

Report on Poverty Reduction Consultations with Spinal Cord Injury BC members and participants

Introduction

Spinal Cord Injury BC (SCI BC) held in-person and virtual (online/phone) small group discussions for our peer members to provide input into the poverty reduction consultations. Our peer staff collected comments from people unable to make the meetings and we also created an online survey for further comments. All consultations were held in late February or in March, 2018. People participated from the Lower Mainland, Okanagan, Northern BC and Vancouver Island. All participants are adults with spinal cord injury or related physical disabilities (some from accidents/illness and some from birth, such as cerebral palsy). Because of the variety of input methods, it's hard to put a firm number on the participants but the largest group had 11 participants and we had numerous submissions from smaller groups and individuals.

Spinal Cord Injury

There are about 15,000 people living with spinal cord injury (SCI) in BC. Causes can be traumatic (motor vehicle accidents, falls, sporting accidents) or non-traumatic (birth defects, diseases, spinal tumour) and the lifelong financial cost of injury are high. SCI affects the entire body and in addition to mobility changes, secondary complications include: bowel and bladder changes, chronic pain, spasticity, fatigue, pressure ulcers, and cardiovascular changes. Individuals with SCI use a variety of medical equipment and supplies to complete daily living activities, be mobile, and maintain health. Accessible housing and accessible transportation are extra but necessary expenses for individuals.

1. What are the issues facing you and people living in poverty right now?

- Costs for: nutrition, hydro, medical equipment and supplies, education, medications, housing, renovations to make homes accessible, repair costs for equipment, adapted vehicles, transit passes, accessible gyms or other accessible sports programs
- Limited work options result in lower income from work and/or use of CPP disability or PWD (which means living in poverty)
- The disproportionate cost of specialized goods and services necessary for people with spinal cord injury as compared to the “regular” market
- Lack of coverage for medical equipment and supplies
- Lack of extended medical insurance coverage
- Extended medical insurance that doesn't fully or even partially cover the equipment and supplies people actually need
- PWD is very low and it is impossible to rent anything, much less anything wheelchair accessible, for \$375 per month
- Lack of subsidized and accessible housing

- Extraordinary costs for basic needs (eg. catheter and related costs simply to urinate) and most people with SCI in BC do not have coverage for this
- Lack of a universal equipment and supplies program, which most other provinces have
- Tax breaks for medical equipment or renovations, for example, only help people who already have employment income
- Lack of choice in where to buy equipment and supplies or where to live because of access to housing or medical services
- Cost of care aides for those who need personal care is not fully covered and services such as housework are not included so people either don't get what they need or they pay out of pocket
- Each pension program and extended medical program covers different things, making it confusing and time consuming to obtain coverage.
- Even for people with extended medical, not everything is covered (eg. van conversions or hand controls are not usually covered) or the program will cover a more expensive power chair, rather than a less expensive power assist device for a manual chair that might better meet the person's needs.
- Coverage for items that would ensure health and prevent disability progression are not covered (eg. many types of medical equipment, recreational equipment, gym membership, nutritious food)
- Government help is only available as a last resort so people spend their savings first before getting help. "Have to be financially screwed" before government will help.
- There is a government expectation that family/friends will help with extra expenses related to disability (including by contributing to trusts) but many families cannot financially assist or people don't have family at all.
- Disincentives to work (eg. clawbacks on income, hard to get back on CPPd if the job doesn't work out, loss of benefits by working part time)
- Had to retire early due to disability, which resulted in a much smaller pension.
- No coverage for dental care
- No legal help when disability-related problems are encountered.
- Have to balance high cost of living close to the centre (eg. in Vancouver) with the high cost of transportation and limited access to medical services when living in other parts of BC.
- Can't be on PWD if spouse works, which means being totally financially dependent on that person and not having the extended medical coverage people on PWD get.
- Having to reuse medical supplies (eg. catheters) because I can't afford to buy more.
- Choosing food vs. medical supplies.
- Lack of coverage/high costs for essential therapy such as physio or massage that would help me to be healthier
- Disability symptoms (eg. fatigue, pain) change daily, making it impossible to hold down a regular job.
- No availability of a doctor who will give a medical marijuana prescription has resulted in evictions and jail time, which have impacted finances.

- Lack of coverage for treatments such as medical marijuana.
- Forced to go back to work too soon after injury because of costs of not working has resulted in poor injury recovery and numerous health issues.
- Has a small trust but can't spend it on essential costs because of trust rules.
- Co-ops losing subsidy money, concerns about losing subsidized housing.
- HAFI rules mean that many homeowners do not qualify because the house value limits haven't kept up with property value increases
- Rules for CSIL funding mean some people have to pay out of pocket, even though they already have lots of extra disability-related expenses
- People spend RRSPs and RIFs on disability-related expenses but then income is higher on paper and have to fight to keep home support and other services
- Cost of extended health plans for people with disabilities are prohibitive and even when covered, rules about what is covered are arbitrary.
- People who are too poor to afford a vehicle (or can't drive) rely on HandyDart, especially in the winter, which severely limits options for recreation, comparison shopping, etc.
- A percentage of all new apartments/condos all over the province should be accessible, thus giving choice to people with disabilities, many of whom are low income
- Long waitlists for public care facilities but private ones are completely out of reach
- Taking 80% of a person's income for a care facility means nothing is left for all the many disability-related expenses that are not covered by government, not to mention anything extra that would enhance quality of life.
- Extreme difference in cost between "regular" products and products for people with disabilities (eg. "regular" skis vs. a sit ski or a typical bicycle vs. a handcycle).
- SCI is draining finances towards zero and no help is available
- No ability to relocate to another part of the province because there is no accessible subsidized housing available
- No money for any extras such as tickets for events, recreational activities, gas money after paying for all the required expenses related to disability
- "I have to save for two years to see my family and they're only 6 hours away".
- Need more homecare hours, especially overnight, due to high-level disability but can't get more CSIL coverage and has no way to pay extra while on PWD.
- Can only get one wheelchair funded through PWD, when having both a manual and power chair would actually improve the person's life significantly (eg. manual chair is better in the home, due to accessibility limitations in the home, and in vehicles because of the high cost of a wheelchair vehicle but the power chair is better when moving around the community)
- Low rent apartments usually not accessible so have to pay higher rent in a building he can't afford to get an accessible unit
- Not everyone can work after injury but still need a reasonable income and support.
- Wait lists to see an Occupational Therapist to get a new chair in his area and can't afford to travel to Vancouver to see one there.

- Can't afford to give his long-term CSIL workers a raise because he needs more hours (not covered) as he ages.
- The need to re-qualify for things like CSIL means people can't move to a new health region for better (cheaper or more accessible) housing without risking their CSIL hours and other supports (eg. Vancouver to Burnaby).
- Limited funding for accessible sports for adults in BC or for recreational sports
- Shopping for food at the dollar store because he literally can't afford more or better
- Closest doctor is 30+ miles away and bus goes once a week, can't afford a taxi. Cheap public transportation is needed across the province, not just in the cities.
- Forced to live in the city (Vancouver) for access to medical services but can't afford housing there or parking

2. What would address these issues and help you or others out of poverty?

- Coverage for medical equipment and supplies (most provinces have programs for this already and we can adopt them here)
- More medication coverage and lower deductibles, including more coverage for seniors
- More tax reductions/incentives to cover the extra costs of disability, including refundable ones so that people with low incomes can benefit
- Raise PWD rates
- Stop clawing back CPPd from PWD.
- More CSIL hours for people with high-level disabilities and more money per hour
- Free transit passes for people with disabilities
- Free parking for people with disabilities
- More employment incentives to hire people with disabilities (government could role model this by increasing its hiring first)
- Cover medical travel (TAP is not sufficient)
- Relax the rules on what is covered by the Ministry for equipment and supplies (eg. better wheelchairs, recreational equipment)
- Cover catheters and other incontinence and bowel supplies for everyone who needs them, not just people on PWD
- Incentives to work (eg. don't claw back earned income, cover equipment/supplies for part time work)
- Guaranteed annual income
- Don't force one spouse into poverty or bankruptcy to pay for the care needs of the other spouse
- Pay for prevention (eg. pay for a wheelchair cushion to prevent a more costly pressure sore). Sometimes paying for a higher-quality product may cost less in the long run if it prevents other health issues from developing (eg. power assist for manual chairs to protect the shoulders from overuse)
- Make it easier to transfer CSIL hours and other care from one health authority to another

- More subsidized and accessible housing, with choice in unit size and location to suit individual needs
- Portable rent subsidy for accessible housing
- Expand SAFER to younger people with disabilities and people on PWD
- Cost of medical travel higher for people with disabilities because may be a need to have a companion/caregiver along or to rent equipment, such as a hospital bed or lift system for the hotel room
- Companies like Greyhound and BC Ferries should give the disability rate without the card (which would eliminate the need for doctors to spend their valuable time signing for these programs)
- Support co-ops to maintain or expand current subsidies to members
- Government should cover the cost of a van conversion
- Provide incentives to companies to hire people with disabilities. Educate employers on the many things people with disabilities can do.
- Offer training or financial assistance after SCI for learning a new profession
- Higher disability exemption in the taxes
- Shouldn't have to pay city taxes on services and facilities he can't physically use (eg. inaccessible venues)
- Cover dental care for everyone below a certain income level (not just people who are on PWD)
- Cover costs like basic home maintenance for people with disabilities because, unlike able bodied people, we have to contract out even minor repairs
- Provide subsidies for the extra costs that people with disabilities have; just because we have worked for some years doesn't mean we can afford these higher costs
- Cover costs like community physio and occupational therapy, massage, chiropractor, etc. so that people with disabilities can maximize recovery and health
- Cover home renovations after injury-HAFI is too restrictive and the process takes too long
- Government should fund people to work from home
- Write off student loans for people with disabilities because working and studying at the same time is very difficult.
- There should be a section of WorkBC specific to people with disabilities as the staff don't understand the challenges of helping people with disabilities to find work
- Assess people individually for funding of medical equipment and supplies as some people need a lot more help and expensive equipment
- Help with nutrition and supplements cost for people with SCI
- Has money in an RDSP but can't take it out and starving today-make the rules more flexible
- More help for childcare costs for people with disabilities
- Simplify processes so people don't have to stress all the time about asking for basic help and fear being rejected. Don't make people re-qualify for help every few years, as SCI is permanent.
- Fast track people with disabilities for housing

- Rebates on paying doctors for medical letters and forms, which are needed to qualify for every program out there
- People with disabilities shouldn't pay any taxes at all, even if working, because of the cost of all the necessary products and services not covered anywhere else
- Have long term care facility options for younger people with disabilities so they can live together, rather than with seniors with dementia who are many years older
- Politicians and public servants should have to experience what people with disabilities do and live on the same amount of money to understand better
- Understand that not everyone can work with a disability but still need support and to not live in poverty
- Need cost of living increases on pensions (CPPd, PWD, etc.)
- Implement information from disability white paper from a few years ago
- Ask people with disabilities (and people in poverty) when implementing new policy
- Individualized funding for personal supports and equipment, without means testing
- Don't increase carbon tax for people with disabilities because a vehicle is essential to traveling around the community
- Make all new buildings, especially housing, accessible. Right now the only options are very expensive because there are so few of them
- Reduce fees for community events and venues for people with disabilities
- Reduce income tax for people with disabilities
- Reduce taxi fares for people with disabilities
- Require fitness facilities to be accessible (including exercise equipment)
- Hire wheelchair users to vet plans for buildings, sidewalk access, etc. into buildings and have them train other staff on why these things matter
- Fund scooters for people with disabilities/seniors who need them
- Don't outsource HandyDart to a private company for profit.
- Hire SCI BC to create a yearly breakdown of the actual costs of having SCI (equipment, housing, medications, etc.) gathered from people with SCI to help the government understand the extraordinary costs
- Duplicate programs from other provinces/countries here to better support people with the extra costs of having a disability
- Allow someone on PWD to keep their benefits and coverage when marrying or living with someone who is working
- Each person on PWD should have a case worker so they don't have to keep re-explaining their story each time. Increase staffing at offices to reduce wait times and allow in-person service.
- Individualized funding, lump sum payments based on need per year, so that people with disabilities can choose their own medical equipment company or other provider and choose the equipment or supplies that they know work best for them.
- Make disability supports a federal program like OAS, topped up by the province of residence where cost of living is high, thereby giving people control and choice over their lives.

Because we gathered data from a number of individual and group sessions, staff consultation with our members, and online surveys, we could not have individuals set priorities with all of the above information. However, some clear themes emerged and we were able to identify the top three solutions:

1. Raise PWD rates and stop clawing back CPPd payments
2. Create a universal equipment, medical supplies, and pharmacare funding program for all citizens. There could be means testing for a portion of the cost for high income earners but many people should qualify for full funding.
3. Immediately create more subsidized and accessible housing and provide coverage for home renovations and portable rent subsidies.

In addition, our members identified some key information they would like government to know about SCI:

- All speciality or medical products are more expensive than the equivalents used by people without disabilities.
- The cost of meeting basic needs goes up significantly after an injury and many people do not have full or even partial help with this.
- Many people spend all their savings on these high costs and still don't qualify for help.
- Not everyone has family who can contribute financially or by doing chores the person with a disability can no longer do.
- Not everyone with a spinal cord injury uses a wheelchair but people with SCI will have higher costs after injury for other equipment and supplies, even without using a wheelchair
- Fighting to get coverage every time something is needed is exhausting, both mentally and physically
- Many things are not covered under our healthcare system but are medical expenses
- People with SCI are the experts on SCI but have to live with policy and equipment coverage decisions made by others
- Daily activities take a lot of energy after injury and so does advocating for coverage; there may not be any energy left for employment.
- Preventative care and coverage is more fiscally sound than paying for a more serious problem once it has developed
- People with SCI have many skills but need support to realize potential