurance in others. Depending on levels of insurance-based coverage in different jurisdictions, the cost of rehabilitation and care exceeds insurance coverage or lump sum payouts. In other provinces, insurance-based coverage is lifelong and exceeds what is available under public systems. Thus, in this investigation, we also examined coverage through workers' compensation programs, motor vehicle insurance, Non-Insured Health Benefits (NIHB), and Veterans Affairs Canada (VAC).

Methods: We performed a policy review analysis to document existing provincial policies regarding aspects of defined essential needs. Following an environmental scan of relevant provincial policies, one to two key informants in each province were interviewed to obtain a critical review of the existing policies and practices in their jurisdiction. Sixteen key informants were selected based on their expertise with these programs and included those working in the field of SCI rehabilitation in each province across Canada (directors, rehabilitation counselors or coordinators, social workers or peer support coordinators employed by provincial nongovernmental, nonprofit SCI, or disability organization). Detailed methods are provided in Appendix 1 with an abridged version of the key informant interview guide included in Appendix 2.

Our findings demonstrate wide discrepancies in the provision of these SCI-specific essential medical services, supplies, and equipment. In several cases, there is no public provision at all. Thus, it is sobering to recognize that we are failing to meet the basic articles of the Convention on the Rights of Persons with Disabilities in Canada.

Relevant Concepts

No-fault motor vehicle insurance is mandatory automobile insurance providing basic coverage to anyone sustaining an injury in any way by a motorized vehicle without regard to fault for the accident. The basic policy provides some degree of medical and rehabilitation coverage and often provides some degree of attendant services, medical supply, and equipment coverage. Limited income replacement benefits may be available for those unable to return to work. No-fault insurance affects those with SCI because costs for rehabilitation, medical supplies and ongoing physical attendant service needs of someone sustaining a serious SCI can be astronomical. No-fault accident benefit systems allow people who sustain an SCI to access necessary treatment and supplies without litigation, based on physical need rather than proportion of 'fault' for the cause of the vehicle accident. Automobile insurance varies across the provinces/territories with no-fault insurance, partial no-fault insurance and a tort model that allows the claimant to sue for damages.

Self-managed attendant care programs exist which enable a person with SCI to direct their own care. A variety of alternative phrases are used to describe such programs depending on the province/territory. These include direct funding, self-managed support, Choices in Support for Independent Living, individualized funding, L'allocation Directe – Chèque Emploi-Service, and family-managed care.

The responsibilities for self-managed care are akin to those of a small business owner. Applications for self-managed care can take several months and are viewed as daunting as they involve extremely

detailed documentation of daily care needs. Work by Kelly and colleagues (2020) provides a detailed summary of directly-funded care programs in each province/territory.

Authors' explanatory notes.

i. For completeness we have referred to provinces and territories through this introduction, however, meaningful research was only conducted in the provinces and hereafter we refer solely to the ten provinces.
ii. Within the environmental scan and key informant interviews terms such as attendant services, home care, and others are used inconsistently and interchangeably, reflective of the different phrases used in each province.
iii. We have chosen to use the phrase assistive devices for wheeled mobility and transfers as an encompassing phrase to include manual and powered wheelchairs, lifting and transfer devices.

Jurisdictions

BRITISH COLUMBIA

BC takeaways

- There is a lack of health care workers, especially in remote areas.
- Lack of health support workers leads to increased reliance on family and friends as well as moves to institutional care facilities, even when inappropriate.
- Home support scheduling is viewed as too rigid; and assessments often viewed as prescribing inadequate care hours.
- Provision and approval of care at a regional health authority restricts ability to move from one health authority to another.
- Public provision of neurogenic bladder and bowel management supplies and wheelchairs is limited only to those receiving Employment and Assistance for Persons with Disabilities (EAPD). Funding model inadvertently encourages people to stay on disability or income assistance to retain coverage.
- Coverage for catheters goes against the Canadian Urological Association's recommendation of single-use coated catheters for management of neurogenic bladder function (Campeau et al, 2020).
- Lack of affordable housing compounds all these issues.

"Part of it is that the general public assumes that people are taken care of when things happen because we have universal health care and the reality is a lot different and people don't know that until it happens to them or somebody they're close to. We don't support anyone very well with significant disabilities and that's one of the reasons why there's still so many problems with people with disabilities being integrated into society, because if the basic needs aren't being met effectively by our systems, whichever one it might be, then people are going to have more difficulty being involved in recreation or family events or work or any of those other things." – key informant BC

Attendant care provision in BC

Provision of home care or self-managed care funding is approved at a regional health authority level and is means tested based on income. Those without earned income have no monthly charge cap.

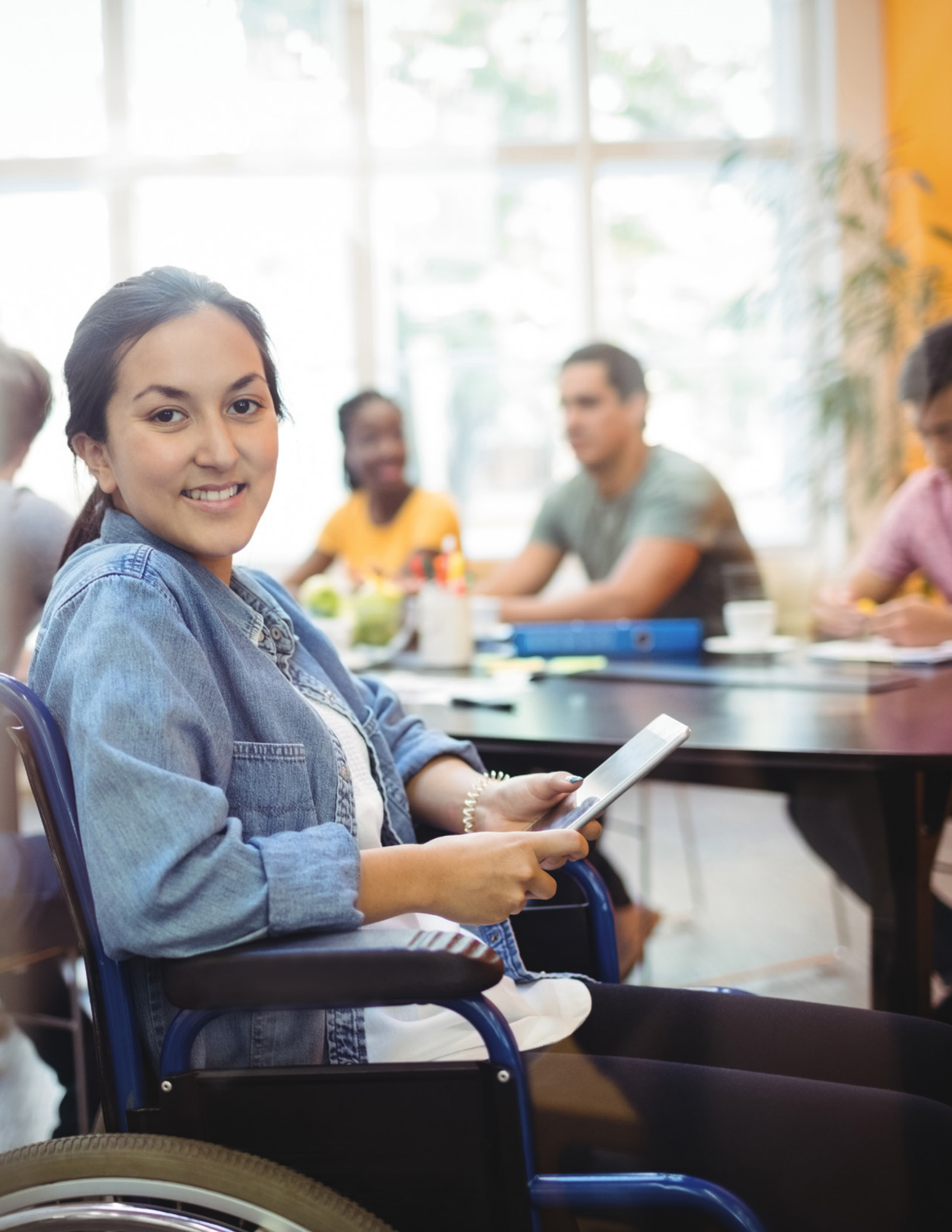


Table 1 *Means Testing in BC*

Attendant services means tested/copay	Medical supplies means tested/copay	Assistive devices means tested/copay
Yes	Yes	Yes
Daily rate calculated by multiplying "remaining annual income" by 0.00138889, capped at a maximum of $300/month if client or client's spouse receives any earned income. Clients are exempt from any costs if they receive the guaranteed income supplement, income assistance, disability assistance, or a war veteran's allowance.	Supplies may be considered for coverage if the individual is receiving EAPD. Financial eligibility for EAPD is based on complex calculations and a variety of factors, including family size, number of applicants/family and number of dependents to calculate 'allowable monthly income'. Provision of supplies is limited only to those earning less than the allowable monthly income. Allowable monthly income is limited to $808.42 to $949.08 for a single person living alone and from $858.42 to $1,597.06 for families with one or more applicants. A $375 shelter allowance may be added to this. Provision of ostomy supplies is means tested and provided under various Fair PharmaCare BC plans.	Similar to coverage of medical supplies, coverage of essential mobility assistive devices is dependent on receiving EAPD, which has income limits as previously noted.

Note. EAPD = Employment and Assistance for Persons With Disabilities

Adequacy of attendant service programs

Clients are exempt from any home care fees if they receive a Guaranteed Income Supplement, employment and income assistance, disability assistance, or a war veteran's allowance, and for those receiving provincial or Canada Pension Plan (CPP) disability allowance (Continuing Care Fees Regulation, 1997). Table 12 summarizes financial eligibility calculations and personal implications for an individual needing attendant services in each province. Hours of care are not formally limited, although health authority caregivers are in short supply. There is no upper limit of home care hours; however, the more hours a client requires, the more likely they are to be guided towards long-term care (LTC). Alarmingly, some clients—especially those in remote and rural settings—may be left with no other option than LTC, even if they are relatively young.

Eligibility for home support services is based on a clinical assessment conducted by a health care professional in which the individual is determined to require personal assistance to prevent or reduce the need for hospital or emergency services or admission to LTC, along with an agreement to pay the assessed client rate (Home and Community Care, n.d.-b). Physical need is assessed while still in hospital by a case manager (typically a nurse), and ideally includes an in-home assessment which is performed by rehabilitation hospital staff prior to discharge.

Hours of care are determined via assessment along with a detailed listing of daily care needs. This assessment can lead to tension, as it sometimes relies heavily on a case manager's opinion and clients may feel they are not adequately consulted. Furthermore, the hours of care a client receives can be significantly lower than prescribed due to lack of staffing. Clients can apply for a reassessment if care needs change within the community, although they are at risk of reduced hours even if need has increased as health authorities struggle with budget management. Appeals are possible (although lengthy and arduous) through the health authority.

Time limits do not formally exist for specific services, although scheduling can be inflexible for clients and is often limited. Clients feel rushed to ensure all ADL are performed and if problems arise or a specific task takes longer than allocated, other procedures are rushed or not performed at that appointment. In practice, limits stem from a lack of workers and supplies or equipment, which leads to an increased reliance on family and friends, a move to LTC, or being left to manage on one's own. Showers may be limited (some clients report one shower/week) or washing only available in the form of sponge bathing. Caregivers are directed not to perform transfers without either a specifically trained second person or a lift assist system.

If bowel/bladder management routines are not easily scheduled, clients are encouraged to access self-managed care. Not all care aides are trained or comfortable providing bowel care as they generally work with seniors. Clients may be encouraged to use an indwelling catheter if they request intermittent bladder management services. Relatively invasive procedures (changing Foley catheters, digital stimulation/disimpaction) are usually restricted to provision by a nurse, although situation-specific delegation of tasks to unregulated providers is outlined as a standard of practice by the BC College of Nurses and Midwives (BCCNM) and within personal assistance guidelines by the Ministry of Health (BCCNM, 2021, 2022; Ministry of Health Services, 2008).

Self-managed care and alternate delivery models

In BC, regional health authorities provide access to self-managed attendant services through Choice in Supports for Independent Living (CSIL). Eligibility for CSIL is based on meeting requirements for home support services and includes an assessed ability to safely coordinate CSIL services and funding (Home and Community Care, n.d.-a.). Clients are provided funding for CSIL through a regional health authority enabling them to become employers who purchase their own home support services and create appropriate scheduling. Clients are also responsible for training and supervision of employees for the appropriate and safe provision of attendant services CSIL is intended for clients with relatively high physical attendant care needs (typically with a minimum of 4-5 hours in daily services), although this is not an official requirement.

Funding is calculated by multiplying eligible hours for home support services by an hourly rate of $33.40 as of April 1, 2021 (Home and Community Care, n.d.-a.). Clients are not normally allowed to hire direct family members unless exceptional circumstances exist such as a language barrier, in which case exceptions must be applied for, and only after self-managed care is established through CSIL. Moving can be difficult as it involves a reevaluation and significant paperwork, and clients are not guaranteed to receive the same number of care hours. Table 13 provides a comparison of alternative attendant service delivery models in each province.

Rural & remote settings

Generally, services and staff are limited in rural and remote settings, and clients access CSIL funding to manage, along with help from family and friends. However, where appropriate caregivers are not available, or if self-managed attendant services are deemed unsafe, clients are strongly encouraged to move to LTC, which may be far from their homes.

Characteristics and limitations of essential medical supplies provision

Medical supplies needed to manage neurogenic bladder and bowel function (e.g., intermittent or

indwelling catheters, gloves, or bowel stimulants) may only be considered for coverage if the individual is receiving EAPD (Employment and Assistance for Persons with Disabilities Regulation, 2002; *British Columbia employment assistance policy & procedure manual,* n.d.-b). Ostomy supplies are means tested and provided through various BC Fair PharmaCare plans or through income assistance programs. Numerical limits are not specifically described, but each item and its quantity require a prescription. Additional supplies may be requested with medical justification, but single use catheterization is not supported. To be funded supplies must be: prescribed by a medical doctor or nurse practitioner; the least expensive supplies appropriate; necessary to avoid an imminent and substantial danger to health; reusable where appropriate; and covered only if no other resources are available to the family unit, as per *British Columbia employment assistance policy & procedure manual* (n.d.-b). Supplies must be purchased through a product distribution centre from a limited variety of centrally stocked supplies.

While funding of some medical supplies is provided to clients of EAPD, the system is reported to be unresponsive to advances in medical technology or improved best practices. Clients report that it is difficult to leave disability benefits unless they have a full-time job to be able to meet medical supply costs. Key informants reported this gap in funding for medical supplies has led to calls for full funding of medical supplies for everyone until a person earns a sufficiently high income. Public funding of these medical supplies for a larger proportion of the population would reduce costs to both the individual and the system as it would lower emergency room visits and incidence of infection. Table 14 summarizes financial eligibility calculations and personal implications for an individual needing neurogenic bladder and bowel management supplies in each province.

Essential wheelchair, seating, and lift and transfer devices

Power and manual wheelchairs, lifting and transfer devices, and essential seating items are provided only to clients receiving EAPD (*British Columbia employment assistance policy & procedure manual*, n.d.-a). Generally, the least expensive appropriate equipment or device is provided, and requires: a prescription by a medical or nurse practitioner and/or assessment by a relevant therapist; pre-approval by the Ministry of Health; and that the family unit have no other resources available for payment (*British Columbia employment assistance policy & procedure manual*, n.d.-a). Devices must also be deemed medically necessary to achieve/maintain basic mobility or positioning or to facilitate transfers or ADL in the home or community (*British Columbia employment assistance policy & procedure manual*, n.d.-a). Each item requested is reviewed on an individual basis, and if medical justification is provided for a specific feature or upcharge, it may also be considered for coverage. Table 15 summarizes financial eligibility calculations and functional implications for an individual needing mobility equipment in each province.

Equipment and devices are provided through service providers contracted by the Ministry of Health unless an item is not available (*British Columbia employment assistance policy & procedure manual*, n.d.-a). These service providers also provide free fittings, equipment trials, delivery, two-year service coverage, preventative maintenance at 12 and 24 months, and free suitable loaner devices during repairs (*British Columbia employment assistance policy & procedure manual*, n.d.-a).

Clients report that access to timely repairs is a significant issue (especially with power mobility devices) which has left some confined to bed without appropriate replacement equipment. The ministry will only pay for service on equipment they purchased. As a result, people otherwise eligible to receive equipment through this program, who received equipment through alternative funding options (e.g., fundraising or charity), would not be eligible to access any publicly funded repair or maintenance services for their mobility equipment.

Insurance programs

Motor vehicle insurance is provided through the Insurance Corporation of British Columbia

(Insurance Corporation of British Columbia [ICBC], n.d.), which switched to no-fault coverage for catastrophic injuries as of May 1, 2021. Home care may be provided through ICBC up to $6,018 per month for those needing less than 24-hour care and up to $10,000 per month for those who do require 24-hour care. Clients are assessed by a support specialist to determine care needs and can hire family members or professionals. Clients can submit receipts for reimbursement or ICBC pays providers directly. Prescribed medical supplies or equipment due to injury are covered when preauthorized by a recovery specialist.

WorkSafeBC funds home care services, medical supplies, and medical equipment to injured workers (WorkSafeBC, 2010). Attendant services are initiated through an assessment and development of a care plan with a registered nurse. Services may include nursing services and attendant services from a health care assistant, but do not include homemaking services (WorkSafeBC, 2022). WorkSafeBC includes an option for self-managed attendant services (WorkSafeBC, 2020). Medical supplies must be preapproved by WorkSafeBC and are provided through vendors which invoice WorkSafeBC directly using relevant fee schedules. Coverage includes catheters (listed as disposable), ostomy supplies, and incontinence supplies. Mobility assistive devices including power and manual wheelchairs, bathroom aids, seating/positioning devices, tilt/recline systems, lifting devices, power assist wheels, and medically necessary exercise equipment are also funded with preauthorization from WorkSafeBC (WorkSafeBC, n.d.; WorkSafeBC, 2021). Home and vehicle modifications may also be approved (WorkSafeBC, 2010).

Discrepancies between policy and experience

Clients are widely dissatisfied with limited available caregivers and rigid scheduling which can become a barrier to freedom of personal scheduling, community participation, and employment. Gaps in the system arise when clients are assessed for hours of care which are inadequate to their needs when unexpected issues arise.

"The home support system was set up for the needs of seniors, and that is the majority of where the home support hours go because we have lots of seniors. But they're not necessarily meeting the needs of other people with more significant disabilities. Health authorities are not very creative in helping people find ways to stay in the community. It seems like the default is facility care even when that's not what the person wants or what would be best for them." – key informant BC

There is a home support worker shortage in the province, and most individuals will go to lengths to avoid facility care if it is possible. However, a reliance on family and friends as caregivers is problematic, as even if people want to help, they may be improperly trained, and responsibilities may lead to burnout, loss of employment, and destroyed relationships.

ALBERTA

AB takeaways

- Attendant services are not means tested and there is no cost-sharing component in Alberta.
- Access to attendant service resources is limited or nonexistent in small or remote communities, leading to increased reliance on family and friends.
- Clients may be forced to remain in LTC beds while waiting for required services to become available in the community. A lack of attendants and resources lengthens hospital stays.
- Medical supplied are means tested and provided on a cost share basis, with clients paying 25% up to a yearly maximum of $500. Clients are exempt from cost share if they earn less than a predetermined low income. Single-use catheters are not supported, and quantities are limited. Restrictions to medical supplies such as catheters limits an individual's choice and right to self-determination and is ultimately shortsighted.
- A restricted range of wheelchair models are available through a loans program without means testing. A grant up to $3,900 is available if a client chooses to upgrade the wheelchair with features for greater functionality, or to purchase a model not available through the equipment pool.

"We know the access to resources [. . .] really gets limited in smaller and rural remote areas and more often than not, we find out that an individual gets more assistance from family and friends or support within the community. Because accessing them is sometimes for either virtually impossible or they have no other choice. I know a majority end up moving to a more urban centre. I'd say anybody living in a more rural area has a lot more difficult time accessing any kind of home care services. The vast majority that I know still that live rurally access self-managed care, because then they can hire somebody within the community." – key informant Alberta

Attendant care provision in Alberta

Attendant services are approved and may be provided through Alberta Health Services (Alberta Health Services [AHS], 2017a). Services may alternatively be provided services through other home care providers (AHS, n.d.).

Table 2 *Means Testing in AB*

Attendant services means tested/copay	Medical supplies means tested/copay	Assistive devices means tested/copay
No	Yes	No
There is no cost-sharing for attendant services in Alberta. Anyone living in Alberta with a valid healthcare card can receive home care as long as needs can safely be met at home, which is determined during an initial home visit by a home care case manager and may include other members of the care team	Catheters, catheter supplies, and ostomy supplies are partially covered for clients receiving medical surgical benefits through AADL. Clients pay 25% of AADL maximums up to a maximum of $500/family/year, disregarding product upgrades (clients are responsible for 100%). This cost share may be appealed if the client believes it will lead to financial hardship. Clients are exempt from the cost share if receiving social assistance, or if their income is less than $20,970 for a single person, $33,240 for a family with no children, or $39,250 for a family with children.	Copay is required for clients opting for funding grants for *upgrade* status chair. Coverage of power and manual wheelchairs, lifting and transfer devices, and essential seating items is provided to clients through AADL. To be eligible for equipment, clients must attend a seating clinic for an assessment. Wheelchairs are loaned through a recycled and refurbished inventory. Clients can also choose to receive a grant for an upgrade status chairs. In this case, the client receives a grant (dependent on category of upgrade chair, up to $3,900 for a lightweight or ultralight chair). The client covers the remaining cost of the wheelchair and its components and becomes the owner of the wheelchair.

Note. AADL = Alberta Aids to Daily Living

Adequacy of attendant service programs

Hours of care are determined by a case manager during the initial home visit after injury (AHS, 2017a). A formal limit on hours of care does not exist, although if a client has significant care needs requiring a team of providers, quality of care would be considered as a potential reason for referral to LTC. Clients can appeal their allotted hours by building a case with their care team to justify requests for additional hours. Time limits do not formally exist for specific services, although services are always optimized for efficiency and may be rushed.

Properly trained nurses are required to perform invasive procedures such as digital disimpaction and catheterization, while health care aides may perform all other services related to ADL. Nurses are also able to delegate specific tasks to health care aides if they deem the situation low risk, the client to be stable with predictable outcomes, and the health care aide is properly trained in the task (College & Association of Registered Nurses of Alberta College of Licensed Practical Nurses of Alberta College of Registered Psychiatric Nurses of Alberta, 2010). Clients are advised to have a backup (family member or friend) for non-scheduled emergency events.

Through the pandemic, more clients remained in institutions while waiting for services they required to become available in the community (client has completed acute care phase of rehabilitation treatment but remains in acute or subacute care bed). Adequacy of other services (bathing, dressing, transfers) varies from client to client, with some clients reporting that switching to self-managed care can improve service delivery.

Self-managed care and alternate delivery models

Eligibility for self-managed care is determined by a case manager and requires unmet, ongoing, and predictable care needs, stable health, and willingness and competency in assuming responsibilities and risks involved (legal representatives may do this on client's behalf). Clients are provided funding to cover their assessed needs and become responsible for the management of their own home care provider. Self-managed care is relatively portable, requiring notification of change of address and an assessment to verify the change. Self-managed care does not allow hiring of family members (AHS, 2017b). See also Table 13.

Cooperative housing is offered via Designated Supportive Living as an alternative delivery model through AHS (AHS, 2014).

Characteristics and limitations of essential medical supplies provision

Medical supplies for neurogenic bladder and bowel management such as catheters, catheter supplies, and ostomy supplies are partially covered for clients receiving medical surgical benefits through Alberta Aids to Daily Living (AADL; Alberta Health, 2021a). Clients pay 25% of costs up to a maximum of $500/family/year. Refer to Tables 2 and 14 for details and implications of copayment and for those on social assistance. Medical supplies must meet AADL generic product requirements and must be purchased through an AADL approved vendor (Alberta Health, 2021d). Quantities are limited and are based on a two-month supply. Of note, intermittent catheters are limited to ~ 1/day (70 per 2 months) and ~1 for a two-week period for Foley catheters (4 per 2 months; Alberta Health, 2021e).

Essential wheelchair, seating, and lift and transfer devices

Provision of basic wheelchairs and assistive devices is not means tested and is provided to clients through AADL and based on client assessment (Alberta Health, 2021b, 2021c, 2021f, 2022a, 2022b, 2022c). Wheelchairs are loaned through a recycled and refurbished inventory. Clients are eligible for power chairs every 7 years, manual chairs every 5 years, (Alberta Health, 2022d, 2022e) and wheelchair cushions and backrests every 3 years (Alberta Health, 2022g). Eligible models are limited and restricted to those outlined under four categories by AADL, and clients are responsible for costs of upgraded components/ options not funded by AADL (Alberta Health, 2022d, 2022e). Repairs are covered up to an annual maximum. Clients can also choose to receive a grant for an upgrade status chair (Table 15). While access to equipment is based on an authorized assessment, it does not involve the user in deciding which equipment would fit their lifestyle, optimize their quality of life, or maintain pre-injury community participation.

Insurance programs

Alberta's motor vehicle insurance is based on a tort system with partial no-fault benefits. Invoices for personal attendant care, medical supplies, and essential mobility assistive devices are provided to Alberta's Motor Vehicle Accident Claims (MVAC) program and costs are covered under one lump sum up to a lifetime maximum of $200,000 (Motor Vehicle Accident Claims Regulation, 1998). Clients do not have direct access to the lump sum, but do have the right to sue in an attempt to receive money beyond the lifetime maximum.

The Workers' Compensation Board (WCB) of Alberta performs their own assessment of compensable injuries to determine needs regarding personal attendant services, and an allowance is paid for as long as it is needed. This care can be agency-managed or self-managed (Workers' Compensation Board – Alberta, 2016, 2019). With medical justification, WCB provides coverage of most medical supplies, including items such as hydrophilic single-use catheters. Following

an assessment, WCB also provides coverage of essential mobility assistive devices, as well as home and vehicle modifications (Workers' Compensation Board – Alberta, 2016). If need can be justified, WCB focuses on emphasizing quality of life, and will cover optional accessories, including items such as handcycles and sports chairs/equipment, recognizing that maintaining health over one's lifespan requires exercise.

Discrepancies between policy and experience

AHS provides comprehensive information on provincial programs supporting those with a disability. The pandemic has tested the health care system and exposed weaknesses related to discharge to the community after initial rehabilitation. Key informants were critical of the need to provide individual justification for coverage for hydrophilic, Coudé tip or other catheters recommended by the CUA (Campeau et al., 2020). Generally, approved vendors and products result in restricted choice, and are at odds with individual right to self-determination.

SASKATCHEWAN

SK takeaways

- Attendant services are means tested.
- Means testing is based on both hours of need and income with large client charges applied once earnings are beyond a very low income level.
- Home care services are reported to be increasingly time restricted.
- Access to attendant services is limited or nonexistent in small or remote communities, leading to increased reliance on family and friends.
- Medical supplies to manage neurogenic bowel and bladder are funded under the Saskatchewan Aids to Independent Living (SAIL) program (a subsidiary of the Paraplegia Program) which is not means tested, in contrast to the other nine provinces examined.
- The Paraplegia Program provides 100% coverage of a limited number of medical supplies such as catheters, ostomy supplies, and accessories. Single-use catheterization is not supported, and quantities are limited.
- Wheelchairs and other assistive devices are offered through Special Needs Equipment Program (SNEP), provision is not means tested. WCs are limited to a few (<5) models and the equipment pool is generally considered as aging, refurbished and inadequate.

"Then we have the other people that aren't covered through the para program like NIHB clients, there's more chance they're getting inferior products. You've got more hospitalizations and things like that. When people haven't had enough supplies, too, and they haven't had their doctor's prescription, then they're limited so you have more chance of more hospitalization." – key informant Saskatchewan

Attendant care provision in Saskatchewan

Provision of care is approved through the Saskatchewan Health Authority (SHA).

Table 3 *Means Testing in SK*

Attendant services means tested/copay	Medical supplies means tested/copay	Assistive devices means tested/copay
Yes	No	No
Flat rate of $8.80 for the first 10 hours of service per month, with each additional hour within a month charged on a sliding scale based on adjusted monthly income and capped at a maximum of $529/month as of October 2021 ($6,348/year). Clients receiving SK Income Support, Employment Supplement, Seniors' Income Plan, or earnings less than $88/month will only be charged for the first 10 hours per month ($88.00/month cap). No fees are charged for services provided by a case manager, nurse, OT/PT, or for short-term acute of palliative home care clients.	Neurogenic bladder and bowel management supplies (including catheters, gloves, lubricant, and suppositories) are 100% covered under the Paraplegia Program, a sub-program of SAIL. Eligibility for SAIL requires Saskatchewan residency, referral by a health care professional, and ineligibility for support through other government agencies such as NIHB or WCB. Eligibility for the Paraplegia Program is dependent on paralysis and requires physician prescription.	Essential mobility assistive devices, including wheelchairs, lifting/transfer devices and essential seating devices are loaned to clients under the SNEP, a subprogram of SAIL, while grants for home and vehicle modifications are offered through the Paraplegia Program.

Note. NIHB = Non-Insured Health Benefits; OT = occupational therapist; PT = physiotherapist; SAIL = Saskatchewan Aids to Independent Living; SNEP = Special Needs Equipment Program; WCB = workers' compensation board

Adequacy of attendant service programs

Assessed needs are used to develop a care plan and a service delivery schedule. A client's progress is reviewed at regular intervals to ensure that services are still required and appropriate (Government of Saskatchewan, Ministry of Health, 2021). Hours of care are not formally limited, although they are reported to be significantly restricted with pressure on family members to take partial responsibility for provision of care. See Tables 3 and 12 for a summary of costs calculations for attendant services and financial implications for individuals with SCI requiring attendant services.

Self-managed care and alternate delivery models

Eligibility for Individualized Funding (IF) is based on eligibility for home care services and includes a client's requirement for LTC with stable supportive service needs, capability to manage the funding successfully, and willingness to accept the responsibilities involved (Government of Saskatchewan, n.d.). IF is provided through the SHA, and clients receive funding to arrange and manage their own support services (Government of Saskatchewan, n.d.). Professional services such as nursing or specialized therapies are not included in IF—and may be accessed through home care. Monthly funding is calculated by multiplying

assessed hours by $29.22 (which includes benefits) and adding a monthly administration allowance of $50.26. The maximum monthly amount for 2021-22 is $7,474, based on average provincial costs for supportive care. Clients are not allowed to hire family members, hire through an agency, or hire anyone who has worked with the health authority within the last three months.

Collective Funding (CF) is an alternative service delivery model provided by the SHA intended to simplify managing, funding, and accounting processes for groups of people living together who are eligible for IF. The collective group designates a representative who is responsible for arranging and managing support services for the group and reporting to the SHA. See also Table 13.

Characteristics and limitations of essential medical supplies provision

Eligibility for the Paraplegia program is dependent on paralysis and prescription by a physician (Government of Saskatchewan, 2016). As shown in Tables 3 and 14, the program is payor of last choice but is not means tested. Supplies are limited to the least expensive generic option available, and intermittent catheters are limited to four per day.

Essential wheelchair, seating, and lift and transfer devices

Essential mobility assistive devices, including wheelchairs, lifting/transfer devices, and essential seating devices are loaned to clients under the SNEP, a sub-program of SAIL, while grants for purchases of home and vehicle modifications are offered through the Paraplegia Program (Government of Saskatchewan, 2016, 2018). Repairs and maintenance are also provided for loaned equipment, and chairs are replaced only if there is a significant change in need or when repairs are required which have become uneconomical. In 2019, SNEP launched a trial of a $2,500 grant-in-lieu option for ultralight wheelchairs as an alternative in which the client would cover the remaining cost and become the owner of the purchased wheelchair (Government of Saskatchewan, 2018). See also Table 15.

Insurance programs

Saskatchewan's auto insurance is mixed, although most individuals use no-fault insurance. Coverage through Saskatchewan Government Insurance (SGI) includes income replacement to a maximum of $105,430, a lump sum payment for catastrophic injuries to a maximum of $258,915, and coverage of medical and rehabilitation costs are capped to a $7,397,579 maximum (SGI, 2022). Living assistance payments are capped to $931 per week for functional impairments. Medical and rehabilitation coverage includes specialized medical supplies, wheelchairs and accessories, mobility aids, specialized bath, and hygiene equipment, and may include the purchase and modification of a vehicle and home modifications (SGI, 2017).

The WCB of Saskatchewan provides coverage of personal and nursing care either directly to an individual or through an agency monthly following an assessment by a home care agency to a monthly maximum of $2,481. Medical supplies and equipment are covered if they are approved by a WCB case manager (Saskatchewan Workers' Compensation Board, 2022). Coverage may include home and vehicle modifications (Saskatchewan Workers' Compensation Board, n.d.).

Discrepancies between policy and experience

The programs available for those in Saskatchewan are comprehensive and well defined. The province considers exceptions and appears more innovative than most to try new programs or allow residents' self-determination of care arrangements. However, key informants indicate home care services are becoming more restricted and rushed, and timely access to repairs of aging, refurbished equipment is becoming increasingly difficult, resulting in some clients stuck in bed while waiting.

MANITOBA

MB takeaways

- Attendant services are not means tested; and are available to all as payor of last resort.
- Key informants report the level of care is often seen as marginal, and generally as inadequate.
- Rural settings typically have restricted service options with the highest level and range of services in urban centres.
- There is no provincial program for supplying catheters, gloves, lubricant, or suppositories for those not receiving home care or Employment and Income Assistance (EIA). If a person is self-supporting or earning employment income, there is no public support for their neurogenic bladder and bowel supplies.
- Although there is no means testing for the provision of wheelchairs, the program is based on a loaned equipment pool run through a nongovernmental charitable organization. If it is deemed that no equipment is available through the equipment pool, a new wheelchair may be ordered for the client. The client is restricted to wheelchairs from one to two suppliers and one or two models for each category of client function and requires an assessment by an occupational therapist (OT).
- If a client requests an upgrade or customization to address their personal physical characteristics (e.g., a shortened seat pan on a power wheelchair to get closer to counters and workspaces) the client is responsible for both paying for the customization and paying for the original seat pan upon return of the wheelchair to the loan program. Clients must return loaned equipment to the pool in its original configuration. Clients are responsible for maintenance on any purchased upgrades or customizations.

"Number one, they're not providing them [catheters] for all people who need them, and they are a medically necessary device, so you know, if you have an SCI and you happen to live independently in the community, none of these are provided for you. Secondly, they limit the number, so in certain countries, single-use catheters are what are the best way to go. Canada [is] I think among the only two [countries] in the developed world that tell people to reuse catheters." – key informant Manitoba

"I would say that there is [are] gross inadequacies in the public-based system compared to these insurance-based systems because there's such a severe curtailing of what they will provide and what hoops you have to go through in order to be able to have the devices that are there . . . they're just not assessed from an actual true functional perspective." – key informant Manitoba

Attendant care provision in Manitoba

Provision of care is approved through five regional health authorities. It is not means tested.

Table 4 *Means Testing in MB*

Attendant services means tested/copay	Medical supplies means tested/copay	Assistive devices means tested/copay
No	Yes	No
Eligibility for home care services is based on an assessment conducted by a case coordinator who is also a health care professional. There is no cost-sharing component for home care services.	Only clients who are receiving home care services or EIA may be eligible for coverage of basic neurogenic bladder and bowel management supplies and equipment, including catheters, gloves, lubricant, and suppositories, and any items deemed necessary by a medical professional. Financial eligibility for EIA is dependent on a client's family's monthly basic needs (basic allowance and ongoing medical costs) and shelter costs exceeding total income and assets. However, clients living with ostomies, wounds, or fistulae and who have been assessed by a nurse specialized in wound, ostomy and continence are eligible for 100% coverage of ostomy supplies through the Manitoba Ostomy Program, regardless of income.	Power and manual wheelchairs are loaned to individuals through the MWP, which is administered by the charity Manitoba Possible. Individual level of function determines eligibility for type of wheelchair (divided into categories, with specific models available only to those within that category of function). Thus, lightweight wheelchairs are only available to those with the highest level of injury. Those with greater function would not be eligible. Eligibility criteria for the MWP include Manitoba residency in the community (individuals in personal care homes are not eligible), a physical disability affecting mobility and requiring a wheelchair for a minimum of 6 months, and prescription by an OT/PT, as well as ineligibility through other programs such as workers' compensation.

Note. EIA = Employment and Income Assistance; MWP = Manitoba Wheelchair Program; OT = occupational therapist; PT = physiotherapist

Adequacy of attendant service programs

Hours of care do not have a formal upper limit, although personal care home placement may be recommended if a client is deemed to be unsafe at home with home care services or if service is deemed to be less efficient than that provided in a care home (Manitoba Health, 2019). Time limits aren't based on specific services but do exist within the more general provision of care (Winnipeg Regional Health Authority Home Care Program, 2013). Services are provided as quickly as possible, and home care calls are limited to four per day. Alternative delivery models, including Fokus units (in which 4-6 persons with high level SCI would rent in the same apartment complex to increase coordination of attendant services delivery) were developed to enable those with high levels of service needs to remain in the community and out of LTC facilities (Ten Ten Sinclair Housing, n.d.-a; n.d.-b; Winnipeg Regional Health Authority, n.d.).

Self-managed care and alternate delivery models

Clients can apply for self- or family-managed care (SFMC) through the home care program. SFMC is accessed through a regional health authority (Winnipeg Regional Health Authority, 2022). Eligibility for SFMC is based on eligibility for home care services and includes an ability to manage services and funding, whether that be completed by the client, their family, or through the Independent Living Resource Centre (Winnipeg Regional Health Authority, 2022; Independent Living Resource Centre, n.d.).

Another alternative delivery model facility was developed at 1010 Sinclair, as a transitional housing setting, to allow those with recent injury to return to the community with supportive attendant services, with the ultimate goal of returning to full community living rather than entry into a LTC facility (Ten Ten Sinclair Housing, n.d.-a). See also Table 13.

Rural & remote settings

Rural settings typically have restricted service options with the highest level and range of services offered in urban centres.

Characteristics and limitations of essential medical supplies provision

Medically necessary supplies are not provided to everyone who needs them in Manitoba. When provided, supplies are limited, and single-use catheters are not supported. If a client is not receiving home care services or EIA, there is no public coverage of catheters, gloves, lubricant, or suppositories (Table 14).

Essential wheelchair, seating, and lift and transfer devices

Power and manual wheelchairs are loaned to individuals through the Manitoba Wheelchair Program (MWP), which is administered by the charity Manitoba Possible (Manitoba Possible, 2021). Individual level of function determines eligibility for type of wheelchair (divided into categories, with specific models available in each category). While add-ons are available for wheelchairs, they must be installed post-assembly, which leads to increased shipping costs, service work, and wait time. Wheelchairs must be returned to the equipment pool in their original ordered configuration, so costs to adapt the wheelchair to the client's physical needs must include costs to return it to its generic condition upon return to the equipment pool (Table 15).

Bath seats, commodes, hospital beds, portable Hoyer lifts, and ceiling track systems (limited to one room) are covered if a client is receiving home care. These items may be considered for EIA clients with a medical recommendation (Department of Families, n.d.). None of these medically necessary devices are provided to anyone with earned income. Pressure redistribution seating surfaces are provided (up to a $600 value) every three years through a partnership of home care and Spinal Cord Injury Manitoba.

Insurance programs

Manitoba Public Insurance uses a no-fault automobile insurance system with a Personal Injury Protection Plan (PIPP; Manitoba Public Insurance, n.d.-a, n.d.-b). Coverage includes up to a $260,541 lump sum indemnity for catastrophic injury and up to $5,918 per month for personal care assistance (Manitoba Public Insurance, n.d.-b). PIPP covers the costs of over the counter and prescription medicines and medical supplies which are required due to injury if receipts are provided. PIPP also covers costs of purchasing, renting, repairing, replacing, fitting, or adjusting devices that are medically required and prescribed, including a variety of brands of wheelchairs and a backup wheelchair with rationalization (Manitoba Public Insurance, 2018). The first home modification after injury and vehicle modifications may also be covered.

The WCB of Manitoba provides funding for personal care, provided the assistance compensates for assistance needs in the most cost-effective way possible (Workers Compensation Board of Manitoba, n.d.-b). Medical supplies and assistive mobility devices are covered if they

are recommended by a recognized health care provider, required because of compensable injury, effective in treatment or ongoing care, and the costs appear reasonable (Workers Compensation Board of Manitoba, n.d.-a). WCB may also pay for repairs or replacement of mobility devices (Workers Compensation Board of Manitoba, n.d.-a).

Discrepancies between policy and experience

Provision of care is reduced to a strictly functional process which is rigidly scheduled and does not adhere to the independent living philosophy. For some clients, scheduling of services may match their lifestyle, but spontaneity in dressing, movement (transfers), and bladder management does not exist. Loaned wheelchairs are covered with numerous stickers stating that it is the property of the charity, Manitoba Possible, which seems paternalistic and does not adhere to the principles of equity, diversity, and inclusion.

The way that this system is constructed is that the Manitoba Health has washed its hands of providing essential wheelchairs to people with disabilities by giving an envelope of money to a nongovernmental nonprofit organization called Manitoba Possible . . . and in contrast, when you do have an amputation and you do require a limb prosthetic, instead what happens is the province of Manitoba develops a care list like they do for other essential health care needs . . . and they make sure that they set the limb to your quality of life . . . They at least assess [what the] pre-injury level of function was and they try to provide you with a piece of equipment that will allow you to live your life the way that you did before. — paraphrased from key informant in Manitoba

ONTARIO

ON takeaways

- Home care is provided through Home and Community Care Support Services (HCCSS). Home care can be accessed either through HCCSS organizations, as family-managed care, or through Direct Funding.
- Home care is not means tested in Ontario and there is no formal limit to hours of care.
- While time limits for specific services do not formally exist, in practice, hours are limited when service providers do not have enough staff to provide the required hours.
- Retention and recruitment of nurses and personal support workers in Ontario is a problem.
- The provision of services is variable depending on setting and the overall level of service is not considered adequate.
- Provision of neurogenic bladder and bowel management supplies is means tested. There is no funding mechanism outside of social assistance or third-party insurance for essential bowel and bladder management supplies. If a person has employment income, they are 100% responsible for their neurogenic bladder and bowel supplies.
- Provision of wheelchairs operates on a 75% Government of Ontario and 25% client payor system. Clients can choose from a list of pre-approved wheelchair suppliers and models (which is the widest published list available across Canada).

"Coverage in Ontario prevents people from accessing gainful employment, it prevents people from accessing social participation, and it creates social isolation, and creates increases the risk of infection. This can be a spiraling effect on overall health and well-being of an individual. If someone needs something that they can't live without… it's not happening, or it's not being defined as essential. There just isn't the coverage for people to access the supplies that they need and so they end up using generic supplies. They don't have enough of them, so they're reusing them, and it's probably causing more UTIs and other issues that could easily be prevented. Let's face it, the cost to the health care system is probably a lot higher because there isn't that coverage." – key informant Ontario

"If you're not on any kind of social assistance finding the 25% yourself is more than difficult. A lot of people fall through the cracks. We know how expensive it is when you have an SCI and all the equipment that you have to have. It's so difficult to get coverage and it's just not equitable across the board. Many people are managing with subpar equipment because they can't afford the copayments for the type [of] equipment that they need. The programs all have limitations, they are scratching the surface and providing the minimum standard—it's basically keeping people alive, not having them thrive." – key informant Ontario

Attendant care provision in Ontario

Provision of care is approved through Ontario Health, comprising five super regions (Government of Ontario, Ministry of Health, 2022a).

Table 5 *Means Testing in ON*

Attendant services means tested/copay	Medical supplies means tested/copay	Assistive devices means tested/copay
No	Yes	Yes
Eligibility for home care services is based on a centralized, regulated assessment, the interRAI CHA, which is used to determine an individual's functional, mental, and health status.	For clients receiving income support through the ODSP, supplies may be covered as Mandatory Special Necessities. ODSP eligibility criteria include a long-term or permanent disability and financial need, which is determined by a caseworker and defined as a household's basic living expenses exceeding a household's income and assets. Income exemptions include the Canada Child Tax Benefit, payments from a RDSP, and Ontario Student Assistance Program loans.	Ontario residents who have a disability requiring a mobility aid for six months or longer are eligible for 75% funding of some essential assistive devices under the ADP and are required to pay the remaining 25% of the cost. Clients receiving financial support from Ontario Works, ODSP, or Assistance for Children with Severe Disabilities receive 100% coverage through ADP.

Note. ADP = Assistive Devices Program; interRAI CHA = international Resident Assessment Instrument Community Health Assessment; ODSP = Ontario Disability Support Program; RDSP = Registered Disability Savings Plan

Adequacy of attendant service programs

Assessment of those with disabilities is based on international Resident Assessment Instrument Community Health Assessment (interRAI CHA), which is designed for seniors and is used to determine hours of care needed. In situations where a service provider can't deliver required hours, clients can apply to HCCSS to have their hours topped up to the number of hours allotted through the interRAI CHA, pending approval of funding.

Self-managed care and alternate delivery models

Eligibility for family-managed home care is based on eligibility for home care and requires a plan of service developed with HCCSS (Home and Community Care Support Services South West, 2021). Government funding is provided to either the family or the client, who then has the autonomy to recruit, train, and manage private attendant services directly. It is not intended as a first option but is available to clients who may not have access to services in their area. Family-managed home care grants full control of care to the client and includes the responsibilities involved with coordination of those services (like running a small business). Services are portable for clients moving within Ontario. See also Table 13.

The Centre for Independent Living in Toronto (CILT) is responsible for interviewing clients and providing direct funding for attendant services (CILT, n.d.-a, n.d.-b). Eligibility criteria are similar to those of family-managed care and additionally require an ability to self-direct and self-manage (CILT, n.d.-b). Clients are provided funding to direct their own care, again with all the associated staffing responsibilities (CILT, n.d.-b). While the hiring of family members is allowed through family-managed care, it is not if a client is receiving direct funding. Family-managed care also covers a wider range of services such as OT and seating assessments, while direct funding is more strictly focused on ADL, and such services would have to be accessed through HCCSS.

Rural & remote settings

Generally, service organizations and supports are more limited in rural settings, although it may be easier to find options for hiring attendants under a direct funding model. Families of clients in rural settings may be forced into offering support where providers do not exist, while clients may be forced to move to a larger centre. The needs of Ontarians in rural and Indigenous communities were explored further in a 2021 policy report on medical supplies (SCIO, 2021).

Characteristics and limitations of essential medical supplies provision

There is no funding mechanism outside of social assistance or third-party insurance for essential neurogenic bowel and bladder management supplies. For clients receiving income support through the Ontario Disability Support Program (ODSP), supplies may be covered as Mandatory Special Necessities (Ministry of Children, Community and Social Services, 2019). Supplies provided through ODSP are limited in both quality and quantity. Hydrophilic single-use catheters are not covered, and it is a struggle to get premium products. In the case of catheters, poor manufacturing practices of 'the most inexpensive option available' may necessitate the use of catheters with rough edges that can tear epithelium during use. Numbers of catheters are limited, for some to one per day, requiring a business case involving comorbidities, rates of infection, and urology recommendations to have supplies funded beyond those limits (Table 14).

Essential wheelchair, seating, and lift and transfer devices

Coverage is restricted to items or features specifically outlined in ADP's Mobility Devices Product Manual (Government of Ontario, Ministry of Health, 2021). Clients interested in receiving items or features not outlined in this manual receive no coverage through ADP (Table 15). Items not covered through ADP include (but are not limited to) commodes, wheelchair lifts/ramps, transport/recliner chairs, as well as most rental equipment, although clients of ODSP may be eligible for coverage of some of these items (Government of Ontario, Ministry of Health, 2022b).

Ultimately, provision of essential assistive devices is seen to be inadequate, as clients are not receiving the equipment that they need to function.

Insurance programs

Motor vehicle insurance in Ontario exists as a mixed tort and no-fault system. Limits to funding are based on an individual's age, demographic, work ability, and level of disability. The sum of medical, rehabilitation, and attendant care benefits cannot exceed $2,000,000 for catastrophic impairment and includes "all reasonable and necessary expenses" (Statutory Accident Benefits Schedule, 2022). Injured persons will generally also pursue litigation for further financial coverage of personal injury accidents.

Ontario's Workplace Safety and Insurance Board (WSIB) benefits function in a closed market which provides a prescription over a person's lifetime. A client's needs regarding housing, equipment, supplies, and attendant care are determined through arbitration, and it becomes WSIB's responsibility to pay out the prescription monthly over the client's lifetime. Coverage definitions are general, including health care supplies and equipment which are used to improve or maintain independent living (Ontario Workplace Safety and Insurance Board, 2007, 2009a, 2009b).

Discrepancies between policy and experience

Key informants indicate that Ontario has such a web of overlapping and intertwined programs that is a struggle for most people to comprehend its complexities and access services. Access to attendants was exacerbated by the pandemic. Agencies try to accommodate nonscheduled emergency events, but clients are also required to have an emergency backup in place.

The system of coverage also creates a disincentive to leave ODSP support, as this would also mean loss of coverage of both essential assistive devices

and medical supplies, the costs of which may outweigh potential income gained. While some clients opt for donated equipment through various community organizations, coverage is inequitable, and many people are forced to manage with inferior equipment and related loss of function(s).

[The system is] "not getting people what they need . . . they're not doing a fulsome assessment around what a person needs, they're doing an assessment of what the government would agree to, right? And it's flawed in its limitation to therapy. It does not focus on functional recovery; it only focuses on the ability to manage in your home. Only the ADP definition does not scope beyond the in-house environment as part of its definition, right? It only looks at the safety and reasonability of devices within the home. Even though you use a manual wheelchair outside of the home . . . it looks at are you able to go from the living room to the bathroom to the bedroom and back again, right? So that's a huge limitation . . . it's not encompassing to individual needs." – key informant Ontario.

QUEBEC

QC takeaways

- Home care support services are funded by the provincial government and delivered via a centre local de services communautaires (CLSC; Gouvernement du Québec. (2022b, 2022c).
- While clients are generally eligible for standard home care tasks covered through CLSCs and service is intended to be identical across the province, some remote CLSCs may not have staff trained to perform relatively complicated bowel or bladder management routines.
- If a client's complicated needs create scheduling conflicts which the CLSC is not able to manage, the client may be advised to move to LTC or left to manage scheduling gaps on their own.
- Medical supplies are means tested and single-use catheterization is not supported. Coverage is viewed as inefficient and ignorant of individualized needs.
- The coverage of medical supplies is a cause of confusion and clients may be sequentially denied and referred to other programs or funders while applying for coverage.
- Provision of wheelchairs is not means tested. Physical needs assessment and management of the devices program is operated by the provincial government.

"I always say to my patients, you're better off not to hire your family because … the difference between the role of family member and caregiver is not easy to do and it's typical for a newly disabled person to overuse their family. When you've got somebody who's a family member and is helping you, you know that they love you subconsciously, so you don't have to be extra careful. So you're not going to be as cautious as you would be with somebody who was being paid because you don't want to upset them." – key informant Quebec

Attendant care provision in Quebec

Quebec's health- and social services system provides care through 18 health regions.

Table 6 *Means Testing in QC*

Attendant services means tested/copay	Medical supplies means tested/copay	Assistive devices means tested/copay
No	Yes	No
Home care support services are funded by the provincial government and delivered via a CLSC. Provision of home care is not means tested and clients are not required to contribute funds for needed services, but they are required to exhaust alternative funding sources such as insurance prior to accessing CLSC services.	Public coverage of neurogenic bowel and bladder management supplies is provided through the PFE. Applicants must have a long-term problem directly related to a disability or autism spectrum disorder and "present a significant need". If the person has private insurance coverage or coverage from the Ministère du Travail, de l'Emploi et de la Solidarité sociale, then PFE may cover the noncovered portion of identified needs. Clients are not required to contribute funds, although program eligibility requires a client to be considered low income. If a client is working and does not have insurance, they may be deemed ineligible for provision of any supplies.	Essential mobility assistive devices are covered through the Devices to Compensate for a Physical Deficiency Program and the ADP. Clients are eligible for 100% coverage without any form of means testing, although wheelchairs remain property of the provincial government and must be returned if the user no longer requires the wheelchair. Small items such as wheelchair cushions, shower chairs, commodes, and lifts are eligible for coverage through the CLSC.

Note. ADP = Assistive Devices Program; CLSC = centre local de services communautaires; PFE = Programme d'aides matérielles pour les fonctions d'élimination

Adequacy of attendant service programs

Home care support services are funded by the provincial government and delivered via a local community health centre (Gouvernement du Québec, 2022b, 2022c). Care needs are typically assessed through an interview by an OT or nurse and a service plan is developed in collaboration with the client. Provision of services is not means tested and clients are not required to contribute funds for eligible services.

Hours of care are calculated based on a pre-set schedule of needs. While individual adjustments may be made, if it becomes clear that a client has not been granted adequate care hours, the CLSC will investigate why the tasks cannot be completed within the standard time frames before granting additional hours. Limits to overall hours are based on a complicated individual client rating. Generally, no overnight service is available, and clients do not receive more than four visits per day. If a client does not agree with their allotted care hours, they may request a re-evaluation with medical documentation justifying the additional need.

Self-managed care and alternate delivery models

Home care support services may also be accessed as self-managed care via chèque emploi-service (CES; Gouvernement du Québec, 2009, 2022c). Eligibility for CES is based on a long-term need for assistance with ADL along with stable health and an ability to manage these services, either alone or with help from a friend or family member (Gouvernement du Québec, 2009). Clients are responsible for recruiting, hiring, training scheduling and supervising service providers. Clients submit a biweekly form to a processing centre which is in turn responsible for paying providers. Clients are allowed to hire through agencies and family members. Key informants indicated it is difficult to find service

providers. Support services through CES are portable throughout the province.

Rural & remote settings

While clients are generally eligible for standard home care tasks covered through CLSCs and service is intended to be identical across the province, some remote CLSCs may not have staff trained to perform relatively complicated bowel or bladder management routines. Clients are much more likely to receive a wider range of services and experienced service providers in urban centres, while clients in remote areas are more likely to access services via CES due to a lack of service options.

Characteristics and limitations of essential medical supplies provision

Public coverage of neurogenic bowel and bladder management supplies is provided through the programme d'aides matérielles pour les fonctions d'élimination (PFE). The PFE places restrictions on supplies offered and only the most inexpensive generic supplies are available for coverage. Refer to Tables 6 and 14 for program eligibility and details. Clients are not required to contribute funds for medical supplies. However, program eligibility requires a client to be considered low income, and if a client is working and does not have insurance, they may be ineligible for any coverage of supplies Table 14). Residents may also be eligible for coverage of medical supplies through the Assistive Devices Program (ADP), social assistance, and the Ostomy Appliances Program (ostomy-specific supplies; up to $1,298 for a permanent ostomy and $865 for a temporary ostomy annually; Gouvernement du Québec, 2020a). These various systems of coverage and ill-defined income limits can lead to confusion and clients may be sequentially denied and referred to other programs or funders while applying for coverage.

Essential wheelchair, seating, and lift and transfer devices

Essential mobility assistive devices are covered through the Devices to Compensate for a Physical Deficiency Program and the ADP (Gouvernement du Québec, 2020b; 2022a). Wheelchair cushions are also provided through these programs. Clients are eligible for 100% funding without any form of means testing, although wheelchairs remain the property of the provincial government and must be returned if no longer required, Table 15 (Régie de l'assurance maladie du Québec, 2020). Items such as shower chairs, commodes, and lifts are eligible for coverage through the CLSC. Repairs are also funded, although for clients who opt for upgraded features and components, CLSC will not pay for repairs of such components. Clients with a long-term disability who are limited in their activities of daily living at home and who are not eligible for coverage under other programs can receive funding for home modifications through the Home Adaptation Program. However, there is a waiting list up to two years long and clients waiting in rehab typically return home prior to accessing the program to inaccessible houses and cannot be reimbursed retroactively. Vehicle modifications are also covered for clients with a disability who are not receiving financial assistance from another source through the Programme d'adaptation de véhicule pour les personnes handicapées.

Insurance programs

Quebec offers a no-fault system of automobile insurance through their public provider Société de l'assurance automobile du Québec (SAAQ) with various benefits to those injured in an accident. Personal home assistance is offered through SAAQ up to a maximum of $949 per week following an evaluation by a compensation officer, which essentially functions as a self-managed care program (Société de l'assurance automobile du Québec, 2016a). SAAQ also provides coverage of medical supplies and devices which preserve or restore health and increase independence and which are prescribed by a physician to address injuries related to their accident (Société de l'assurance automobile du Québec, 2016b).

Additionally, backup wheelchairs and sporting equipment are available for coverage through SAAQ as well as both home and vehicle modifications (Société de l'assurance automobile du Québec, 2016c).

The Commission des normes, de l'équité, de la santé et de la sécurité du travail (CNESST) provides coverage for clients injured at work. CNESST offers a personal home assistance allowance up to a monthly maximum of $1,805 (as of January 2020) for those with a permanent disability which affects ADL (CNESST, n.d.-a; Regulation Respecting the Standards and Tables of Personal Home Assistance, 2022). CNESST offers reimbursement for medical aid which includes "supplies and incidental costs related to such care, treatment, professional services or technical aids" prescribed by a health care professional (CNESST, n.d.-b; Regulation Respecting Medical Aid, 2022). Recreational equipment and home modifications are also eligible for coverage through CNESST.

Discrepancies between policy and experience

Time limits are not based on specific services, but CLSC staff are generally overworked and understaffed. Clients are restricted to morning and evening dressing routines and one to two baths per week. Clients may also be restricted to bed baths due to staff shortages, time restraints, and inaccessible bathrooms. If a client's complicated needs create scheduling conflicts which the CLSC is not able to manage, the client may be advised to move to LTC or left to manage service gaps on their own. Key informants indicate bathing services are considered inadequate and home support services are underfunded and short-staffed. However, attendant services for clients with typical needs and scheduling requirements are generally considered adequate.

NEW BRUNSWICK

NB takeaways

- While there are no formal time limits to attendant services, many restrictions were reported, due to the home support worker shortage in New Brunswick.
- Home support workers are underpaid and lack proper training.
- Home care services include a cost-sharing component and are generally considered inadequate.
- Provision of medical supplies is limited to those persons with very limited income (i.e., just within living income range). Additional costs of disability are not factored into calculations of eligibility for coverage, and key informants indicate many people are unable to afford needed supplies and forced to reuse or do without.
- Mobility equipment is loaned through the Recycling Program and purchased only if unavailable through the equipment pool.
- Wait times are considered excessive regarding provision of mobility assistive equipment.

"We have a lot of people in New Brunswick choosing medical assistance in dying because they cannot get the support they need from the Disability Support Program. Access to specialists such as pain management specialists is also failing." – key informant New Brunswick

"[T]he eligibility ceilings are just within a living income range and, there's so many people that go without or have to double use things, or because they can't fit the financial criteria. It's not based on the actual living wage, plus consideration of the costs of disability… a lot of people fall into that gray area where they're apparently making too much money, but they can't afford the items." – key informant New Brunswick

Attendant care provision in New Brunswick

Provision of care is funded by the Department of Health and Department of Social Development and managed by Medavie Health Services New Brunswick or the Department of Social Development (New Brunswick Health Council, n.d.).

Table 7 *Means Testing in NB*

Attendant services means tested/copay	Medical supplies means tested/copay	Assistive devices means tested/copay
Yes	Yes	No
Home care services include a cost-sharing component. A financial assessment is completed, although relevant formulae are not shared as they differ by region, income, and disability. Every NB resident is eligible for home care services, and typically, clients with a relatively low income receive 100% coverage of home care services. Clients with a relatively high income may be assessed with copayments so high that self-funding attendant services becomes a more economical option.	Essential neurogenic bowel and bladder management supplies are available through the Health Services Ostomy/Incontinence Program. This income-based program is limited to those with income less than around $25,000. Calculations for program eligibility include a comparison of eligible income to need (budget deficit method). The program operates as 'payor of last resort' and clients must exhaust all other forms of insurance coverage to be eligible.	The Health Services Program includes the MAELP, which loans specific, medically essential equipment not covered by Medicare or private health insurance plans. Through partnership with Easter Seals New Brunswick, eligible equipment is recycled (via the Recycling Program) through an equipment pool for reuse. All items provided by MAELP are fully covered, except for where specific limits are mentioned.

Note. MAELP = Mobility and Adaptive Equipment Loan Program

Adequacy of attendant service programs

Residents are eligible for home care services which may include a cost-sharing component, which is determined through a financial assessment (Department of Social Development, 2015, 2018). Clients with a low income receive 100% coverage of home care services, while those with higher income may be assessed with cost-sharing fees so large that self-funding needed attendant services becomes more economical (Table 12). Key informants indicate home care service levels are considered inadequate. Hours of care are based on need and not specifically limited, although funding programs have ceilings on numbers of hours of service, beyond which clients would have to apply for exceptions. Many restrictions in service are also thought to arise from the home support worker shortage in New Brunswick.

Self-managed care and alternate delivery models

Clients can apply to manage their in-home services through self-managed support, a program offered through Disability Support Program (DSP) or Long-Term Care Program (LTCP), Table 13 (Social Supports NB, 2022). Clients are given a monthly lump sum payment, based on an approved hourly wage to cover the costs of the services they require. Clients are responsible for overseeing their own care needs including coordinating, managing, and directing services (Social Supports NB, 2022). Clients are responsible for hiring and training staff as well as related bookkeeping and are not eligible for reimbursement for these associated costs (Social Supports NB, 2022). Clients may hire family members not living in the same residence and may carry over unused funding within the same calendar year. A social worker aids in reviewing the care plan and expenditures at the end of the year (Social Supports NB, 2022). Moving within the province is allowed and does not lead to disruption of services, although it does require being assigned a new social worker.

Rural & remote settings

There are less home support agencies in rural and remote settings, which leads to clients being forced to hire privately.

Characteristics and limitations of essential medical supplies provision

Essential neurogenic bowel and bladder management supplies are available through the Health Services Ostomy/Incontinence Program, which is means tested (Department of Social Development, n.d., 2016; New Brunswick Regulation 95-61, 1995). Private insurance and all forms of medical coverage must be exhausted prior to accessing the program. Key informants report the program is generally considered adequate for eligible clients, but ineligibility thresholds on earned income are so low (just above a living income level, Table 14) many people are completely ineligible for provision of supplies. As a result, clients are unable to afford the quantity and quality of supplies needed, leading to reuse.

Essential wheelchair, seating, and lift and transfer devices

The Health Services Program also includes the Mobility and Adaptive Equipment Loan Program (MAELP), which loans specific, medically essential equipment not covered by Medicare or private health plans (Department of Social Development, 2020). Eligibility for the program is based on an assessment by an OT or PT. Through partnership with Easter Seals New Brunswick, this equipment is recycled (via the Recycling Program) through a refurbished equipment pool. New equipment may be ordered if needed equipment is not available through the recycled pool (Table 15). Coverage includes bath and power lifts, bath chairs, commodes, and seat cushions (Department of Social Development, 2020). Wait times for provision of equipment are considered excessive, with the entire process taking between two months to over three years in some cases (Ability New Brunswick, n.d.).

Insurance programs

Limits and inclusions of motor vehicle insurance vary, depending on the insurance provider in New Brunswick. Key informants indicate WorkSafe New Brunswick (WSNB) is considered the best provider for meeting the medical service needs of clients and includes personal care allowances up to $2,039.87 per month (WSNB, 2022). WSNB also funds prescriptions and medical supplies, as well as assistive devices and equipment, mobility aids, and home or vehicle modifications (WSNB, 2017, 2020a, 2020b).

Discrepancies between policy and experience

New Brunswick Disability Support Program policy documentation appears well structured and easily accessible, but its programs are considered inadequate for meeting the needs of clients with SCI. Inadequacies arise from insufficient numbers or quality of medical supplies and services provided. Means testing cut-offs for allowable earned income levels are considered too low to meet the costs of these supplies once a client is deemed as ineligible, creating a strong disincentive for those attempting to attain gainful employment.

PRINCE EDWARD ISLAND

PEI takeaways

- AccessAbility Supports (AAS) is a personalized and flexible program aimed at supporting a range of physical needs of persons with SCI, including wheelchairs, cushions, ramps, and medical supplies. AAS supports are means tested, with a sliding scale of client contribution from 10-39% of relevant costs for annual incomes between $51,700 to $119,708. No coverage is provided for those with higher incomes. Equipment value is amortized over its intended lifespan and converted to a monthly expenditure to determine an individual's funding envelope and contribution level.
- There is no formal program for clients once they reach 65, and eligibility for new AAS applications ceases.
- Care of clients with complex needs may be forced into LTC due to limitations in care hours available in-home care.
- The most significant issues for people with disabilities living in PEI are reported to be accessible housing/transportation and income security.
- In some cases, formal programming and policy may not exist to meet a particular health need. However, key informants indicate a person's needs are often addressed once raised and rationalized.

"The biggest barrier to any person, and it's not just people like us with the spinal cord injury there, anybody with a disability, it's not so much the disabling condition. People adapt and learn and move their lives on. But it's the poverty that people experience now that can be soul destroying for people. I always feel that was more disabling for people to have, no decent income and having to face life with a disability without having the ability maybe to be able to get a job, to access education, to access a vehicle or home." – key informant PEI

Attendant care provision in Prince Edward Island

Provision of care is approved through a single health authority, covering the population of 165,000 residents. Home care services are provided by Health PEI.

Table 8 *Means Testing in PEI*

Attendant services means tested/copay	Medical supplies means tested/copay	Assistive devices means tested/copay
No	Yes	Yes
The home care program is provided free of charge through Health PEI and is coordinated via one of five local home care offices. Eligibility is based on permanent residency and an assessed need of support to continue living safely at home, as determined by a home care coordinator. Personal and housing supports are also available through AAS, which is means tested and involves potential copayments. Applicant contributions are determined annually and calculated by multiplying eligible annual income by a set percentage (on a sliding scale), while eligible annual income is calculated by subtracting a set annual income threshold (which increases with family size) from line 236 of a client's income tax return. Income thresholds begin at $19,708 for a family unit of one and grow to $62,321 for a family unit of 10. AAS is not means tested for clients under 18.	AAS provides prescription medications and medical supplies to applicants through Assured Income funding along with basic optical and dental care. Ostomy supplies are also covered, although they are listed as a funded support as a technical aid/assistive device. Any supplies which can be justified are typically covered by AAS and limits to quantity and quality/function (such as hydrophilic coated catheters) are based on medical justification by an appropriate medical specialist. Eligibility and client contributions are as previously outlined. Ostomy supplies are also eligible for coverage through PEI's OSP, with up to 90% coverage (dependant on income) and up to a maximum of $2,400 per year.	AAS coverage of technical aids/ assistive devices includes "an aid or device that is used to support or improve the ability of a person with a disability to function at home, in the community or in a workplace". Aids and devices covered include bathroom/bedroom/household aids, positioning and ambulation aids including power and manual wheelchairs, and prosthetics. Once again, eligibility and client contributions are as previously outlined. Clients with private insurance are expected to exhaust insurance coverage prior to AAS funding, and clients with insurance which covers a portion of the total cost may apply to have the remaining balance covered through AAS, although contributions from private insurance are not applied as client contributions. Items for which AAS provides coverage of 75% or more of the cost must be returned to the program when the need no longer exists.

Note. AAS = AccessAbility Supports; OSP = Ostomy Supplies Program

Adequacy of attendant service programs

AAS benefits are intended to meet basic needs and are not intended to replace existing government or community resources (AAS, 2021b). Only clients under 65 are eligible to apply for AAS (AAS, 2021a). Unofficially, this is solved through a reliance on community donations, but this reflects an obvious gap as no formal programming is in place.

While a formal process for calculation of care hours is unknown, the home care program involves a consideration of "availability of other supports, including family, community resources and other programs" and some clients report not receiving as many hours as they need. Clients are generally eligible for any services which have been recommended by a medical professional.

Rural & remote settings

PEI's small size means that service delivery is available in all areas of the province.

Characteristics and limitations of essential medical supplies provision

Refer to Tables 8 & 14 for details of medical supplies coverage.

Essential wheelchair, seating, and lift and transfer devices

For public coverage of wheelchairs and seating/positioning equipment, clients must attend a seating clinic, typically with an OT. AAS coverage of technical aids/assistive devices includes "an aid or device that is used to support or improve the ability of a person with a disability to function at home, in the community or in a workplace" (AAS, 2022). Aids and devices covered include bathroom, bedroom and household aids, positioning and ambulation aids including power and manual wheelchairs, and prosthetics. Eligibility and client contributions are as previously outlined (see also Table 15). Clients with private insurance are expected to exhaust insurance coverage prior to AAS funding, and clients with insurance which covers a portion of the total cost may apply to have the remaining balance covered through AAS, although contributions from private insurance are not applied as client contributions (AAS, 2022). Key informants indicated wait times can be extensive.

Insurance programs

Motor vehicle insurance is private with variable coverage based on provider. Coverage is comprehensive. Insurance providers must provide medical, rehabilitation, and funeral coverage for all reasonable expenses which a physician deems "essential for the treatment, occupational retraining or rehabilitation of said person, to the limit of $50,000 per person" incurred within four years from the date of the accident (Insurance Act, 2016). Clients are also able to pursue personal injury lawsuits for additional coverage.

The Workers Compensation Board of PEI provides relatively good coverage of personal care, independent living, respite care allowances, and assistive devices for workers with long-term physical functional deficits, as well as medications and medical supplies through their Drug Program (Workers Compensation Board of PEI, n.d., 2018, 2019, 2021).

Discrepancies between policy and experience

The most significant issues identified in PEI were lack of accessible housing and transportation as well as income security and access to employment. Local politicians are uniquely sensitive to individual requests from a relatively small population, and while formal programming and policy may not exist, needs are often addressed once raised.

NOVA SCOTIA

NS takeaways

- Home care services are means tested and divided into home support services (such as personal care, respite, and essential housekeeping) and nursing services. Home support services are provided by agencies outlined by the Department of Health and Wellness, while nursing services (such as catheterization) are provided by the Victorian Order of Nurses (VON; Department of Health and Wellness, n.d.-a).
- Clients are restricted by agency scheduling and may be forced to follow 'tuck-in' scheduling as early as 7 pm.
- Provision of neurogenic bladder and bowel management supplies is means tested. Medical supplies can be covered through the Disability Support Program (DSP) as special need items if medically justified and documented as effective and required by a qualified medical practitioner. Items must be confirmed as the most economical option available.
- Wheelchairs are provided, without means testing for those under 65, based on prescription from an OT through a loan-based equipment pool managed by Easter Seals.

"In many ways, I find it amazing that we can have a system like that in our province and get that level of support. But as always, those most in need are the ones who are not getting their needs met." – key informant Nova Scotia

"The purchase of wheelchairs, inserts, and repairs for DSP participants aged 65 and over and the purchase, rental and repair of other types of medical equipment for all DSP participants may be approved as a special need when the participant's need for the requested item or service has been verified through documentation provided by a physician or health care practitioner and it is confirmed to be the most economical option available for purchase." – key informant Nova Scotia

Attendant care provision in Nova Scotia

Provision of care is approved through two health authorities; Nova Scotia Health Authority and the Izaak Walton Killam (IWK) Health Centre for pediatrics and women's health and delivered through four health zones.

Table 9 *Means Testing in NS*

Attendant services means tested/copay	Medical supplies means tested/copay	Assistive devices means tested/copay
Yes	Yes	No (Yes - requires DSP eligibility for clients over 65)
While nursing services are provided free of charge, home support service costs are based on income (from the previous year's tax return), family size, and specific services required. There are no charges for single individuals earning up to $26,165, families of two earning up to $41,165, and families of three or more earning up to $51,165. Beyond these amounts, clients pay $12.45 per hour to a tiered range of monthly maximums with the highest monthly maximum being $622.50.	Medical supplies such as (but not limited to) incontinence and ostomy supplies can be covered through the DSP as special need items if medically justified and documented as effective and required by a qualified medical practitioner and confirmed as the most economical option available. Monthly amounts exceeding $200 must be approved by a casework supervisor. Eligibility for DSP requires a determination of being "in need". This is calculated through a financial assessment which involves applicable income, assets, and all associated costs.	Requests for wheelchairs and repairs for DSP participants under 65 years of age are referred directly to the ADP, administered by Easter Seals Nova Scotia for assessment and eligibility for funding. ADP eligibility criteria used to include a client receiving income assistance but has recently changed to only require a prescription from an OT.

Note. ADP = Assistive Devices Program; DSP = Disability Support Program; OT = occupational therapist

Adequacy of attendant service programs

While nursing services are provided free of charge, home support service costs are based on income, family size, and specific services required (Department of Health and Wellness, 2011). See also Tables 9 and 12.

Eligibility and determination of hours of home care services (regardless of program) are based on an assessment of capacity regarding ADL (Department of Health and Wellness, 2011). This assessment is completed by a care coordinator and involves a financial assessment. 24-hour care is not provided, and clients with relatively high care needs may have to advocate strongly to receive adequate hours of care.

Time limits do not formally exist for specific services, although home care agencies and VON are extremely busy, and hours are limited within a client's assessed allotment. If home care agencies are not available to provide hours, some clients may have to go on a wait list and hire privately in the meantime. Clients are reimbursed for these hours, although private companies charge for three-hour minimum shifts even if clients only require one hour. Clients are eligible for whichever services are determined through their assessment and are asked to have family or friends available in case of non-scheduled emergency events.

Self-managed care and alternate delivery models

To apply for self-managed care, individuals must be over 18, have a physical disability, be in stable health, and require support in their own home

(Department of Health and Wellness, n.d.-b, 2013). Clients receive funding to hire their own care providers and manage their own care needs, while also entering into a legal agreement with the health authority and taking on the associated responsibilities such as accounting and payroll. Clients may appoint a third-party care manager to oversee the management and administrative tasks related to their care (Department of Health and Wellness, 2013). Clients can move within the province without interruption of service and are not allowed to hire family members. It is reportedly difficult to find individuals to hire with self-managed care funding, especially in rural settings. See also Table 13.

Rural & remote areas

Clients in rural settings (most of the province) may have significant privacy concerns with income assessments and relatively invasive care such as bowel and bladder management routines, as anonymity may be difficult or impossible in these settings, and some opt to manage on their own as a result.

Characteristics and limitations of essential medical supplies provision

Neurogenic bladder and bowel management supplies are referred to as incontinence and ostomy supplies and can be covered through the DSP (Department of Community Services, 2016). Monthly amounts exceeding $200 must be approved by a casework supervisor (Department of Community Services, 2016). Eligibility for DSP includes an individual with a physical disability which affects functioning about ADL as well as a determination of being in need (Department of Community Services, 2016). This is calculated through a financial assessment which involves applicable income, assets, and all associated costs (Department of Community Services, 2016), Table 14. This form of coverage is criticized as not allowing for quality of life, and leaving many clients without any coverage of supplies, which can be extremely expensive.

Essential wheelchair, seating, and lift and transfer devices

Requests for wheelchairs and repairs for DSP clients under 65 years of age are referred directly to ADP, which is administered by Easter Seals Nova Scotia, for assessment and eligibility for funding (Department of Community Services, 2016). ADP eligibility criteria used to require a client be receiving income assistance but has recently changed to only require a prescription from an OT. Easter Seals manages several programs in partnership with the Nova Scotia Department of Community Services, including the ADP (Easter Seals Nova Scotia, n.d.-a) and the Wheelchair Recycling Program, funded by the Department of Community Services (Department of Community Services, n.d.). Clients can apply to obtain and receive new or refurbished wheelchairs through the Recycling Program and can borrow a variety of refurbished health equipment which has been donated to Easter Seals through the ADP (Easter Seals Nova Scotia, n.d.-b). See also Table 15.

Insurance programs

Medical, rehabilitation, and funeral expenses are outlined in the province's Insurance Act Regulations and capped to a maximum of $50,000 for "all reasonable expenses incurred within four years from the date of the accident as a result of the injury" (*Automobile Insurance Contract Mandatory Conditions Regulations, 1989)*. These expenses include medical services and supplies which are essential for treatment as determined by a physician *(Automobile Insurance Contract Mandatory Conditions Regulations, 1989)*. For compensation beyond this financial limit, individuals must pursue a personal injury lawsuit (Office of the Superintendent of Insurance, 2010).

The Workers' Compensation Board (WCB) of Nova Scotia has agreements with various home care specialists (including nurses and home support workers) to provide care to injured workers at home (Workers' Compensation Board of Nova Scotia, n.d.). Medical aid benefits include measures to prevent further injury or complications and to assist a client in meeting basic needs. Generally, home maintenance items are not included in medical

aid benefits through WCB, and recreational items will typically be denied (Workers' Compensation Board of Nova Scotia, 2012). Cost is a factor in determination of whether medical aid will be approved (Workers' Compensation Board of Nova Scotia, 2012). Relevant fees are outlined in WCB's schedules, which are established through negotiation with WCB approved health care service provider groups (Workers' Compensation Board of Nova Scotia, 2011). Clients are viewed as more likely to receive wider coverage through WCB and private insurance, while publicly funded coverage is viewed to be more highly restricted and of lower quality.

Discrepancies between policy versus experience

Generally, home care services are not seen to fit all clients' needs. Clients who have relatively simple and stable care needs and who have a lifestyle which aligns with agencies' scheduling may be adequately served. However, the limited availability of care aides and restrictions which arise from scheduling can significantly limit independence. While self-managed care may be a viable solution for some clients, others are left to manage on their own or with help from family and friends for certain care needs.

Bowel and bladder care is officially provided by VON, but in practice, clients prefer to either manage on their own or through self-managed care. Clients are restricted by agency scheduling and may be forced to follow "tuck-in" scheduling as early as 7 pm. Clients are typically restricted to two baths per week, which may be further restricted to sponge bathing if their bathroom is not fully accessible.

NEWFOUNDLAND & LABRADOR

NL takeaways

- The Home Support Program is means tested and provided via four regional health authorities. They can be accessed either as provided by home care agencies, or as self-managed care (Department of Health and Community Services (n.d.-a, n.d.-b).
- The public is the payor of last resort.
- Clients must agree to pay prescribed contributions for home support service before a financial subsidy is provided.
- Provision of neurogenic bladder and bowel management supplies is means tested, with eligibility determined after financial assessment. Supplies are limited to the cheapest option available and intermittent catheters limited to one per week.
- Provision of wheelchairs is means tested and wait times for a wheelchair are currently around three to four months.
- The only seating clinic in the province is in St. John's, and clients may have to travel significant distances to attend the clinic.
- There is an accessible housing shortage in the province.

"Any individual that has an injury that don't have another source of income that depends on our government system got no other choice but to live in poverty." – key informant Newfoundland.

Attendant care provision in Newfoundland & Labrador

Provision of care is in a state of reorganization with four regional health authorities (RHA) changing to one.

Table 10 *Means Testing in NFLD*

Attendant services means tested/copay	Medical supplies means tested/copay	Assistive devices means tested/copay
Yes	Yes	Yes
Clients "must agree to pay prescribed contributions for home support service before the financial subsidy is provided". These contributions are based on a sliding scale and are determined through a financial assessment. Income tests are based on line 236 of a client's income tax return and are utilized when clients are requesting home support services or access to the SAP. Needs tests are more complex, involve a consideration of allowable expenses and debt, and are utilized when clients request additional allowances or supplementary benefits.	Coverage of basic medical supplies and equipment for assistance with ADL is provided through the SAP for clients under 65. Suppositories are not included. Clients must exhaust all other forms of coverage, undergo a clinical assessment by a health professional and meet financial eligibility criteria. Clients may be required to pay a portion of the cost depending on a financial assessment, which follows the same tiered range of contributions outlined for home support services. Clients who are receiving income assistance automatically meet financial requirements of SAP.	Clients eligible for SAP coverage can also receive mobility assistive devices through the program. Generally, there is more leniency here with calculation of expenses involved, and clients usually receive 100% coverage for equipment unless they have private coverage.

Note. SAP = Special Assistance Program

Adequacy of attendant service programs

Home support services are generally seen as adequate. While clients may not initially receive the hours of care they require, they typically receive them following a reassessment. Eligibility for home support services is based on a need for assistance with ADL and includes a financial assessment (Department of Health and Community Services, 2005). For patients in rehab, an assessment is completed by an OT or PT to determine independence level and hours of care for the development of a care plan. Clients' needs are reviewed on an annual basis, typically by a social worker. If clients do not agree with the results of their assessments, they can appeal to receive another assessment, again conducted through the RHA. See also Tables 10 and 12.

Time limits do not formally exist for specific services, although services must be completed within each general hour allotment. Clients are eligible for whatever services are required. Most clients rely on family members or friends in case of a non-scheduled emergency event. Support workers are required to stay with clients in the event of a storm which restricts travel until the next support worker can make it to the client's home.

Self-managed care and alternate delivery models

Clients who are eligible for the Home Support Program can apply for self-managed care. In this form of care delivery, again provided by the RHA, clients become the director of their own care and are provided with funding, either directly or as forwarded to a bookkeeper (Department of Health and Community Services (n.d.-b). Clients are responsible for hiring, training, and supervision of their support workers, as well as accounting and payroll duties. Clients are allowed to have the agreement of a supporting person for the

assumption of these functions individually or jointly but are not allowed to hire family members as home support workers (Department of Health and Community Services, n.d.-a). However, exceptions to this rule are made, especially in small communities with limited hiring options. Clients may also access self-managed care through paid family caregiving, where they are allowed to hire family members who are not spouses or common-law partners as support workers. Moving within the province is relatively easy—a client's file is transferred, and a new social worker assigned. Clients with relatively high care needs may also receive home support services through shared living arrangements (again organized by the RHA), where multiple clients share the costs of a living arrangement and home support staff (Department of Health and Community Services, n.d.-c). See also Table 13.

Rural & remote communities

It is also more difficult to receive home support services in smaller communities. Clients are typically encouraged to move to larger centres, as many small towns don't have ramps or sometimes sidewalks, which can make them isolated regardless of support worker availability.

Characteristics and limitations of essential medical supplies provision

Coverage of basic medical supplies and equipment for assistance with ADL is provided through the Special Assistance Program (SAP) for clients under 65, Table 14 (Department of Health and Community Services, 2016). Clients must exhaust all other potential forms of coverage, undergo a clinical assessment by a health professional, and meet financial eligibility criteria (Department of Health and Community Services, 2016). Clients may be required to pay a portion of the cost depending on a financial assessment, which follows the same tiered range of contributions outlined for home support services. Clients who are receiving income assistance automatically meet financial requirements of SAP (Department of Health and Community Services, 2016).

Suppliers deliver the supplies to clients monthly. Clients are eligible for quantities as requested by an OT and are restricted to the most inexpensive generic options available through the supplier. Any products exceeding the cost of these options must be medically justified by a doctor (Department of Health and Community Services, 2016). Clients are typically limited to one catheter per week. Quantities beyond the numerical limits initially outlined may be requested. Many clients would prefer to choose their catheters, and the requirement of a doctor's appointment for requests of necessary and appropriate medical supplies is considered onerous and overly complicated. The fact that clients must reuse catheters is viewed as 'disgusting' and as increasing risk of infection.

Essential wheelchair, seating, and lift and transfer devices

Clients eligible for SAP coverage can also receive mobility assistive devices through the program (Department of Health and Community Services, 2016). Generally, key informants indicate there is more leniency here with calculation of expenses involved, and clients receive 100% coverage for equipment unless they have private coverage. Clients are assessed by an OT at a seating clinic and are eligible for models/features which are prescribed and medically justified through the assessment. Following discharge from rehab, requests for new equipment require the person to attend the only seating clinic in St. John's, and clients may have to travel significant distances to attend the clinic. Thus, scheduling and expenses associated with this requirement are viewed as a barrier. Wheelchairs are not loaned but become property of the client. Clients are eligible for a wheelchair at a minimum of once every five years. Wait times for a wheelchair are currently around three to four months. See also Table 15.

Clients are also eligible for coverage of lifting/transfer devices and essential seating through SAP. Clients are eligible for wheelchair cushions every five years. Ceiling lifts are relatively difficult to receive and require additional justification. Coverage of mobility assistive devices is seen to be adequate, as clients typically end up receiving what they require.

Insurance programs

Motor vehicle insurance includes medical and rehabilitation expenses (outlined as accident benefits) and capped to a maximum of $25,000 for all reasonable expenses incurred within four years from the date of the accident (Government of Newfoundland and Labrador, 2020). These expenses include medical services and supplies which are essential for treatment or rehabilitation as determined by a physician (Government of Newfoundland and Labrador, 2020). For compensation beyond this financial limit, individuals must pursue a personal injury lawsuit.

Workplace Newfoundland provides coverage of home support services as well as medical supplies and equipment to workers (WorkplaceNL, 2016, 2019). Home support services are fully covered, typically provided through an agency (WorkplaceNL, 2019). If the client is in a remote community, these services may be provided by nonprofessionals such as family or friends (WorkplaceNL, 2019). Coverage of medical supplies and equipment is defined as any item which improves functional abilities, minimizes risk of further injury or aggravation, reduces severity of symptoms which impact ADL, or improves the likelihood of return to work (WorkplaceNL, 2016). It also includes funding for an accessible vehicle, construction of an accessible home, and exercise equipment with prescription from an OT (WorkplaceNL, 2016). Workplace Newfoundland is seen to provide relatively good coverage.

Discrepancies between policy and experience

The annual income exception assessment process involves numerous steps as well as multiple ‘handoffs’ and decision points, and some consider this process burdensome for both clients and staff involved. Clients may request a reassessment at any time if their financial situation changes.

Some clients may be living in housing that’s not suitable, and priority is being given to clients who are waiting for housing options in hospital, some of whom have been waiting up to two years. Without advocacy, it’s believed that many clients would end up in LTC.

FEDERAL PROGRAMS

Indigenous people living with SCI

The First Nations and Inuit Home and Community Care Program (FNIHCC) is provided under the First Nations and Inuit Health Branch (FNIHB; Indigenous Services Canada [ISC], 2016). Eligibility for the program requires the client to have First Nations or Inuit membership or citizenship, to be living in a First Nations or Inuit community, and to have undergone a formal assessment of needs (ISC, 2016). Eligibility requirements for coverage pose a significant concern as the Indigenous population does not have control over their own membership, and some community members may have lost or never had status. While the federal government has recently recognized Métis people as their own nation, they do not currently qualify for benefits under this program.

In First Nations and Inuit communities with nursing stations, in-home nursing services are provided by registered nurses and licensed practical nurses who are often employed to work intermittently within the community. Service restrictions largely stem from a lack of accessible and clean running water, a lack of accessible housing in good repair, and a lack of trained available staff (ISC, 2019). The ongoing lack of clean running water in some First Nations and Inuit communities create a significant challenge for clients, specifically regarding bowel and bladder management routines within the context of this report. Some clients report a commode in their bedroom as a bathroom, and for many clients, sponge bathing is the norm.

While home care services are sometimes delivered to First Nations and Inuit communities from outside agencies, home care already faces significant challenges in rural staffing across Canada and community members aren't always comfortable going to an urban centre for training. As a result, there is often a lack of trained people within communities available for hire. Furthermore, typically the only alternative for clients with significant care needs to remain in their community is to live in a LTC facility which is intended for elders and inappropriate for younger clients.

All of these issues create service and lifestyle challenges which pressure clients to move to an urban centre. However, some people may choose to stay in their own community even if their care needs are not being met as their emotional and social needs may not be met in an urban centre. As such, care needs which cannot be met within a client's community often fall to family and friends of clients who choose not to move away.

"The psychosocial support of their community is very much key, and this goes back to the intergenerational trauma the residential schools the Sixties Scoop, day schools, all of this has had, and it is affecting these communities as a whole in how healthy they are, what their abilities are and what they're willing and not willing to do." – anonymous key informant.

Medical supplies and equipment are provided to First Nations and Inuit people both through FNIHCC and through NIHB (ISC, 2019, 2022b). Medical supplies are eligible for 100% coverage with no means testing. Coverage of supplies is intended to address medical needs relevant to ADL. Items not included in the equipment and supplies benefit list may be considered for coverage under exception status on a case-by-case basis. Numerical

limits to medical supplies are outlined which include four indwelling or 360 intermittent catheters every three months. Typically, only the most inexpensive generic options available will be covered outside of special circumstances such as clients with product allergies. Single-use catheterization is not generally supported.

Both mobility and self-care equipment are covered through NIHB benefits (ISC, 2022a, 2022c). Eligible NIHB clients receive 100% coverage with no means testing. Generally, a prescription is required along with prior NIHB approval, and clients are eligible for features and components which are medically justified. NIHB also provides coverage of self-care equipment including but not limited to bath chairs, transfer boards, commodes, grab bars, and ceiling and hydraulic lifts (ISC, 2022c).

"Most communities have housing issues where you will have a family of, say, ten people living in a two-bedroom house. The issues are deep and systemic. A lot of communities are doing the best they can, but quite often they're limited in what they can do because of federal funding. There are some communities where our people can't go back through because they lack clean water. The lack of housing, the lack of water, the lack of support. They all kind of add up." – anonymous key informant.

Veterans

Veterans Affairs Canada (VAC) provides coverage for a range of services through the Veterans Independence Program (VIP; VAC, 2013). Services available for funding through VIP include personal care, housekeeping, LTC, professional health care and support (including in home visits), grounds maintenance, access to nutrition (including meal delivery services), home adaptations, and transportation (VAC, 2021b). Clients applying to the VIP are assessed to determine health-related needs and appropriate services to support self-sufficiency within the home. Currently, the delay involved with applications is reported to be a barrier, with wait times up to 18-24 months for review. Reviews and appeals of decisions are available through the Veterans Review and Appeal Board (VAC, 2021a).

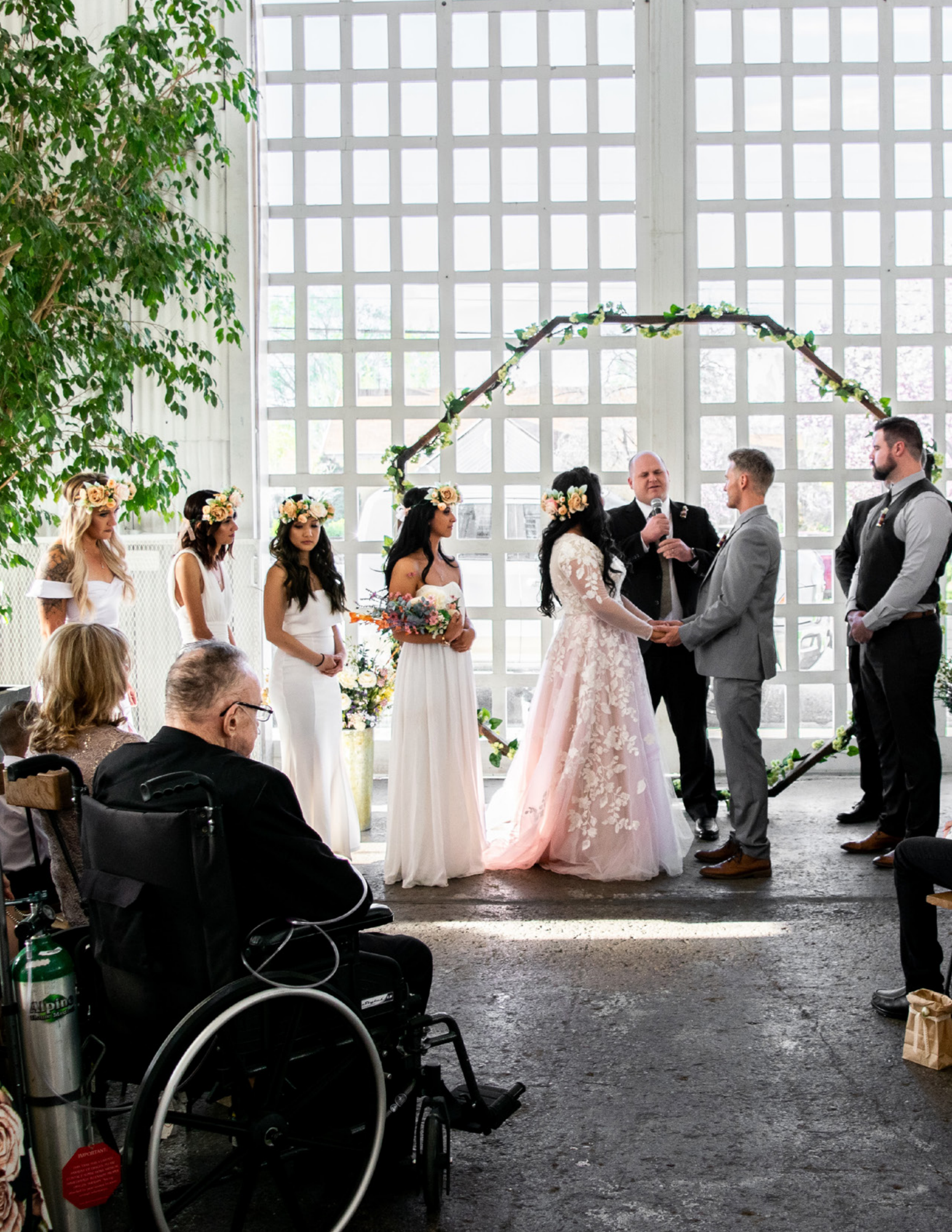
Financial assessments are only required by the VIP for applications for exceptional health care needs and circumstances. Maximum rates available are outlined for various forms of personal care services through the program. However, these rates may be exceeded in certain situations regarding acceptable minimum standards of available care, consideration of a client's (and their families') health and well-being, and a client's right to refuse a move to a health care facility. Personal care services are also provided through Attendance Allowance (AA), which provides funding for hiring a personal caregiver for support in ADL (VAC, 2019b). Monthly payable rates are based on the level of disability.

VAC provides coverage of medical supplies through the Treatment Benefits Program (VAC, 2019a). Medical supplies are defined as items "essential to effectively monitor or treat an illness or injury; and primarily used to serve a medical purpose, and, generally, not useful to a person in the absence of an illness or injury." Supplies prescribed by a health professional and listed on the benefit grids are eligible for coverage. Items which do not appear on the benefits grid but are prescribed and justified as essential to effectively monitor or treat an illness or injury or to avoid a negative effect on general health may also be approved. If a prescription for supplies exceeds cost or frequency limits, the program requires contact with a doctor or relevant health professional. Catheter supplies are eligible for coverage up to $350 per month.

The Treatment Benefits Program also provides coverage of essential mobility assistive devices under the Special Equipment and Aids for Daily Living Programs of Choice (VAC, 2020a, 2020b). Clients who have documented, disability-related needs are eligible for coverage of equipment and are generally approved for funding of items outlined through the benefit grids. Equipment must be prescribed by a health professional and be appropriate, beneficial, and safe for independent functioning and/or medical stabilization. Items not listed on the benefit grids may also be approved if prescribed, supported as effective for needs by research, and validated by a VAC health professional. Approved items become property of the client.

Funding for power wheelchairs is limited to the type and model of device which most reasonably addresses the client's mobility needs (VAC, 2012b). Power wheelchairs are normally limited to a cost of $9,000 and are expected to last for at least three years, while manual wheelchairs are limited to $4,000 every 3 years (VAC, 2019c). Coverage is also available for specialized cushions, sport chairs, shower chairs, and transport chairs. Other items outlined in the benefits grid include manual and electric hospital beds, pressure reduction mattresses, exercise equipment, commodes, shower chairs/benches, and transfer aids.

In home lifting and transporting devices and their installation fees may be approved as a treatment benefit if deemed to be "the only intervention which can reasonably address the client's medically-based and functional needs and will assist the client in remaining independent in the home." Such devices include but are not limited to elevators, stair glides, lift slings, and ceiling, bathtub, platform, porch, and wheelchair stair lifts (VAC, 2012a). Vehicle modifications are eligible for funding if recommended by a health professional (VAC, 2012c). Home adaptations are eligible both through the Treatment Benefits Program (for modifications facilitating usage of assistive devices) and the VIP (for facilitating self-sufficiency and performing normal ADL; VAC, 2012d).



Essential Spinal Cord Injury Medical Need Domains

Table 11 *Overall Summary of Means Testing for Each Area of Essential Need, by Province*

	Means testing of attendant services	Means testing of medical supplies	Means testing of assistive devices
BC	Yes	Yes	Yes
AB	No	Yes	No
SK	Yes	No	No
MB	No	Yes	No
ON	No	Yes	Yes
QC	No	Yes	No
NB	Yes	Yes	No
PEI	No	Yes	Yes
NS	Yes	Yes	No
NL	Yes	Yes	Yes

A) Attendant Services for Activities of Daily Living

The availability of attendant services for ADL of those with SCI is fundamental to their health, well-being, self-worth, and independence. Each province provides some level of attendant services as home care services to those with a disability. Restrictions and limitations to attendant services—- as well as means testing and copay requirements—- vary by jurisdiction. All provinces appear to struggle with a lack of available and properly trained personal support workers (or equivalent). This situation has become exacerbated through the pandemic and caused hardship for those with a disability. Attendants are often reported not to show up for scheduled care.

Home care services and access to attendant services are provided by regional health authorities in each province. Table 12 illustrates that there is disparity across the ten provinces regarding means testing for attendant services. Refer to the respective provincial summaries for the explanation and conditions.

B) Medical Supplies for Neurogenic Bladder and Bowel Management

Access to appropriate medical supplies is essential to SCI-related bladder and bowel management. Levels of support and means testing for the provision of catheters, ostomy supplies and other needed supplies vary by province. Saskatchewan is the only province

that does not means test for provision of medical supplies.

Medical supplies are provided by regional health authorities in each province. Table 13 demonstrates disparities of means testing and financial implications to individuals with SCI across provinces. Refer to the respective provincial summaries for the explanation and conditions.

C) Essential Wheelchair, Seating, and Lift and Transfer Devices for Those Unable to Ambulate

For those unable to ambulate, wheeled mobility assistive devices are essential. To be effective, assistive devices need to be customized to the functional level and physical characteristics of the user and their personal setting. They enable and assist movement and transfers as well as prevent injury to both the user and caregivers. The provision of assistive devices varies significantly across different provinces.

The provision of assistive devices is provided by regional health authorities in each province. Table 15 illustrates the disparities and financial implications for a person living with SCI in each province. Refer to the respective provincial summaries for the explanation and conditions. While all provinces provide some wheelchair options, the levels of coverage and restrictions in personalization and types of models differ substantially across the country. Some provinces purchase wheelchairs for the client while others use equipment from refurbished loan pools. As a person's physical function is reduced, each person's ability to function becomes more and more dependent upon a customized mobility device that maximizes the person's ability to function in their environment. However, it appears that the definitions and restrictions within many of the programs are aimed at the most inexpensive appropriate device or have such limited availability of models that it would not be possible to provide adequate or appropriate equipment within their programs. Key informant observations support this conclusion.

The inclusion of lifts varies greatly along with provincial approaches to repairs or replacement of equipment. Wait times in most jurisdictions are a significant issue, and assistive devices rarely meet the full needs of the client.

Table 12 *Summary of Attendant Services/Home Care for ADL by Province: Means Testing and Financial Implications for a Person Living With SCI*

Province	Means testing	Financial implication modelling for a person living with SCI
British Columbia	Yes	Calculation of home care fees are not based on hours of need, but are based on income. A detailed formula exists to calculate home care fees based on net family income, with various allowances for non-earned and earned income and RDSP contributions. Thus, based on the formula, a single person (assuming 15% income tax) is allowed to earn < $41,511. They would then start paying a daily fee of their additional earned income multiplied by 0.00138889 in home care fees (not based on hours of care received) until the person earns > $50,0000 annually. After this point, the person pays a yearly maximum of $3,600 in home care fees.
Alberta	No	
Saskatchewan	Yes	Calculation of home care fees are based on hours of need and income. Each person receiving home care pays a flat rate of $8.80 per hour for the first 10 hours service per month (capped at $88/month) regardless of whether they have earned income or receive pension or social assistance. A detailed formula is then used to calculate home care fees based on net family income, a basic income exemption and a sliding scale of hourly fees for additional hours of care received (beyond the 10 hours noted in the preceding paragraph). Thus, for a single person, the basic income allowance is $1,667/month ($20, 004/year). Beyond this point, additional home care charge rates apply, outlined below. A single client would pay hourly home care fees on a sliding scale with higher fees for higher income. For example, for a single person earning > $20,000 annually requiring 15 hours/week of care these fees represent 88-100% of their additional income (i.e., beyond their allowable monthly allowance of $1,667) as home care fees until they earned > $27,192 annually. This person would reach a maximum home care fee of $529/month. For comparison, a person requiring 10 hours/week of care would pay 60-100% of their additional earned income in home care fees until the person earns > $22,400 annually. This person would reach a maximum fee of $371/month. The yearly maximum a person pays in home care fees is $6, 348, which would be reached if requiring > 15 hours/week of services.

Province	Means testing	Financial implication modelling for a person living with SCI
Manitoba	No	
Ontario	No	
Quebec	No	
New Brunswick	Yes	Calculation of home care fees are not based on hours of need and are a subsidy-based system based on income. For example, there are $0 fees for persons earning up to the current social assistance level (< $8,460 annually). They would then pay 5% for each additional dollar between $8,460 and $19,410.36 (numbers based on current levels of old age security and pension benefit levels). A single person with income between $19,410.36 and $25,000 would then pay 30% of additional income in home care fees. If a person's income is greater than $25,000 annually, 100% of this additional income is expected to be paid in home care fees. Thus, regardless of the number of hours per week of care, a single person earning $20,000/year would be required to pay $59/month ($708 annually) for their home care services. If they earned $25,000, they would pay $184/month ($2,208 annually) for home care services. A person earning $50,000 annually would be required to pay $2,267/month ($27,204 annually). The implication of this fee structure is that there is a significant financial disincentive to continue to use the public home care program once income exceeds a certain threshold. Home care fees are not capped at a maximum amount.
Prince Edward Island	No	

Province	Means testing	Financial implication modelling for a person living with SCI
Nova Scotia	Yes	Calculation of home care fees are based on hours of need and income. There are $0 fees for a single person earning up to $26,165 annually. They would then pay $12.45/hour of care to a monthly maximum of $124.50 ($1,494 annually) for income between $26,166 and $41,165. For a single person earning more than $41,166, the same hourly rate applies, and monthly charges are capped at $249 for earnings between $41,166 and $51,165; $373.50 for income between $51,166 and $61,165; $498 for income between $61,166 and $71,165; and $622.50 for earnings above $71,166. After this point, a single person living alone pays a yearly maximum of $7,470 in home care fees. Calculation of home care subsidy and client contributions are not based on hours of need but are based on income.
Newfoundland & Labrador	Yes	For example, there are $0 fees for a single person earning up to $13,000 annually. They would then pay 24% for each additional dollar income between $13,001 and $18,000. A person with income between $18,001 and $23,000 would then pay 34% of this additional income in home care fees. A person with income between $23,001 and $28,000 would then pay 42.8% of this additional income in home care fees. With income beyond $28,001 and less than $150,000, 18% of total income would be paid in home care fees. Maximum annual subsidies exist for home support, which is capped at $4,985/month for those under 65, and capped at $3,490/month for those over 65, years of age. If a person earns > $150,000 they are not eligible for a home care subsidy.

Note. RDSP = registered disability savings plan

Table 13 *Summary of Attendant Services/Home Care for ADL by Province: Do Alternative Delivery Models Exist and What are the Financial and Functional Implications for a Person Living With SCI?*

Province	Alternative attendant care service arrangements
British Columbia	Self-managed attendant care, called CSIL in BC. No maximum coverage is stated; individually calculated by multiplying CSIL hourly rate and assessed hours of need, although in practice, key informants indicated those with very high needs are often encouraged to seek out institutional LTC facilities.
Alberta	Self-managed attendant care. No maximum coverage is stated, and key informants indicate those in rural setting may be limited to self-managed care due to lack of availability of publicly provided services. Cannot hire family members. Family-managed attendant care. Indirect funding: Community-based group supportive living (Designated Supportive Living).
Saskatchewan	Self-managed attendant care. Monthly maximum coverage of $7,474, based on assessed hours of care needed. Cannot hire family members. Indirect funding: Collective Funding for those living in grouped arrangements exists.
Manitoba	Self and family-managed attendant care accessed through Centre for Independent Living in Winnipeg. No maximum coverage is stated. Family members are not allowed to be hired except in unique circumstances. Indirect funding: Community-based supportive living indirect funding (Supportive Housing Models e.g., Fokus, 1010 Sinclair).
Ontario	Family-managed home care accessed through home and community care support services Direct funding (self-managed attendant services accessed through the CILT). According to Direct Funding Ontario website, "The amount of service is individually negotiated. Current guidelines specify that the total service funded for any one individual is a maximum of 7 hours per day (212 hours per month)." Attendant outreach services enable expanded services outside of the home. Indirect funding: Community-based supportive living. Other: Emergency support available in Toronto/York through Mobile supportive housing attendant service.

Province	Alternative attendant care service arrangements
Quebec	Self-managed attendant care called L'allocation Direct or chèque emploi-service in Quebec. No maximum coverage is stated. Clients are allowed to hire family members. Indirect funding: Community-based supportive living exists as special cases.
New Brunswick	Self-managed attendant care. No maximum coverage is stated, although in practice, key informants indicated those with very high needs are often encouraged to seek out institutional LTC facilities. Paying family members not living in the same household is allowed. May carry over unused funding within the same calendar year (month to month). Indirect funding: Community-based supportive living options exist (e.g., shared housing).
Prince Edward Island	AccessAbility Supports Program provides a range of supports, from home modifications to home care services to wheelchairs and medical supplies. A monthly maximum allowance exists and can be directed to the individual's specific needs. It is unclear if self-managed attendant care services could be supported by this program. At the time of printing, we had not received clarification of this question from PEI government staff. Indirect funding: Community-based supportive living indirect funding (e.g., Kay Reynolds Centre).
Nova Scotia	Self-managed attendant care. NS home care policy manual indicates the maximum amount of home support hours per 28-day service plan which may be authorized is 100. Key informant stated that many clients with high care needs apply for self-managed care as scheduling flexibility is increased.
Newfoundland & Labrador	Self-managed attendant care. Maximum coverage not stated. Can hire family members. Indirect funding: Community-based supportive living (e.g., Shared Living Arrangements).

Note. CILT = Centre for Independent Living in Toronto; CSIL = Choice in Supports for Independent Living; LTC = long-term care

Table 14 *Summary of Neurogenic Bowel and Bladder Supplies for ADL by Province: Means Testing and Financial Implications for a Person Living With SCI*

Province	Means testing	Financial implication modelling for a person living with SCI
British Columbia	Yes	Provision requires medical prescription and financial assessment. Public coverage of supplies is dependent upon receiving EAPD. Thus, a single person with no dependents receives 100% coverage for supplies when receiving < $983.50/month ($11,802/year). Single-use catheterization is not supported, and quantities are limited (limit may be exceeded with justification). Quality is limited to most inexpensive generic option available. No coverage is provided once a person does not receive EAPD.
Alberta	Yes	Provision requires medical prescription and financial assessment. Public coverage of supplies is provided for a single person earning up to $20,970, beyond which point they would pay 25% of costs on eligible basic supplies to an annual maximum contribution of $500. Single-use catheterization is not supported, and quantities are limited (35 intermittent catheters per month, two Foley catheters/ month, limit may be exceeded with justification).
Saskatchewan	No	Provision requires medical prescription and confirmation of paralysis, and ineligibility for funding through other government agencies. Single-use catheterization is not supported, and quantities are limited (four intermittent catheters per day, limit may be exceeded with justification). Quality is limited to most inexpensive generic option available.
Manitoba	Yes	Provision requires medical prescription and financial assessment. In some cases, supplies may be provided if the person receives home care for ADL. Public coverage of supplies may be provided if receiving EIA, depending upon individualized assessment. Single-use catheterization is not supported, and quantities are limited. No coverage is provided once a person does not receive EIA.

Province	Means testing	Financial implication modelling for a person living with SCI
Ontario	Yes	Provision requires medical prescription and financial assessment and is only provided if receiving income support through ODSP. Financial eligibility is reviewed on an individual basis and does not include specific income limits. Single-use catheterization is not supported, and quantities are limited (~1 intermittent catheter per day, limit may be exceeded with justification). Quality is limited to most inexpensive generic option available. No coverage is provided once a person does not receive income support.
Quebec	Yes	Provision requires medical prescription and financial assessment and is only provided for those with very low income and significant need. Financial eligibility and need are individually assessed and does not include specific income limits or coverage amounts. Single-use catheterization is not supported, and quality and quantities are limited (limit may be exceeded with justification).
New Brunswick	Yes	Provision requires medical prescription and financial eligibility is reviewed on an individual basis (budget deficit method). Single-use catheterization is not supported. Quantities are limited (four intermittent catheters per day, four indwelling per month, limit may be exceeded with justification). Quality is limited to most inexpensive generic option available. No coverage is provided once a person's income ~ $25,000/annum.
Prince Edward Island	Yes	Provision requires medical prescription. Through the AAS program, a single person would pay $0 for medical supplies up to an annual income of $21,707. A single person would then be required to contribute 10% of relevant costs until income reaches $51,707. Beyond this income level a person's contribution would increase from 10.5% up to 39% as income increases to $119,707. No coverage is provided once a person's income > $119,708/annum.

Province	Means testing	Financial implication modelling for a person living with SCI
Nova Scotia	Yes	Provision requires medical prescription and financial eligibility is reviewed on an individual basis and does not include specific income limits. However, assessment includes income, assets, and associated costs. Single-use catheterization is not supported. Quantities are limited. Quality is limited to most inexpensive generic option available.
Newfoundland & Labrador	Yes	Provision requires medical prescription and financial assessment. Calculation of a medical supply subsidy and client contributions are not based on hours of need but are based on income. For example, there are $0 fees for a single person earning up to $13,000 annually. They would then pay 24% for each additional dollar income between $13,001 and $18,000. A person with income between $18,001 and $23,000 would then pay 34% of this additional income in fees. A person with income between $23,001 and $28,000 would then pay 42.8% of this additional income in fees. With income beyond $28,001 and less than $150,000, 18% of total income would be paid in fees. Single-use catheterization is not supported and quantities (one intermittent catheter per week, limit may be exceeded with justification). Quality is limited to most inexpensive generic option available. If a person earns > $150,000 they are not eligible for a subsidy.

Note. AAS = AccessAbility Supports; ADL = activities of daily living; EAPD = Employment and Assistance for Persons With Disabilities EIA = Employment and Income Assistance; ODSP = Ontario Disability Support Program

Table 15 *Summary of Essential Wheelchair, Seating, and Lift and Transfer Devices by Province: Financial Implications and Functional Limitations Caused by Means Testing or Limited or Loan-Based Assistive Technology for a Person Living With SCI*

Province	Means tested	Financial implications for individuals with SCI	Functional implications for individuals with SCI
British Columbia	Yes	Provision requires financial assessment, pre-approval, and that family unit has no other resources for payment. Public coverage of assistive equipment is dependent upon receiving EAPD. Thus, a single person with no dependents receives 100% coverage for supplies when receiving < $983.50/month ($11,802/year). No coverage is provided once a person does not receive EAPD.	Wheelchairs • equipment restricted to least expensive equipment which is prescribed and deemed medically essential to achieve/maintain basic mobility or positioning. List of models/manufacturers not publicly available • cushions eligible every 2 years • backrests may be covered as positioning device • recreational, lift, and backup chairs not covered • wait times include 6-12 months for assessment by OT and at least an additional 2 months for wheelchair manufacturing and shipping • lengthy delay for repairs • repairs limited to equipment/components funded by province. Bathroom, transfer, positioning, and floor/ceiling lift devices may be covered with medical justification
Alberta	No for basic wheelchair is provided by loaned inventory. Copay is required for clients opting for upgrade status wheelchair or components	Basic loans program not means tested. If an appropriate wheelchair is not in the loaned equipment pool it can be ordered through an approved vendor list. Wheelchair remains the property of AHS. Clients can choose to receive a grant for an upgrade status wheelchair. In this case, the client receives a grant (dependent on category of upgrade wheelchair, up to $3,900 for a lightweight or ultralight wheelchair, e.g., TiLite). The client covers the remaining cost of the wheelchair and its components and becomes the owner of the wheelchair.	Wheelchairs • models limited to a few (< 5) by a few manufacturers, list is publicly available • power wheelchair eligible for replacement every 7 years • manual wheelchair eligible for replacement every 5 years • cushions and backrests eligible every 3 years • clients must attend seating clinic for assessment • 2 month wait for assessment, additional 3-4 month wait for wheelchair delivery • if person self-funds, repairs of upgraded items not covered • clients responsible for rental costs while waiting for assessment and delivery of equipment • repairs limited to equipment/components funded by province. Bathroom, lifting, and transfer devices may be covered with medical justification.
Saskatchewan	No Copay required for new *grant-in-lieu* option	Provision of basic loaned program wheelchair is not means tested. Operated through SAIL of the Ministry of Health. As of April 1, 2019, trial of *grant-in-lieu* program for ultralight wheelchairs, wherein, client receives $2,500 grant for the purchase of wheelchair. Client covers remaining costs and becomes owner of wheelchair.	Wheelchairs • models limited to a few (< 5) by one or two manufacturers, list is publicly available • chairs only replaced if clients have significant change in need or repairs have become uneconomical • cushions are loaned • backrests and adaptive seating options may be loaned if requisitioned by licensed specialist • eligibility requires referral by health care professional and ineligibility with regard to other government agencies • clients cannot opt to pay excess costs for *upgrade* features/components • lengthy delays for repairs • equipment is generally aging and often refurbished. Bathroom, transfer, and lifting devices loaned to clients. Grants are available for home and vehicle modifications.

Province	Means tested	Financial implications for individuals with SCI	Functional implications for individuals with SCI
Manitoba	No	Provision of basic loaned program wheelchair is not means tested. Loans program operated by non-governmental nonprofit charity organization (Manitoba Possible) with funding envelope for equipment pool provided by provincial government. Wheelchair is the property of Manitoba Possible. Client is 100% responsible for any component upgrades to the wheelchair, and only certain upgrades are allowed. Further when returning the wheelchair to the equipment pool, wheelchair must be returned in its original loaned state.	Wheelchairs • models limited to a few (< five) by one or two manufacturers, list is publicly available • physical assessment of need and application form must be completed by an OT, although specialization in wheelchair mobility not required • excessive lengthy delays in referral (6-12 weeks), assessment of eligibility and approval of request (6 to > 12 weeks), wait time to receive chair once ordered (12 weeks) and time for initial set up (2-6 weeks). Wait times to receive wheelchair currently typically ~ 6 months or more, and have exceeded 40 weeks. Significant contributor to delays in release from in-patient rehabilitation hospital • if person self-funds a component, repair of *upgraded item* not covered • lengthy delays for repairs of loaned equipment • cushions are covered up to $600 every three years and must be accessed through SCI MB and Home Care • backrests not considered for coverage unless client is receiving EIA. Loan program—wheelchair must be returned if new equipment is requested. Client only allowed to keep chair as a backup if it is so damaged that it is considered *irreparable*. Bathroom, transfer, and lifting devices are only considered for coverage if client is receiving home care or EIA.
Ontario	Yes	Ontario residents who have a disability requiring a mobility aid for six months or longer are eligible for 75% coverage of some essential assistive devices under the ADP and are required to pay the remaining 25%. Clients receiving financial support from Ontario Works, ODSP, or Assistance for Children with Severe Disabilities receive 100% coverage through ADP. Clients assessed through list of approved OT or PT, order equipment through list of approved retail vendors.	Wheelchairs • models must be on pre-approved list, list is publicly available • multiple manufacturers and multiple distinct wheelchair approved • approved models not as limited as AB, MB, and SK • wheelchair must be ordered through approved list of vendors • clients interested in items/features not outlined in approved lists of eligible equipment do not receive any coverage • cushions eligible every 2 years • backrests are eligible for coverage • equipment eligible for replacement if needs have changed and device no longer appropriate or if unable to be repaired economically. Transfer/lift devices not covered outside of ODSP.
Quebec	No	Provision of basic loaned program wheelchair is not means tested. Equipment remains property of provincial government. Prescription required and ordered through pre-approved list of rehabilitation centres located throughout province.	Wheelchairs • models must be on pre-approved list, list not publicly available • available models are generally inexpensive, although clients can apply for equipment outside provincial list with medical justification • clients eligible for new chair when repair cost becomes 80%+ the cost of a new chair • cushions and postural supports covered • if person self-funds, repairs of *upgraded items* not covered • backup wheelchair only covered if client working or attending school • equipment must be returned if new equipment is requested. Bathroom, transfer, and lifting devices are eligible for coverage. Funding for home modifications available, although wait list for program up to 2 years. Funding for vehicle modifications available.

Province	Means tested	Financial implications for individuals with SCI	Functional implications for individuals with SCI
New Brunswick	No	Loans program operated through Easter Seals with funding from provincial government. If no suitable wheelchair in existing equipment pool, wheelchair can be ordered. Wheelchair must be returned if new wheelchair is requested. Wheelchair in the equipment pool can be re-loaned, but only if in good condition, and < 5 years old.	Wheelchairs • clients must be assessed and have equipment medically justified • only basic functional needs addressed • if wheelchair not available in equipment pool, it may be ordered by Easter Seals • model restrictions are not specified, list of available models not publicly available. Rather, limits are $8,500-$12,000 for power, $3,000 for folding frame manual and $6,000- $7,500 for rigid frame manual wheelchairs • cushions and seating/positioning aids covered • excessive wait times ranging from 2 months to over 3 years, with referral and prescription alone taking up to 2 years. Bathroom, transfer, and lifting devices are eligible for coverage.
Prince Edward Island	Yes	Through the AAS program, a single person would pay $0 for medical supplies up to an annual income of $21,707. A single person would then be required to contribute 10% of relevant costs until income reaches $51,707. Beyond this income level a person's contribution would increase from 10.5% up to 39% as income increases to $119,707. Equipment is purchased through vendors. No coverage is provided once a person's income > $119,708/annum.	Wheelchairs • wheelchair eligibility is based on medical justification by health care practitioner • if 75% or more of wheelchair is funded by AAS, it remains the property of AAS and must be returned • cushions and positioning equipment are covered following assessment at seating clinic • wait times can be significant. Bathroom, transfer, and lifting devices are eligible for coverage. Funding for home and vehicle modifications available.
Nova Scotia	No if < 65 years (Yes for clients > 65 years – require Disability Support Program (DSP) eligibility)	Loans program operated through Easter Seals with funding from Provincial Government. Eligibility for DSP includes determination of *need*. This is calculated through a financial assessment which involves applicable income, assets, and all associated costs.	Wheelchairs • clients apply to receive new or refurbished chairs (as well as mobility aids and assistive devices) from an equipment pool • requires prescription by OT • public cannot view available equipment pool list • equipment eligibility based on prescription • equipment must be *most economical option available*. Medical equipment recommended by a health care practitioner may be approved under DSP. Bathroom and bedroom safety equipment may be available through a donated equipment pool.
Newfoundland & Labrador	Yes*	Requires calculation of Needs Test, which involves consideration of income, RRSP/RRIF contributions, and allowable expenses (approximately 20). Calculations are complex, requiring significant time and professional involvement, following a flowchart with multiple decision points. Chairs are ordered through the SAP. **Key informant reported that, in practice, calculation of expenses for those needing wheelchair relatively understanding of the significant costs associated with SCI, such that most clients receive 100% coverage for wheelchair unless their income is relatively high or they have private coverage.*	Wheelchairs • clients must attend seating clinic for assessment • wheelchairs are prescribed and features/components are eligible based on medical justification • wheelchairs become the property of the individual • models are restricted to supplier availability, not restricted to an approved list • cushions and backrests covered with justification • wait time for wheelchairs are currently around 3-4 months • wheelchairs become the property of the individual. Bathroom, lifting, and transfer devices are eligible for coverage.

Note. AAS = AccessAbility Supports; Disability Support Program; EAPD = Employment and Assistance for Persons With Disabilities; EIA = Employment and Income Assistance; OT = occupational therapist; SAIL = Saskatchewan Aids to Independent Living; SCI = spinal cord injury

Conclusions and Recommendations

Essential health care needs as discussed in this report requires a standard of practice to ensure that every Canadian receives the same baseline of essential services, supplies and equipment. Access to such healthcare should not limit a person's ability to achieve independent and full community participation and gainful employment. In this report 'essential' is defined as medical services, supplies or equipment that, if withheld, could result in death of a person with SCI within days or weeks. The identification of appropriate medical supplies, equipment and support will be unique to each person because of their physical and functional status, and should be aimed at optimizing health and function, rather than limited to the fewest, most inexpensive options available.

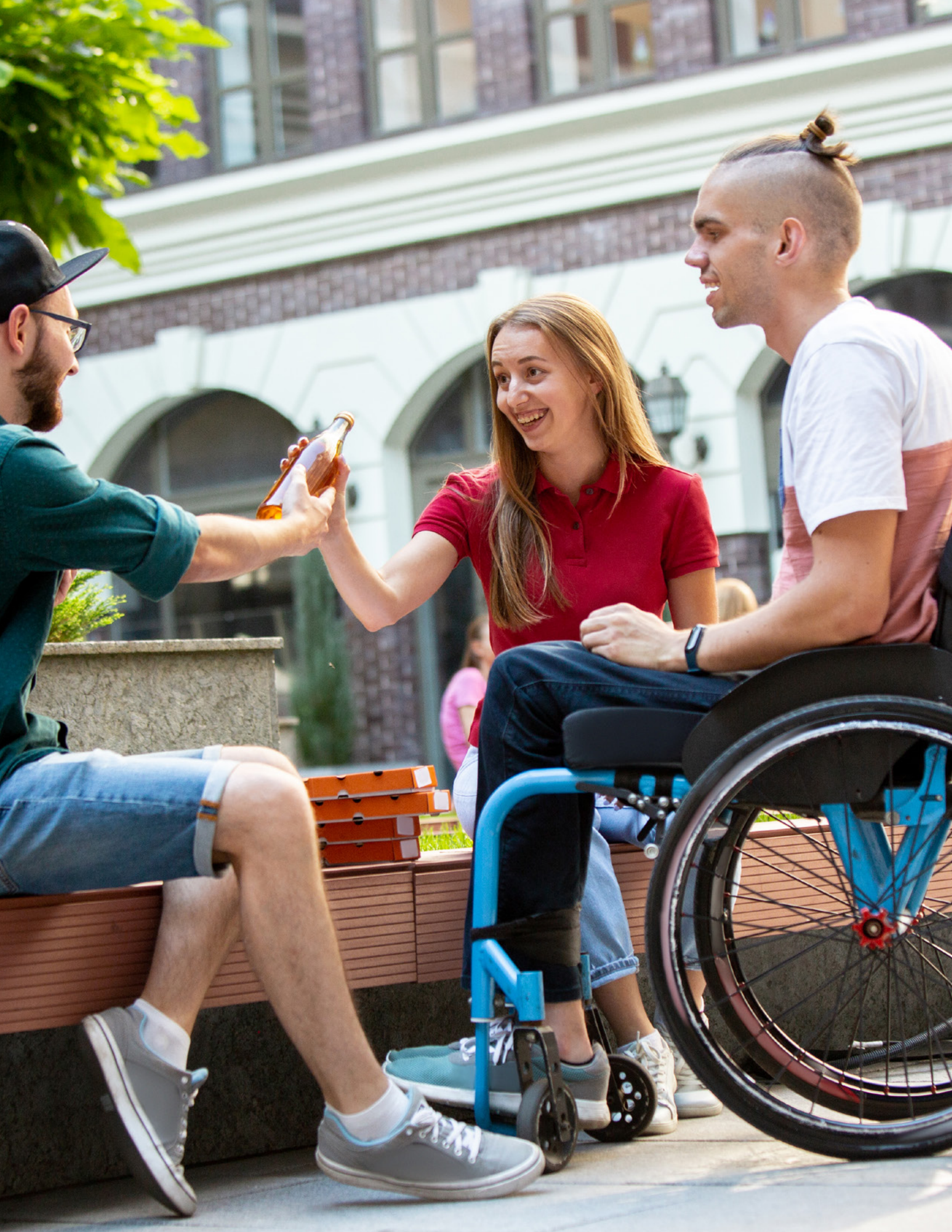
This research demonstrates the stark reality that, for the most part, the ten provinces expect Canadians with spinal cord injury to pay out of pocket for essential health services, supplies and equipment. Citizens are means tested to determine copayments. These findings call into question whether our provincial and federal governments are meeting the tenets of the Canada Health Act and the Convention on the Rights of Persons with Disabilities in Canada.

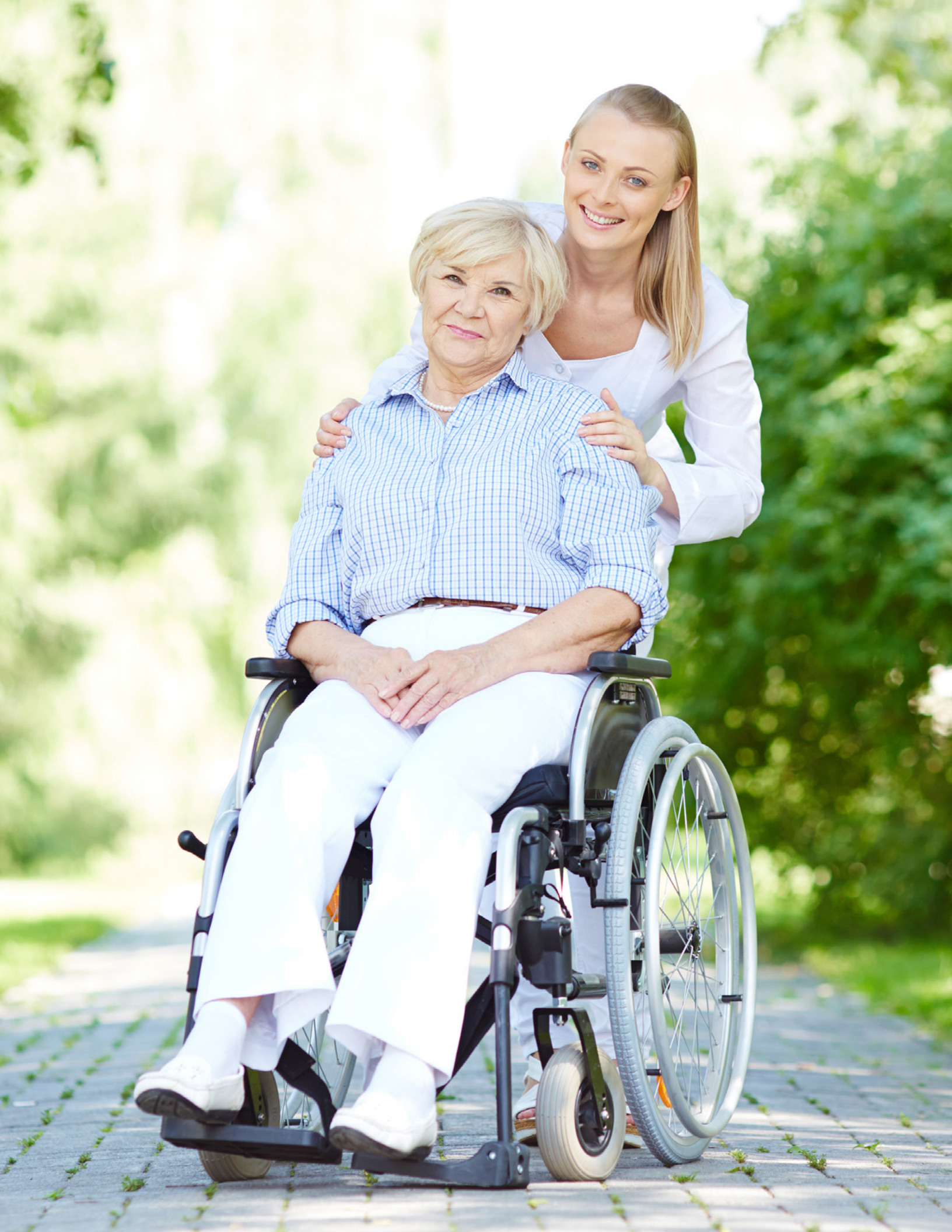
The authors make the following recommendations

- The Government of Canada has a critical role to play in establishing consistency regarding provision of essential healthcare across the country.
- Canadian citizens should not be hindered in living independently with full community participation or in achieving gainful employment by healthcare restrictions that represent a failure in essential health provision. If we are committed to a fully inclusive Canada, health care policies that restrict the ability for people living with SCI to enter the workforce should be replaced with policies that ensure these essential needs are being met, regardless of income. Limitations in, or failure to provide, essential health care services and supplies create barriers to full citizenship for persons living with SCI.
- The governments of each province and territory must review and evaluate the effectiveness of their coverage program.
- Federal, provincial/territorial, and local services must be flexible to meet the unique needs of Canadians, particularly those with disabilities. Local services should be transparent to citizens seeking to navigate the health care system. The pathway to accessing essential health care services, supplies and equipment should be explicit.
- Provinces/territories need to follow Health Canada guidelines and keep pace with health technology recommendations such as single-use coated catheters and the delegation of regulated acts, including bowel management routines.
- A nonpartisan, objective scientific review committee/body should determine definitions of 'essential' SCI-related health care in Canada.

Future research

The research highlighted some consistent themes, including inadequacies in addressing essential medical needs of persons with SCI and the use of means testing to reduce public responsibility for these life sustaining medical services and supplies. Research should be performed to identify an appropriate means and structure for providing these essential health care needs. Although not the focus of this report, it became abundantly clear that there is a lack of affordable housing options for those with disabilities in every jurisdiction. Clients may be forced into continuing care facilities with no other affordable options even when such facilities are completely inappropriate. There is a lack of appropriately trained staff in each province/territory. The lack of support and service options for those in rural or Indigenous communities demonstrates additional inequalities.





Glossary

direct funding—care refers to when caregivers or individuals are given funds or budgeted hours to arrange their own home care services. It may be referred to as self-managed care.

essential needs—medical services, supplies or equipment that, if withheld, could result in death of a person with SCI within days or weeks.

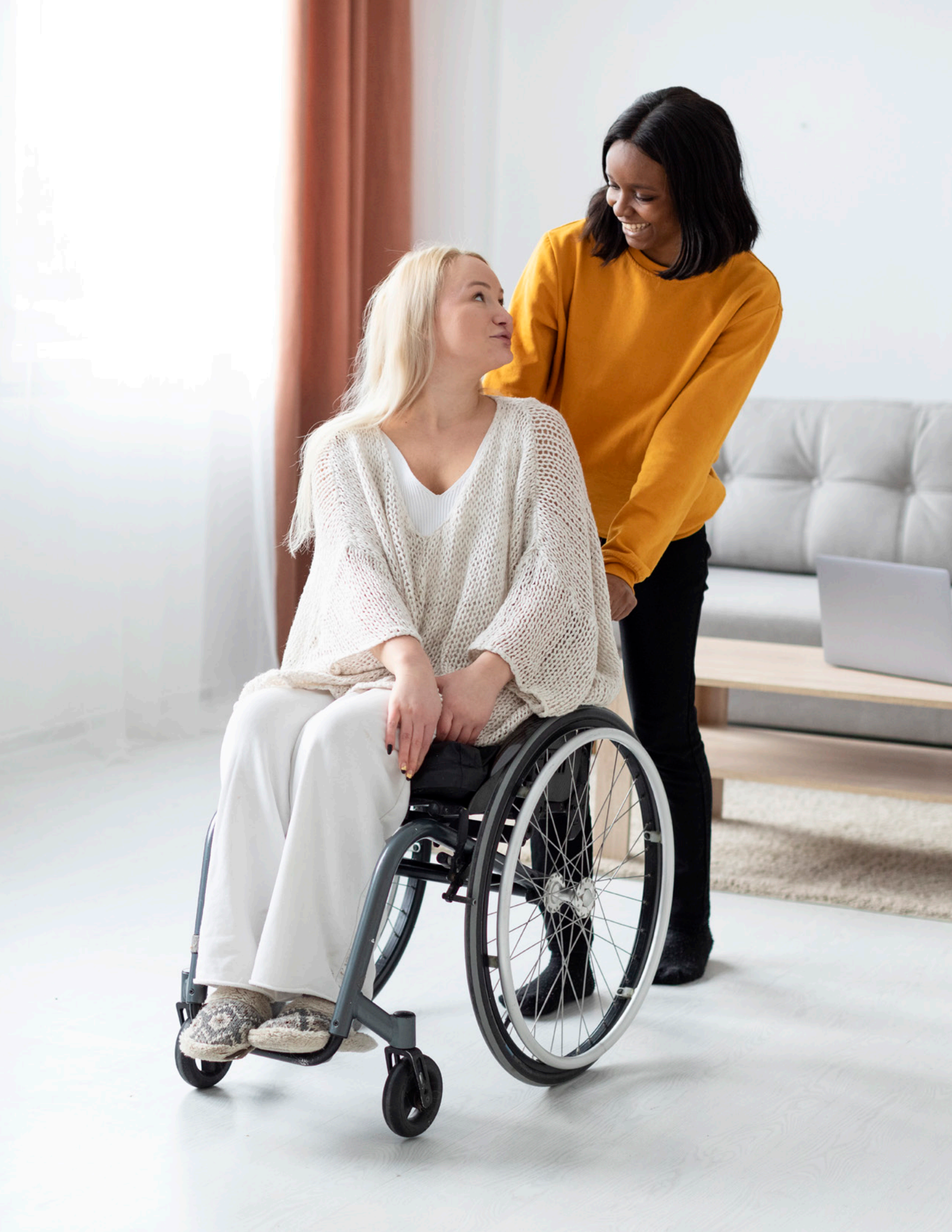
interRAI CHA—an instrument for assessing elderly persons to prevent or stabilize early functional or health decline.

means tested—a determination as to whether a person or household is eligible to receive some sort of benefit or payment. Means tested benefits include many government assistance and state and federal welfare programs that measure a family's income against the federal poverty line.

no-fault motor vehicle insurance—mandatory automobile insurance providing basic coverage to anyone injured in any way by a motorized vehicle without regard to fault for the accident.

Abbreviations

AA	Attendance Allowance
AADL	Alberta Aids to Daily Living
AAS	AccessAbility Supports
ADL	activities of daily living
ADP	Assistive Devices Program
AHS	Alberta Health Services
BCCNM	BC College of Nurses and Midwives
CES	chèque emploi-service
CF	Collective Funding
CILT	Centre for Independent Living in Toronto
CLSC	centre local de services communautaires
CNESST	Commission des norms, de l'équité, de la santé et de la sécurité du travail
CPP	Canadian Pension Plan
CSIL	Choice in Supports for Independent Living
CUA	Canadian Urological Association
DSP	Disability Support Program
EAPD	Employment and Assistance for Persons With Disabilities
EIA	Employment and Income Assistance
FNIHB	First Nations and Inuit Health Branch
FNIHCC	First Nations and Inuit Home and Community Care
HCCSS	Home and Community Care Support Services
ICBC	Insurance Corporation of British Columbia
IF	Individualized Funding
IWK	Izaak Walton Killam
LTC	long-term care
LTCP	Long-Term Care Program
MAELP	Mobility and Adaptive Equipment Loan Program
MVAC	Motor Vehicle Accident Claims
MWP	Manitoba Wheelchair Program
NIHB	Non-Insured Health Benefits
ODSP	Ontario Disability Support Program
OT	occupational therapist
PFE	Programme d'aides matérielles pour les fonctions d'élimination
PIPP	Personal Injury Protection Plan
RHA	regional health authorities
SAAQ	Société de l'assurance automobile du Québec
SAIL	Saskatchewan Aids to Independent Living
SAP	Special Assistance Program
SCI	spinal cord injury
SFMC	self- or family-managed care
SGI	Saskatchewan Government Insurance
SHA	Saskatchewan Health Authority
SNEP	Special Needs Equipment Program
UTI	urinary tract infection
VAC	Veterans Affairs Canada
VIP	Veterans Independence Program
VON	Victorian Order of Nurses
WCB	Workers' Compensation Board
WSIB	Workplace Safety and Insurance Board
WSNB	Work Safe New Brunswick



Appendices

APPENDIX 1 ENVIRONMENTAL SCAN METHODOLOGY

Online environmental scan

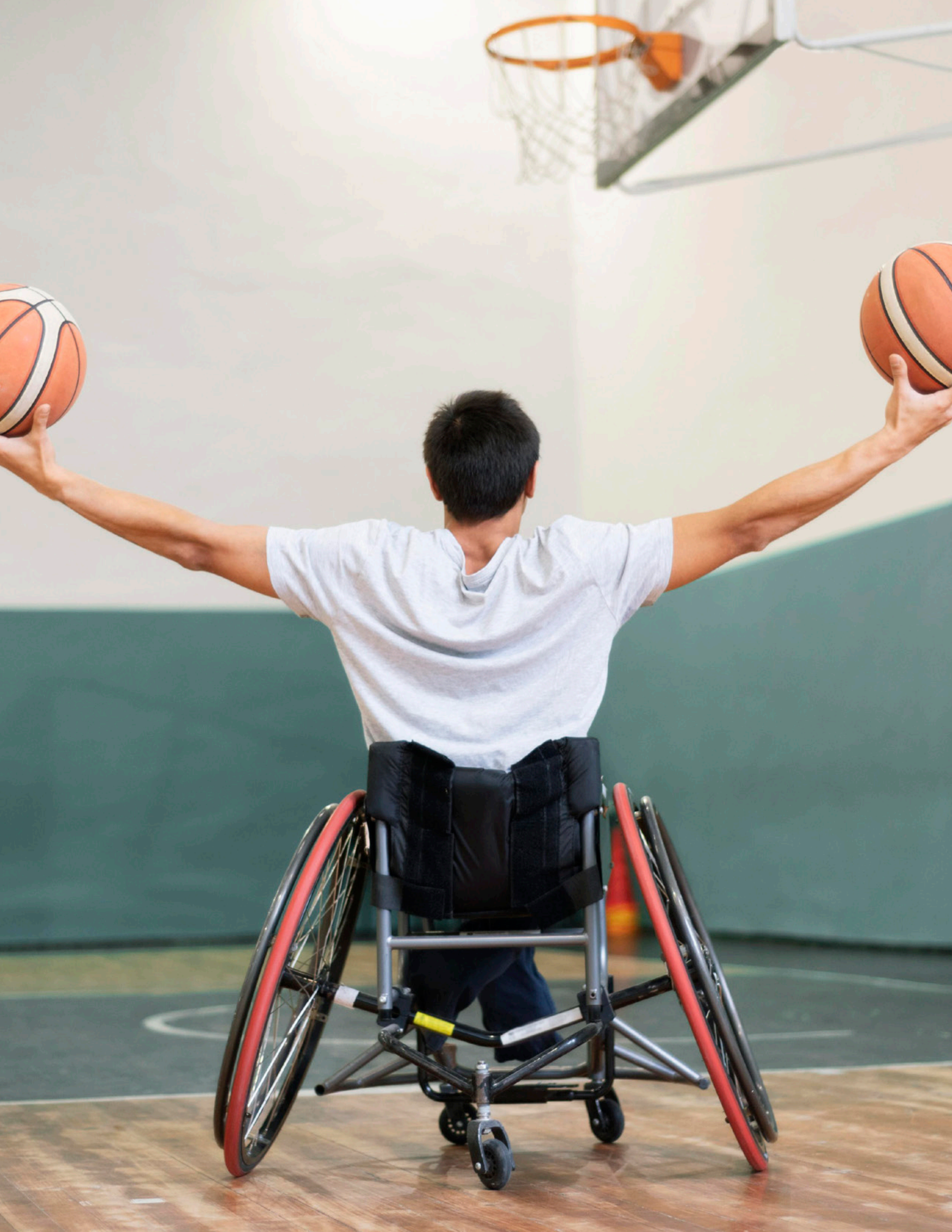
An environmental scan was coordinated by John Gregory reviewing available provincial health policy documentation regarding public and insurance-based provision of these three areas of essential need for people living with SCI in each province across Canada. Online research was conducted between September 2021 and January 2022. Many individuals and organization contributed to this environmental scan, which was conducted as an open collaborative exercise. The scope of the research focus was utilized to formulate matrix as a Google Sheet. Individuals were invited to a shared Google Drive folder containing a separate Google Sheet matrix for each province/territory. Individuals were invited to assist in populating and fact-checking the information. Links to sources of information were captured and pdf files saved.

Key informant interviews

Semi-structured interviews were conducted by Peter Warkentin with one or two key informants per province (n=16) using an expanded questionnaire. Two of these informants were selected due to their expertise regarding federally funded provision of essential care needs (NIHB and Veterans Affairs). Informants were selected based on professional expertise and lived experience regarding publicly funded provision of these essential medical services and supplies. Informants were also questioned on provision of these services and supplies through insurance-based systems where appropriate.

Individual interviews were conducted remotely by a research assistant using a secure University of Manitoba Microsoft Teams platform. The interviews ranged between one to three hours in length based on level of expertise, and took place between October 2021 and May 2022. Follow-up questions and clarifications were explained via email. Meetings were recorded with live transcription to ensure accurate reporting of interviewee responses. Automatic live transcriptions were assessed for accuracy and corrected using recorded videos as appropriate.

Informants were offered an honorarium for their participation. Personal information of key informants was kept strictly confidential. Informants were provided with a copy of the questionnaire prior to the interview for review along with a consent form. This consent form provided background and explanatory information and included a ‘Permission to Quote’ section which outlined various options for direct or anonymous quotation for publication. The consent form also stated that participation was voluntary, and refusal of participation or withdrawal was possible at any time. No key informants withdrew from the study or refused to participate.



In order to include Quebec, a French-speaking research assistant was hired for data collection and translation. This research assistant also participated as a key informant for the province of Quebec.

Limitations

This publication relies on semi-qualitative interview response data cross-referenced with publicly available documentation. This research was conducted from March 2021 to June 2022. A draft of each provincial summary was provided to key informants to review for accuracy of their responses. The research focus was on the provision of services and supplies to individuals between 18-65, although alternative programs were noted where appropriate. The purpose of key informant interviews was to identify or confirm policy-based mechanisms for providing these essential health needs in each province and to determine whether and how policy may differ from practice. Key informants were selected based on their expertise in working within the SCI community-based rehabilitation field and attempted to generalize where regional variation existed in provision of essential care needs.

As the study covered a broad range of health care topics, key informants may have had specific areas of expertise. In this event, we interviewed more than one informant in the province to address knowledge gaps. Some questions were subjective and open ended in an effort to optimize the likelihood of identifying limitations with programs. These relied on a small sample size and likely does not reflect the full range of experiences in each province. As policy may differ from actual practice data gathered from interviews sometimes challenged or contradicted policy data. We addressed this by repeated cross-referencing with policy documents in developing the date tables included in the report. Our responses are limited to the ten provinces since we were unable to recruit key informants from the territories with our limited resources and timeframe.

APPENDIX 2 KEY INFORMANT INTERVIEW GUIDE

Research will focus on the following three essential spinal cord injury-specific needs 1) Personal attendant care for ADL; 2) Essential neurogenic bowel and bladder management supplies; and 3) Essential mobility assistive devices (power and manual wheelchairs for those unable to ambulate).

Specific Items within each area of need:

1. Personal attendant care for ADL will focus on the following: neurogenic bowel management routine; neurogenic bladder management routine; dressing (clothing); and bathing.
2. Essential neurogenic bowel and bladder management supplies will be: catheters [intermittent & indwelling (Foley or condom drainage), stoma/urinary diversion supplies]; ostomy supplies; nonsterile examination gloves; lubricant; and suppositories.
3. Essential assistive devices will be: power wheelchairs; manual wheelchairs; lifting/transfer devices (e.g., Hoyer lifts); and essential seating for pressure relief for power and manual wheelchairs.

As experts in these areas you will likely have documentation regarding the delivery of these services and supplies within your jurisdiction. As part of our environmental scan, we would very much appreciate any and all documentation available. So, as you go through the questions and you are reminded of documentation/URLs etc. that you use, please provide this information.

A. Please describe your employment role(s) relating to assisting persons with SCI in obtaining the above-noted essential services and supplies.
B. Please indicate if you are a person with lived SCI-experience in obtaining the above-noted essential services and supplies: Yes or No.
C. Either per year, per month or per week, on average, how often do you help individuals with SCI obtain these supplies/services (approximately).
D. Recognizing that these questions cover broad areas of service or equipment delivery, as you go through these questions, please let us know your level of expertise and/or indicate if you don't feel comfortable in commenting due to a lack of familiarity.

Questions regarding each item within each area of need:

1. Public provision of personal attendant care for ADL

With respect to personal attendant care for ADL:

- How are each person's care needs determined and prescribed and who is responsible for the assessment?
- Does your jurisdiction have a 'delegated care act'? If so, please describe.
- Are there options for self/family-managed care delivery of these services? If so, how is this process organized and delivered? What are the eligibility criteria? How portable is self/family-managed care (i.e., what happens when a person moves)?
- What are the different service delivery models available for home care (supported housing, congregate care such as 'Fokus' units in MB or the 'hub and spoke' model in ON)? If so, please list and describe, including the process for determining eligibility and limits/restrictions in terms of levels/extents of service?
- What is the process to determine hours of care needed? Is there a formal or standardized assessment (e.g., interRAI)? If so, please describe as appropriate

for: initial discharge from in-patient SCI rehabilitation stay; when needs change in the community.
- Is there an upper limit of hours at which point the person would require institutional or other forms of supported care (e.g., grouped care settings)? If the limits vary, please indicate.
- Is there a cost-sharing income-based component to delivery of these services? If so, please describe.
- How are these services provided in your jurisdiction, who is permitted to deliver each service and are there restrictions on service delivery (e.g., only a nurse can change an indwelling catheter; a home care aid can provide bathing services but a home support worker cannot)?
- Is there an appeal process if the person disagrees with either the type or level of service? If so, please describe.

With respect to neurogenic bowel management routine; neurogenic bladder management routine; dressing (clothing); and bathing:
- What specific services are eligible?
- Are there time limits per service?
- Are there restrictions in the level of service?
- What is the process if there is a nonscheduled emergency event that requires care?
- Is the level and extent of service generally considered adequate?

Can you comment on any differences in level of service or limits to services depending upon rural versus urban or other living situation?
Does the publicly funded system state that it adheres to the Independent Living Philosophy Act? In practice, does the publicly funded system adhere to the Independent Living Philosophy Act (i.e., does not limit # of showers per week).

2. *Publicly funded essential neurogenic bowel and bladder management supplies*

With respect to essential neurogenic bowel and bladder management supplies:
- What are the specific supplies that are eligible?
- Are there limits to the number provided during a given time period? If so, express as unit per day/week/month/year.
- Are there restrictions based on supplier or individual's circumstance (e.g., income based, limits or restrictions on the type of product)?
- Are there certain essential medical supplies that are publicly funded but only in certain circumstances (e.g., catheters if a person is receiving homecare)?
- In your opinion, what are the limitations/concerns with provision of these essential genitourinary supplies?

3. *Public coverage for essential mobility assistive devices*

With respect to essential assistive devices:
- What are the specific components/features eligible (e.g., tilt or height raising feature on power chairs)?
- Which components/features are only eligible for public coverage based on a specific additional justification (e.g., tilt feature on power chairs)?
- What are the specific model restrictions on publicly funded manual or power chairs (e.g., only Quickie Xperience2 power wheelchairs is funded)?
- Are additional features available as 'add-ons that are self-funded or co-paid' for either power or manual wheelchairs (e.g., raise feature on power chair)? If so, please list. Describe the process and funding model for ordering the original and upgraded components.
- What essential mobility/care devices are not funded at all (e.g., Hoyer lift systems, transfer boards, bath seats)?
- Are there certain essential equipment items that are publicly funded but only in certain circumstances (e.g., wheelchair cushions, indwelling catheters if a person is receiving home care)?
- Regarding your assistive device program, can you provide us with a 100% 'funded' list of devices.
- Is there a list of items that are subsidized on a 'copay' basis? If so, please provide.
- Where does the public go to learn this information?
- In your opinion, what are the limitations/concerns with provision of these essential assistive mobility devices?

4. Nonpublic coverage

What are the inequities between the public and insurance-based systems? This includes provincial insurance-based (motor vehicle and worker's compensation based) or federally funded (NIHB and Veterans Affairs) systems. If you can, provide limits, inclusions/exclusions, additional coverages, eligibility criteria, etc., as they relate to personal attendant care for ADL, essential neurogenic bowel and bladder management supplies, and essential assistive devices.

Motor vehicle insurance-based systems (e.g., MPI). Indicate if these are torte-based or no-fault. If a mixed system, please state the circumstances that determine whether under torte-law vs. needs-based provision.

NIHB-based coverage
Do you provide counseling services to Indigenous peoples – If so – we would like to learn about how the provision of these essential services differs for this population.

Any other comments regarding how you would compare these nonpublic insurance-based providers to each other?
Any other comments regarding how you would compare these nonpublic insurance-based providers to the public payor?
Finally, how would you rank them? Are some/one better than others in terms of their coverage?

APPENDIX 3 PROVINCIAL CALCULATORS

As this Essential Needs research advanced, we sometimes struggled to understand the complexities of means testing coverage. Provincial calculators evolved to work through what this means in reality for someone with SCI with different levels of income. British Columbia is presented here as an illustration. Comparable calculators are in development and can be requested from the principal investigator, Dr. Kristine Cowley. Kristine.Cowley@umanitoba.ca.

BC definitions and formula

"earned income" means the sum of the following amounts as reported on lines 10100, 10400, 13500, 13700, 13900, 14100 and 14300 of the relevant notice of assessment or reassessment of the client or the client's spouse, as applicable:
(a) employment income;
(b) other employment income;
(c) net business income;
(d) net professional income;
(e) net commission income;
(f) net farming income;
(g) net fishing income;

"remaining annual income" means an amount calculated using the following formula:
RAI = C + S – CT – UCCB – CI – I – RDSP
where:
"RAI" means remaining annual income;
"C" means the net income of the client as reported on line 23600 of the client's relevant notice of assessment or reassessment;
"S" means the net income of the client's spouse as reported on line 23600 of the spouse's relevant notice of assessment or reassessment;
"CT" means the total income tax paid by the client and, if the value of S is greater than 0, by the client's spouse, as reported on line 43500 of the relevant notice of assessment or reassessment of the client and, if applicable, the client's spouse;
"UCCB" means the amount of the annual benefit under section 4 of the *Universal Child Care Benefit Act* (Canada) that

a. is paid to the client, as reported on line 11700 of the client's relevant notice of assessment or reassessment,
b. is paid to the spouse of the client, as reported on line 11700 of the spouse's relevant notice of assessment or reassessment, or
c. is paid to both the client and the spouse of the client, as reported in the manner referred to in paragraphs (a) and (b).

"CI" means the annual earned income for the client and, if the value of S is greater than 0, for the client's spouse, to a maximum of $25 000 per person;
"I" means the amount of income that corresponds to the client's family unit size in the following table:

Family Unit Size	Amount of Income
1	$10 284
2	$16 752
3	$19 164
4	$20 880
5	$22 716
6	$24 312

Daily charge for clients receiving home support services

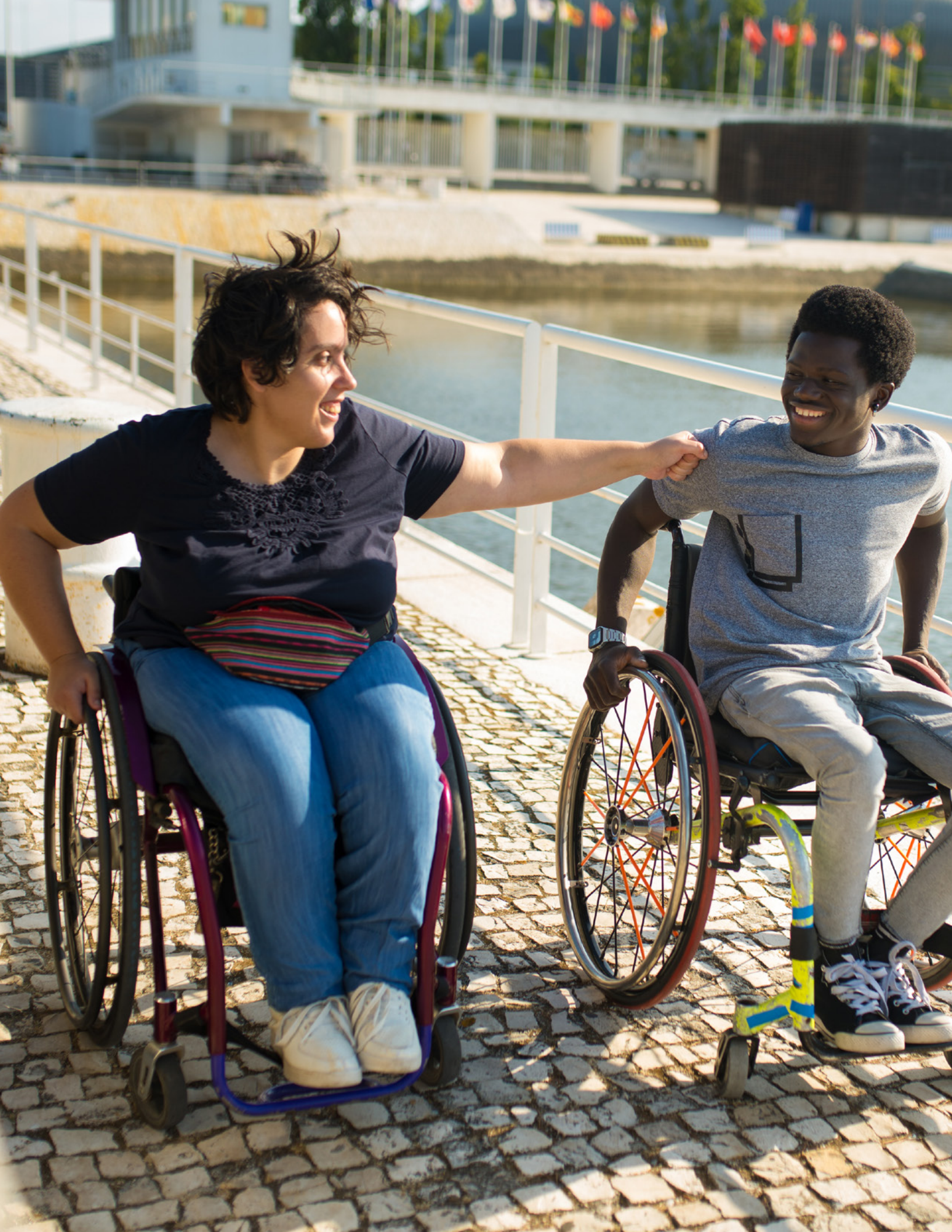
3 (1) A client who receives home support services must pay a daily charge calculated as the client's remaining annual income multiplied by 0.00138889.
(1.1) A client is not required to pay more than $300 for home support services in a month if the client, or the client's spouse, receives earned income.
(2) Despite subsection (1), a client is not required to pay a daily charge for home support services if the client receives any of the following:
(a) the guaranteed income supplement, the spouse's allowance or the survivor's allowance under the *Old Age Security Act* (Canada);
(b) income assistance under the *Employment and Assistance Act*;
(c) disability assistance under the *Employment and Assistance for Persons with Disabilities Act*;
(d) a war veteran's allowance under the *War Veterans Allowance Act* (Canada).

BC Sample Calculations

$RAI = C + S - CT - UCCB - CI - I - RDSP$

Family unit of 1; no net income; no income tax; no UCCB; no RDSP
RAI = 0 + 0 – 0 – 0 – 0 – 10,284 – 0
RAI = -10,284 (0)
Family unit of 1; net income $42,000 (all earned); income tax $6,300; no UCCB; no RDSP
RAI = 42,000 + 0 – 6,300 – 0 – 25,000 – 10,284 – 0
RAI = 416
RAI * 0.00138889 = $0.58 / day
Family unit of 1; net income $50,000 (all earned); income tax $7,500; no UCCB; no RDSP
RAI = 50,000 + 0 – 7,500 – 0 – 25,000 – 10,284 – 0
RAI = 7,216
RAI * 0.00138889 = $10.02 / day (equivalent to the maximum cap of $300/month with 'earned income')

Note. The information above has not been independently verified for accuracy. No liability is accepted for errors or omissions.



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