

Disability With Possibility

What We Learned from
Disabled People Across
Canada on Shaping the
Canada Disability Benefit



A plain-text version of this report is available to download at disabilitywithoutpoverty.ca/shape-the-cdb-final-report disability without poverty le handicap sans

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Statistics on Disability and Poverty in Canada

DID YOU KNOW?



16.5%

of disabled people in Canada live in poverty. This is more than 1.5 million people.¹ **27**%

of people in Canada are disabled. This is approximately 8 million people.² 41%

of people who live in poverty are disabled.³



89%

of Canadians said that disabled people should not live in poverty.⁴

No provincial or territorial disability assistance payment raises people above the poverty line.5

PURPOSE & GOALS

The Shape the CDB project was aimed at helping the government learn and understand the needs of disabled people.

We did this by reaching out to communities of people with disabilities and making space for their meaningful input.

Our goals were to:

- a. Connect with many disabled people across Canada to understand their views.
- b. Make special efforts to include people with disabilities who are often overlooked and left out of important decisions.
- c. Share widely what people with disabilities are experiencing and their suggestions for the Canada Disability Benefit.
- d. Build a community of disabled people in Canada and work together to eliminate poverty for people with disabilities.



WHAT WAS THE SHAPE THE CDB PROJECT?

In September 2020, the federal government said that they would make a new benefit called the Canada Disability Benefit (CDB). The CDB would reduce poverty and support the financial security of disabled people.

In response, Disability Without Poverty launched this project to assist the government in understanding the needs of disabled people by reaching out to disabled communities directly.

PHASE 1

ONLINE SURVEY

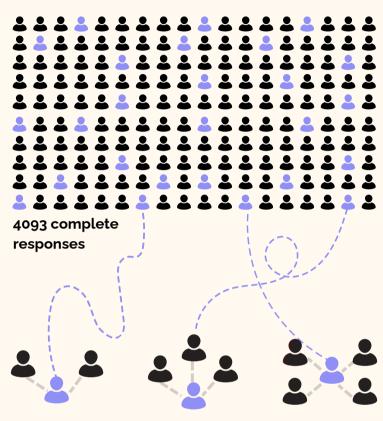
We used an online surveying tool and received the views of over 4000 disabled people. This survey asked about the values and issues that disabled people care about.

PHASE 2 PEER-TO-PEER CONVERSATIONS

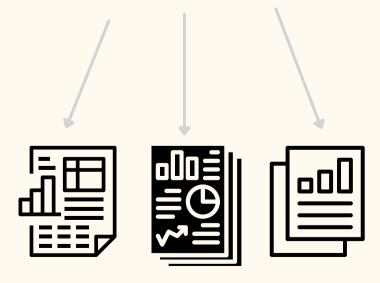
In the peer-to-peer action weeks, almost 300 people with disabilities participated in over 50 in-depth conversations about the CDB.

PHASE 3 REPORTS & RECOMMENDATIONS

The third phase of the Shape the CDB project is the publication of three project reports. These reports will be delivered to the Government of Canada, showcasing what people with disabilities need from the benefit so they can live with more dignity, autonomy, power and possibility.



>50 small group conversations

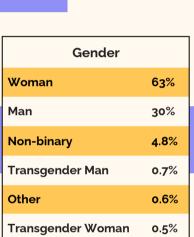


3 reports

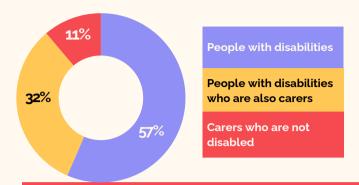


WHO WE REACHED - PHASE 1 ONLINE SURVEY





Prefer not to answer



Nearly one in three people with disabilities who responded to the survey is <u>also</u> a carer to a person with disabilities.

Annual Incom	ne
Less than \$24,000	62%
\$24,000-\$40,000	14%
\$41,000-\$60,000	8.6%
\$61,000-\$100,000	7.2%
More than \$100,000	3.5%
Prefer not to answer	4.5%

Age	
Under 18	0.5%
18-35	19.6%
36-64	72.5%
65+	7.0%
Prefer not to answer	0.4%

Equity-Seeking Representation

1.5%

Disabled people with intersecting identities are often left out of consultation and decision making.

The respondents to this survey identified as follows:

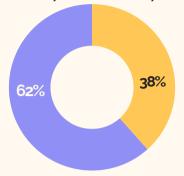
18% 2SLGBTQIA+
15% racialized
7% transgender, non-binary & other
6% Indigenous
4% immigrants, newcomers & refugees
4% previously incarcerated
1% currently living in an institution

Ontario	40%
British Columbia	20%
Alberta	15%
Quebec	9%
Manitoba	4.5%
Nova Scotia	4%
New Brunswick	2.6%
Saskatchewan	2.3%
Newfoundland and Labrador	1.6%
Prince Edward Island	0.5%
Yukon	0.2%
Northwest Territories	0.1%



WHO WE REACHED - PHASE 2 PEER-TO-PEER CONVERSATIONS

All 298+ participants in the Shape the CDB peer-to-peer process identified as disabled. 38% of them also identified as a carer to somebody with a disability.



Not carers
Carers

OTHER INTERSECTIONS

55 participants have been unhoused or precariously housed
53 participants are under the 2SLGBTQIA+ umbrella
52 participants live in a rural or remote place
32 participants live or have lived in an institution
8 participants are or have been incarcerated
5 participants are refugees
3 participants have lived in Canada for less than 5 years

Gender	
Woman	57%
Man	29%
Non-binary & Gender non-conforming	8.6%
Transgender Man	1.3%
Transgender Woman	< 1%
Prefer not to answer	2.2%

Annual Incom	ne
Less than \$20,000	54%
\$20,000-\$40,000	30%
\$41,000-\$60,000	8%
\$61,000-\$100,000	7%
More than \$100,000	< 1%

Age	
Under 18	< 1%
18-24	4%
25-44	39%
45-64	44%
65+	10%
Prefer not to answer	2%

Ontario	27%
British Columbia	21%
Alberta	16%
Quebec	12%
New Brunswick	8%
Nova Scotia	5.7%
Manitoba	3.4%
Saskatchewan	3.4%
Newfoundland and Labrador	2%
Prince Edward Island	1.7%

Ethnic and Racial Background	
Black (e.g., African, Afro-Caribbean, African-Canadian descent)	3.54%
East/Southeast Asian (e.g., Chinese, Korean, Japanese, Taiwanese descent; Filipino, Vietnamese, Cambodian, Thai, Indonesian)	2.21%
Indigenous (First Nations, Métis, Inuk/Inuit)	10.18%
Latino (e.g. Latin American, Hispanic descent)	2.65%
Middle Eastern (Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish)	3.98%
South Asian (e.g., Indian, Pakistani, Bangladeshi, Sri Lankan, Indo- Caribbean)	3.10%
White (European descent)	66.81%
Multiple answers	2.21%
Prefer not to answer	5.31%

KEY FINDINGS

01	Urgency
I	
02	Dignity
I	
03	Added Costs
I	
04	Inclusive Eligibility
I	
05	Simple Application
I	
06	A Fair Benefit
I	
07	Keep Disabled People Involved
	

1. Urgency

Disabled people overwhelmingly agree that the CDB is needed urgently. The current situation is described as critical, with some facing extreme hardship and life-threatening challenges. Several participants expressed concerns that disabled people are choosing medical assistance in dying (MAiD) due to experiencing poverty and intolerable living conditions. There is a shared sense of anger and disappointment at the pace of the government's action. This is compounded by the rising costs of living across the country.



66

40% of disabled Canadians live in dire poverty. It is unconscionable that some must avail themselves of MAiD because they can't live in dignity or a modicum of comfort.



TED R.

Ted is a retired academic from Fredericton who has advanced MS.



Having this federal disability [benefit] would actually help me keep a roof over my head. Keep in mind that people on disability are one paycheck away from being homeless. I CANNOT emphasize that enough.



KRYSSY B.

Kryssy has multiple disabilities. Her main disability is mild Cerebral Palsy (brain injury from birth). Kryssy also lives with mental health related disabilities.



2. A Life with Dignity and Possibility

97% of survey respondents agreed that a successful CDB would actually lift disabled people out of poverty and provide an income that is above Canada's Official Poverty Line.

The CDB is seen as a transformative opportunity for disabled people. It would allow them greater financial independence and promote their opportunity to live with dignity.

Disabled people are often hindered more by their poverty than by their disability. Financial assistance through the CDB would permit people with disabilities to participate more actively in society and contribute to the economy.

Agree

97%

Prefer not to

Disagree

answer

1.5% 1.5%

A successful CDB would actually lift disabled people out of poverty and provide an income that is above Canada's Official Poverty Line.





I'm lucky, I have family who helps or else the \$1100 a month I currently receive would not be enough to live on. I'm too sick to enjoy life so even with a million dollars I'd be doing the same thing as I am now to be honest. That being said, the CDB would allow me to stop putting pressure on others. It would allow me to pay my fair share.



MIKE C.

Mike is a former science teacher, former weight lifter and former golfer. Mike is currently a musician and cut down on his hobbies due to COVID-19 and chronic fatigue syndrome.

Respondents shared a powerful call to recognize the potential of disabled individuals. They emphasize the need for systemic change that genuinely acknowledges and supports the diversity and possibility of all people with disabilities.

A well-funded CDB could provide disabled people with the support they need to manage their cost of living, to break free from the constraints of poverty and to live proud and productive lives.



1st & most important is that it is both properly funded AND not going to create a clawback from another disability benefit whether provincial or national. This benefit will enable me to buy some medications (not all); eat better quality food & continue to pay my rent. It will also contribute to me dreaming about the possibility of a future where I'm a valued & contributing member of society.

— 99 —— PAULA L.

Paula is a first generation immigrant to Canada from South America and does not identify as Latin. She lives with invisible disabilities and chronic pain. Paula is the mother of 3 young adults.

3. The Added Costs of Disability

Disability brings a lot of additional living expenses that must be considered when determining the amount of the CDB. Extra costs can push individuals with disabilities into poverty or prevent them from escaping it. This is especially critical for those who cannot work or whose disabilities incur very high expenses.

Almost 94% of survey respondents agreed that the additional costs of disability should be factored into calculations on how much the CDB should offer. Over 90% of respondents also agreed that the cost of disability should take into account costs related to food and groceries, housing, disability-specific equipment, over-the-counter and prescription medications, treatments such as physiotherapy, massage, naturopath, osteopath and care providers.

Other extra costs of disability were also raised. These include: medical supplies and equipment, transportation and vehicle modifications, medications and healthcare providers not covered by health insurance, special diets and food, disability-related modifications, care and personal support, mental health services, assistive technology, personal protective equipment, access to sign language interpreters and many other forms of specialized needs.



This benefit would help to purchase food, clothing and medical care that is not covered by OHIP. It would assist me in obtaining a healthier lifestyle and a safer home environment. A service dog would be a tremendous asset for me if funding could be received.



REBECCA M.

Rebecca is a mother of 2 who suffers from a permanent disability. She lives in Ontario. She enjoys baking, reading, and spending time with family, friends and her pets.





I feel that the CDB would really make a huge impact on my life. As a person who lives with low vision and is not able to drive, it can get quite expensive to travel.... By having access to the CDB this can minimize my travel and delivery costs for items I may need. Also, as a person with a disability I am also in need of extra needed assistive equipment that can be essentially costly for me. Ultimately, this can put me at an equal level to my sighted counterparts.



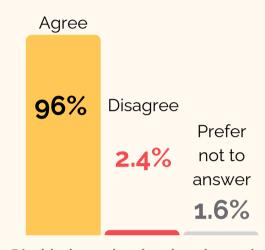
BERNARD A.

Bernard is a Black male of Ghana West African descent who lives with low vision. He is a registered social worker who advocates for the discussion of race and disability.

4. Inclusive and Reasonable Eligibility Requirements

96% of survey respondents agreed that disabled people who already receive a federal, territorial or provincial benefit should get immediate access to the CDB.

Only 53% of survey respondents agreed that anyone who identifies as a disabled person should get access to the CDB. Regarding the mechanism to prove disability, some people felt that applicants should be able to self-diagnose as disabled. This would help avoid bureaucratic hurdles, additional strain on the healthcare system and potential disqualification for those with invisible or episodic disabilities. However, it was also felt that a healthcare provider should be charged with establishing an individual's eligibility or confirming a self-diagnosis.



Disabled people who already receive a federal, territorial or provincial benefit should get immediate access to the CDB.



I would be able to buy fresh food tailored to my kidney diet which I can't afford right now. It would be nice to not lose sleep worrying about where the next meal is coming from. I will also be able to afford transportation to dialysis. Sometimes I need to miss treatment

as I cannot afford to get there.

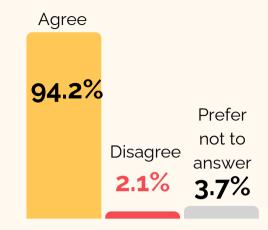


STACIE B.

Stacie is a 46-year-old mother of 1 son. She has been on dialysis for kidney failure since 2018 due to a rare autoimmune disease. She loves long walks with her dog and cuddles with her cat.

4. Inclusive and Reasonable Eligibility Requirements

There was strong support for a flexible and inclusive definition of disability. This is meant to account for the diverse and often changing nature of disabilities including invisible, episodic and temporary disabilities. Over 94% of respondents believe that disabled people whose level of disability changes must be able to access the CDB as their situation changes too.



Disabled people whose level of disability changes must be able to access the CDB as their situation changes.

Generally, people felt that eligibility considerations should be comprehensive. The federal government should not limit an applicant based on their employment, income or citizenship status. In order to promote independence, eligibility should be based on an individual's income and not connected to the income of one's family or spouse.



A well organized and funded CDB could change my life. Living so far under the poverty line is exhausting, trying to hustle to have enough money to pay rent frequently makes my disability worse. I would love to be able to pay for health treatment, decent food, help doing the housework that makes me ill. I'd love to be able to leave my house more and be with my community and have a social life, but public transport isn't accessible for my disabilities and everything else is too expensive. My disability community are some of the most incredible, generous, kind and creative humans I've ever met and Canada can only benefit by helping us stay alive, well and able to participate in the world.

- 66 –



INDIGO M.

Indigo is a gay (and happy) weirdo based in Montreal. They live with chronic post concussion symptoms, migraines, seizures, lots of plants and their dog Muesli.

5. Simple and Accessible Application Process

Many respondents believed that since the process of applying or proving eligibility can be difficult, painful and expensive, individuals already receiving federal, territorial or provincial disability benefits should be automatically enrolled in the CDB.

Approximately 94% of respondents thought the application should be available through existing government services and portals and come preloaded with the information the government already has access to. This would simplify the task and make it much more accessible for people with disabilities.

Over 95% of survey respondents indicated they want an application process that is easy, seamless, fast and simple. The form should be written in plain language and available in multiple languages as well as various accessible formats. Over 96% of respondents want the application to be available online and accessible any time of year.



It would give me the resources to buy special foods I require, a cleaner for my house, medications that are out of reach, and mobility equipment. It would also make it possible to go to massage therapy, and occupational therapy. Also, it would help instill self resilience and self confidence.



DAWNA S.

Dawna is a 55-year-old woman who lives with Multiple

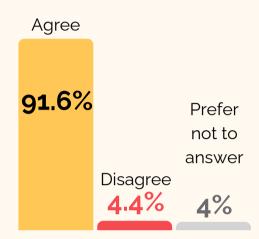
Sclerosis. She lives in beautiful Fredericton, New Brunswick.



5. Simple and Accessible Application Process

The application process should consider and accommodate the unique challenges faced by prospective applicants. This includes those without permanent housing, who do not have a family doctor or who face transportation barriers.

Overall, it is important for the application process to be mindful of the realities and lived experiences of disabled people who need these supports. The entire application system should be barrier-free and designed to help applicants, treating them with respect and offering useful guidance.



The CDB should partner with disability organizations to assist with the application process.



?

Receiving the CDB would make such a difference between struggling to exist and having a life worth living. People shouldn't have to decide between paying rent and buying groceries.



TAMMY H.

Tammy is a 55-year-old single woman with multiple medical issues including lipedema, fibromyalgia and Ramsay Hunt Syndrome. She lives in Nova Scotia and loves to paint, thrift shop, up-cycle, and spend time with her cat, Archie.



The CDB would have changed my life if I had it during my working and child-raising years. Instead, I needed to work constantly and was tired all the time. Disabled people have a broad range of needs, many of which could be met with extra funds to support our individual conditions. It may not cure us but our quality of life would improve with a realistic and respectful CDB.



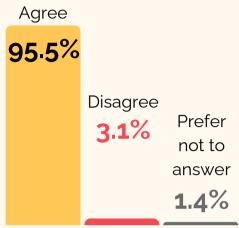
ARLO Y.

Arlo is a Saskatchewan Cree mother and grandmother who lives with an incurable neuro-muscular disease and 3 support cats.

6. An Equitable and Responsive Benefit

The CDB must be responsive to the lived realities of disabled people. This includes adequately addressing the higher cost of living, the challenges of finding and keeping steady employment and the additional financial burdens that come with disabilities.

The CDB cannot be a one-size-fits-all solution. Disability needs and expenses vary significantly from person to person. This variation is due to different disability types and severity levels, as well as individual circumstances including location, employment, family status and many other factors. The benefit must be flexible and indexed to inflation to maintain its usefulness as financial environments shift.



The CDB should be responsive to the changing circumstances of applicants.



With adequate funding, a Canada Disability Benefit would revolutionize my life, making basic necessities accessible rather than luxuries. It would alleviate the barriers that currently hinder my daily existence, offering a newfound ease and comfort.

ANDY F.

Andy is a 58-year-old filmmaker with complex posttraumatic stress disorder (c-PTSD) from British Columbia.

6. An Equitable and Responsive Benefit

The benefit should also be mindful of the additional financial risk faced by disabled people with intersectional identities such as newcomers and refugees, members of the 2SLGBTQIA+ community, Black people, racialized people, Indigenous people and women.

It is imperative that the CDB be offered on top of territorial or provinvial benefits and that disabled people who are eligible for the CDB do not suffer clawbacks to any other assistance they are receiving.

The CDB should be between \$2000 and \$3000 per month.





Because I don't qualify for provincial funding at the moment, a lot of supports (therapy, noise cancelling headphones, etc) are financially out of my reach, even though I require them. I am also finding keeping full-time employment difficult as I don't have enough time to recover from my days. Having a funded benefit would allow me to reduce some of my work hours so that I can balance my mental well-being with my job.



BRUCE P.

Bruce is the Autistic Advocate for Autism Canada and lives in Vancouver, British Columbia. He toured the world for 40 years as a professional musician, composer and music director.

7. Ongoing Inclusion of Disabled People

Almost all survey respondents (98%) agreed that the government should include people with disabilities in developing, implementing and monitoring the CDB program.

The varied lived experience of people with disabilities is essential in the design, management and delivery of the CDB. There is a perceived lack of understanding and empathy from policymakers and service providers towards the challenges faced by people with disabilities. Therefore, the policy and program must include and represent the perspectives of those directly affected. Since the experience of disability can be so different from person to person and can change over time, it is important to include many different disabled people in an ongoing manner.



Having a proper disability benefit could lift me and my family from a life below poverty and allow us the opportunity to be a more productive part of society. It is hard to tell 3 young kids they cannot have or do things all their friends get to because their dad is disabled. I would use it to help with costs and to put [money] aside for post secondary.



THOMAS C.

Thomas is a 43-year-old father of 3 young children. He has lived all over Alberta and wants to feel like he is doing the best he can for his family.



WHAT POSSIBILITIES WOULD THE CDB PROVIDE?

In Phase 3 of the project, the Shape the CDB team reached out to project participants and asked them to share how the CDB could change their lives.

What would you be able to afford? What would you be able to do?



Spending the CDB

The CDB would significantly improve the quality of life of disabled people.



1. Health and Nutrition

The CDB would help people afford special diets for their personal health needs and better quality food in general.



2. Medicine, Medical Treatment & Equipment

The CDB would offer funding for life-saving equipment not covered by insurance, medications, physiotherapy, massage therapy, occupational therapy and other health services like acupuncture or naturopathic treatment that respondents currently cannot afford.



3. Housing Stability

The CDB would help cover rent and mortgage costs, in some cases preventing homelessness or facilitating independent living.



4. Mobility & Transportation

The CDB could help people access necessary transportation for medical appointments, work, social engagements or errands, thereby enhancing their health, independence and participation in community life.



5. Personal Care

The CDB would allow for expenses like haircuts, new clothing and other personal needs that contribute to a sense of dignity and self-confidence.



6. Financial Security & Planning

The CDB could enable some people to gain greater financial stability and set aside money for future needs, such as their senior years, education for children or short trips.



7. Social and Community Participation

The CDB is seen as a pathway to greater social involvement, allowing for expenses related to community participation, hobbies or simply being able to afford to do things for fun. Beyond mere survival, the CDB could help disabled people and their families actively and pleasurably participate in society.



8. Independence

The funding offered through the CDB would allow many disabled people independence and allow them to pull out of a constant struggle to survive poverty and instead consider what their life could be. The CDB would fund optimism and possibility.

CONCLUSION

This process included the perspectives of over 4000 disabled people through the survey and 300 disabled people through the peer-to-peer process. The findings are clear. A fully funded CDB is needed urgently. This benefit would make a huge impact in the lives of people with disabilities, now representing over a quarter of Canada's population.

This benefit is critical to help disabled people pay for the basic necessities of life, manage the extra costs associated with disability and have a chance to live productive lives full of dignity and possibility.





A CDB of \$3000/month would allow me to afford disability-accommodating rentals, medical transportation, medical procedures that aren't available in Canada that can cure my illnesses so I'm not disabled anymore, and independent safety from crime & abusers. Being disabled has made me a target for physical, mental, property, financial, social, sexual, emotional, mental, animal, medical, authority abuse. Being reliant on failed systems costs us more and makes us unable to give-back to the economy.



PRESTON P.

Preston (they/them) is an intersex, genderfluid, two-hearted middle-being with mixed ethnicity and heritage living as an impoverished survivor of domestic/family violence with 78 diagnoses that disables them. 20 of them are conditions that lower quality of life and the 1 called synesthesia is their joyful "superpower"!



The Canada Disability Benefit would enable me to be more independent, and secure my future financially. Currently I am 29 years old and still living with my parents. I have Cerebral Palsy and though I am fully capable of living on my own, my mobility challenges make the job market a little smaller for me. If I got this new benefit, it would make living in my own place a bigger reality for me. I have loved living with my parents, but I also would love the independence of having my own place. It would make me feel a bit more grown up. I just want to live out



my full potential, and have the means to do that.

KATE L.

Kate is a white 29-year-old young woman living with moderate Cerebral Palsy. She lives in beautiful Invermere, BC, and loves being outdoors and active with family and friends.

PHOTOS AND CAPTIONS

The photos, quotes and self-description captions featured throughout this report were submitted by participants of the peer-to-peer process. Each participant was offered a small honorarium for this contribution.

SOURCES

- p. 2 ¹ Disability Without Poverty. 2023, <u>Disability Poverty in Canada: A 2023 Report Card</u>. (PDF).
- p. 2 ² Government of Canada, Statistics Canada. "<u>Canadian Survey on Disability,</u> <u>2017 to 2022.</u>" The Daily, 18 Dec. 2023.
- p. 2 ³ Government of Canada, Statistics Canada. "<u>Insights on Canadian Society Low Income Among Persons with a Disability in Canada.</u>" Low Income among Persons with a Disability in Canada, 11 Aug. 2017.
- p. 2 ⁴ Angus Reid Institute. "<u>Canadians Concerned about Disability Poverty, on-Board with Proposed New National Benefit.</u>" Angus Reid Institute, 2021.
- p. 2 ⁵ Laidley, Jennefer, and Mohy Tabbara. Welfare in Canada, 2022, 1 July 2023.

LINKS

For more information about the Shape the CDB project by Disability Without Poverty please visit our website at disability without poverty.ca or follow us on social media.

Sign up for our newsletter at <u>disabilitywithoutpoverty.ca/newsletter</u>.





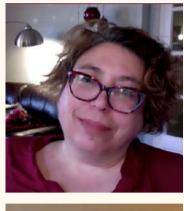






Please read the full report from the Shape the CDB Online Survey at https://www.disabilitywithoutpoverty.ca/shape-the-cdb-phase-1/

Please read the full report from the Shape the CDB Peer-to-Peer Conversations at https://www.disabilitywithoutpoverty.ca/shape-the-cdb-phase-2/

























Murielle is 59-year-old woman with Spina Bifida and Scoliosis, advocate, on & off artist and enjoys graphics and communications. She is the founder of the New Brunswick Coalition of Persons with Disabilities.

Ruby is a 24-year-old girl with multiple physical and cognitive disabilities. She lives in Ontario, has a passion for fashion, and enjoys photography and design.

Angela is a 41-year-old mother of one from Georgetown, PEI. She has Complex Regional Pain Disorder, Endometriosis and Disc Protrusion in multiple areas of the spine. Due to her disability, she has never had a place to call her own and has struggled to make ends meet most of her adult life.

Tarah is a white auntie with a disability who lives in Grande Prairie, Alberta, and loves ♥ music ₺ Tom is an adult with high-functioning Autism, and is an advocate for acceptance of people on the autism spectrum.

Heather is non-binary 54year-old. She is queer and has multiple mental and physical disabilities, yet you'd not know it to look at her. She was born and raised in Alberta, has travelled the world and is now back in Alberta. She is almost constantly in a state of housing precarity.

Samantha-Anne is a 60-year-old woman from a rural community in SW Manitoba.

Melinda is a 51-year-old wife and mother who is the primary support for her family. She works with people who have physical disabilities and brain injuries.

Sandra is a 57-year-old Indigenous Cree-Métis mother of four now-adults and a grandmother of one. Originally from The Pas, Manitoba, she was born with congenital birth defects including scoliosis, being hard of hearing, and some mobility challenges. She currently resides in Burnaby, BC with her 6 ½ month-old pomsky (pomeranian-husky).

Shelley is a 53-yearold woman from Fredericton NB. She has Multiple Chemical Sensitivity and can only leave her house wearing her respirator, and even then her life is at risk.

Mike is a 30-year-old man who lives with a disability in Alberta, Canada.

Rozina is a 53-year-old with one eye blind and other chronic diseases from Halifax, NS.
Originally born in Kuwait, a Middle Eastern country. Rozina is a mother of 2 girls.

Colin. Cree First Nations. They/them. 2 Spirited. Mildly Autistic.



le handicap