

# Shape the CDB Phase 2 Report: PEER-TO-PEER CONVERSATIONS

Disability Without Poverty's Initiative to Bring the Perspectives of People with Disabilities to Government



A plain-text version of this report is available to download at disabilitywithoutpoverty.ca/shape-the-cdb-phase-2/ disability without poverty le handicap sans

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# 1. Plain Language Summary

In the peer-to-peer process, disabled people had conversations and shared with each other their wants, needs, and hopes for the Canada Disability Benefit (CDB). Most were happy to be asked about the benefit and would like people with disabilities to be a part of creating the CDB and putting it into action.

Almost everybody wants the benefit to happen very quickly, because living with a disability in Canada is difficult and expensive. Right now, things like housing and health care are challenging for everybody, and even harder for people with disabilities. It is more expensive to be disabled. It is harder to get a job. This stress can affect people physically, emotionally, and mentally. As one group shared: "Poverty itself is disabling." Nobody should be poorer because they have a disability.

At the same time, people have hope that the CDB can bring real change. When it is easier to afford the things they need to live comfortably, people with disabilities can have more time and energy to live proud and productive lives. More money can mean more independence and more dignity.

Most of the peer-to-peer participants want to make sure that the CDB is easy to apply for and receive, no matter who they are or what shape their disability or disabilities take. They want a benefit that can work well for everybody who needs it, no matter where they live and who they live with, how much money their spouse or family makes, whether or not they have a job, and what other benefits they have.

People with disabilities deserve to thrive, and this group hopes the CDB can help make this happen.

# 2. Executive Summary

The participants in the peer-to-peer process had substantive and in-depth conversations about their needs, hopes, and expectations for the CDB. They consistently expressed appreciation for being engaged on the topic and hoped the perspectives of people with lived experiences of disability would be integrated into the design and implementation of the CDB in an ongoing manner.

Overwhelmingly, they highlighted the urgency of the need for this benefit and the dire and challenging environments that disabled people are living in across the country. One group of women located in BC and Ontario who all share memory, invisible, and pain-related disabilities noted that "disabled people disproportionately bear the impacts of the failures of other systems and issues such as housing and health care." There was widespread agreement that disability-related poverty must end.

At the same time, they shared a sense of hope that the CDB could bring real change for people with disabilities, providing them 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. As one group of low-income white people from Alberta said, "This is a great and promising program that for the first time will give those with a permanent disability and who are unable to work ... a better chance at living with dignity."

The major challenges that participants raised were around the added costs of living with disability, the obstacles with employability, and the compounding physical, mental and emotional distress caused by the experience of poverty. One low-income duo in Ontario, a South Asian man who has lived in an institution and experienced precarious housing and a Black woman, suggested that "poverty itself is disabling."

Participants generally advocated for an inclusive, flexible, and individualized CDB that encompasses the variety of forms that disability can take. They want a CDB that accommodates the various circumstances that people find themselves in with regard to living situation, family, employment and income status, and other intersectional components to their identities.

While appreciating the need to build a benefit that is financially sustainable, the BC/Ontario group noted that "there is no just future where it remains easier to



access MAiD [Medical Assistance in Dying] than to see a specialist or access the disability benefit." Accordingly, there was widespread support for an application process that is streamlined, accessible, and simple.

As stated by a group from BC and Ontario consisting of transgender people with invisible, mental health, and pain-related disabilities, "disabled people want to live and thrive, and not simply exist." Shape the CDB participants urge the government to develop and implement a CDB that can make this a reality.

### A Note on Quotes

The quotes presented in this report are taken directly from debriefs submitted by field team members from their peer-to-peer conversations. They have been included in their original form—verbatim, maintaining the original tone and style—to faithfully convey the views and experiences of the contributors.

# 3. Purpose and Goals of the Project

In September 2020, the federal government said that they would make a new benefit called the Canada Disability Benefit (CDB). The CDB would go to disabled people who live in poverty.

The statistics about disabled people living in poverty are awful:

- At least 1.4 million disabled people in Canada live in poverty. 1
- More than 2 in 10 people in Canada are disabled.<sup>2</sup>
- But 4 in 10 of the people who live in poverty are disabled.<sup>3</sup>
- Provincial disability assistance payments are below the poverty line.<sup>4</sup>
- When Canadians were asked, 89% said that disabled people should not live in poverty.<sup>5</sup>

At Disability Without Poverty, we believe creating the benefit must:

- Include disabled people in all aspects of the design.
- Get the money into the hands of disabled people as quickly as possible.

We aim to assist the government in understanding the needs of disabled people by reaching out to these communities ourselves.

In response to the government's announcement and to guide the development of the CDB, Disability Without Poverty created the Shape the CDB project. Throughout this project we will:

- Engage with a lot of disabled people in Canada to learn their thoughts.
- Make exceptional efforts to gather perspectives of those people with disabilities who are hard to reach and often left out of decisions.
- Write a report for the government that tells them what people with disabilities think, and share the recommendations people with disabilities have for the regulations, policies, and procedures of the Canada Disability Benefit.
- Create a community of disabled people in Canada and work together to eliminate poverty for disabled people in Canada.

### 3. Purpose and Goals of the Project

### The Shape the CDB Project

We want to answer questions on regulations, policies, and procedures. In other words, we will be looking to get the perspectives of disabled people on:

Regulations: The rules and/or law that will define the standards and requirements of the CDB.

*Policies:* The high level guidelines that help decision-making and action related to the CDB.

*Procedures:* The details of how the CDB would be carried out in terms of access, eligibility, and content.

There are three separate parts to this initiative:

**Part 1** (October 17- November 19, 2023) Learn from almost 5000 disabled people

We asked for the views of 5000 disabled people using an online surveying tool. This survey asked about the values and issues that disabled people care about.

**Part 2** (November 27- December 8, 2023) Peer-to-peer action weeks

A survey is a great way to learn what a large number of people think, but we wanted to ensure we also captured the nuance and depth available from people's lived experiences. We are able to understand more detailed thoughts from people when we engage with them, one-to-one or in small groups. In the peer-to-peer action weeks, more than 50 people with disabilities held conversations with other disabled people in their communities and beyond about the CDB. We provided training to help those who conducted the interviews and a small honorarium to everyone who took part.

### Part 3 (Early 2024)

The third phase of the Shape the CDB project is the publication of three project reports:



### 3. Purpose and Goals of the Project

- The survey report, which shares responses from over 4500 people with disabilities about what they want from the CDB;
- This peer-to-peer report;
- The Shape the CDB capstone report, which links the data from the survey and the peer-to-peer report to ensure that the government can access a more complete picture about what a great number of people with disabilities, from many different walks of life, need from the benefit so they can live with more dignity, autonomy, power, and possibility.

# 4. About the Peer-to-Peer Process

### a. What is the Peer-to-Peer Process?

The Shape the CDB peer-to-peer process occurred between November 27 and December 15, 2023. 100 volunteers living with disabilities in Canada were selected to become "Field Team Members" and asked to host a guided, 30-60 minute conversation with other people with disabilities – friends, family, neighbours, colleagues, and strangers – about the Canada Disability Benefit. Of the 100 selected, 67 were able to complete their conversations. Several people were ultimately unable to participate due to a variety of reasons including COVID, disability-related illness, and competing commitments.

Field Team Members received a Conversation Guide (linked here). This guide was provided to offer context to the process, assist in inviting and hosting conversations, and propose potential topics or questions to facilitate meaningful discussions. Members were urged to host their conversations in a way that felt most comfortable and convenient for them and their group, whether online through video conferencing software, over the phone, in person, or another way. These conversations could take place in whatever language and format was preferred by the participants.

Hosts of these peer-to-peer conversations were encouraged in particular to discuss:

- Eligibility and Application
- The Amount of the CDB
- The Cost of Disability

Some hosts held one or several one-on-one conversations; others hosted larger groups. Field Team Members ultimately held over 90 conversations with more than 200 people with disabilities across Canada.

To share what they learned from their conversation(s) with the Shape the CDB project team, Field Team Members were sent a "Debrief Tool" (questions linked here). This tool included 21 questions to help Field Team Members synthesize the perspectives of their group members and to surface major items of agreement, tension, and importance. The Debrief Tool was offered in French



and English with the option to read or listen to the questions and to record responses by text or audio. Field Team Members were also encouraged to record their conversation and to share the recordings with the Shape the CDB Team, though it was not always possible to do so.

Participants in these peer-to-peer conversations were offered a flat \$25 honorarium for their time. Hosts of the conversation were offered variable compensation depending on the number of people they spoke with, but received at minimum \$75.

### b. Outreach Process

Field Team Members were chosen in two ways. The first group included individuals selected by Disability Without Poverty due to their close ties to harder-to-reach demographics. This ensured that diverse perspectives were included in the peer-to-peer process. The second group expressed their interest in participating by filling out an online survey that included some demographic details. Shape the CDB then randomly selected Field Team Members from these volunteers using a lottery system, ensuring the group represented various demographics with particular emphasis on including people with intersecting identities whose perspectives are often left out of policy-making conversations.

### c. Strengths and Weaknesses

The heart of this project lies in the enthusiasm, time, hard work, and effort put in by both hosts and participants during the conversations. Participants approached the project with diverse perspectives, life experiences, subject matter expertise and interests, generously sharing all of this with the Shape the CDB project.

One particular strength of this process was that the conversations were entirely



### 4. About the Peer-to-Peer Process

composed of people with disabilities in small settings. This led to a sense of comfort and community that larger roundtable discussions or other forms of engagement would not have produced.

While the conversation guide offered suggestions and prompts for the discussions, the hosts and participants were free to take the conversation in any direction they wanted. The freedom of this type of process encouraged frank and open dialogue that led to robust insights.

While many expressed interest in participating, some couldn't due to the tight timeline of the process. Having a longer time frame could have likely resulted in a greater number of available hosts and conversations.

Mid-December, being a busy holiday season, posed challenges for some. Factors like hectic schedules, difficult weather conditions limiting mobility, and seasonal illnesses made it tough for people to find time to host conversations and led to some drop off in participation.

This process involves a significant amount of organizational and socialemotional work, which can be more challenging for individuals with specific cognitive disabilities, mental health considerations, and neurological conditions. As a result, some invaluable perspectives were challenging or impossible for the process to comfortably capture.

Although efforts were made to address barriers one-on-one, not every aspect of the project was easily accessible to people across the full range of disabilities. Some tools, documents, and procedures were uncomfortable or impossible for certain participants to use. The project team is committed to the long-term goal of universal accessibility, and the challenges faced will guide improvements in process design and support systems for future work.

# 5. Peer-to-Peer Demographics

### **Demographics**

Both the Field Team Members who hosted peer-to-peer conversations and the interviewees who joined them were asked several questions about their demographics. The option "Prefer not to answer" was always available, and a write-in option was available whenever appropriate.

The hosts and participants of the peer-to-peer conversations all identified as a "Disabled Person, person with a disability or disabilities, a d/Deaf person, a person with a chronic physical health condition(s), and/or a person with a mental health condition(s)". These demographics combine both hosts and guests of the peer-to-peer process. Around 38% of participants indicated that they are also the caregiver to a person or persons with a disability.

The majority of participants – about 60% – identified as cisgender women, while only 28% identified as cisgender men. The remaining 11.5% identified outside these categories, including non-binary, transgender men or transgender women, two-spirit, or as a write-in option not listed.

## 5. Peer-to-Peer Demographics

Conversations took place across Canada and people with disabilities from every province joined in. However, despite strong personalized recruitment efforts in the North, the peer-to-peer process was unable to engage anybody from Yukon, Northwest Territories, or Nunavut. Generally, participation in this process was roughly proportional to provincial populations. Quebec and Ontario were somewhat underrepresented relative to the population, whereas British Columbia and Atlantic Canada were slightly overrepresented.

Geography	P2P Participants (%)	StatsCan (%)
Alberta	16.22%	12%
British Columbia	20.61%	14%
Manitoba	3.38%	3%
New Brunswick	8.11%	2.09%
Newfoundland & Labrador	2.03%	1.38%
Nova Scotia	5.74%	2.62%
Ontario	26.69%	38%
Prince Edward Island	1.69%	0.42%
Quebec	12.16%	23%
Saskatchewan	3.38%	3%

Just over 10% identified as Indigenous (First Nations, Métis, Inuk/Inuit) and 19% identified as racialized. About 70% of participants identified as White (European descent). Just over 3% of respondents selected more than one option.

Group	P2P Participants (%)	StatsCan (%)
Black (e.g., African, Afro-Caribbean, African- Canadian descent)	3.54%	4.3%
East/Southeast Asian (e.g., Chinese, Korean, Japanese, Taiwanese descent; Filipino, Vietnamese, Cambodian, Thai, Indonesian)	2.21%	9.3%
Indigenous - (First Nations, Métis, Inuk/Inuit)	10.18%	5.0%
Latino (e.g. Latin American, Hispanic descent)	2.65%	1.6%
Middle Eastern (Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish)	3.98%	2.9%
South Asian (e.g., Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean)	3.10%	7.1%
White (European descent)	66.81%	73.5%
Multiple answers	2.21%	-
Prefer not to answer	5.31%	-

Participants were most likely to be of low income, with more than half living on an income of less than \$20,000 per year and a further 30% at \$20,000-\$40,000. The highest income bracket available, over \$100,000 per year, was not meaningfully represented in this process.

### 5. Peer-to-Peer Demographics

All employment and student status levels were represented among peer-to-peer participants, including full and part-time employment, full and part-time studies, retirement, unemployment, and being unable to work because of disability. People were able to select more than one option. The largest group, nearly half of all respondents, comprised those unable to work due to disability.

Participants were also asked to indicate if they fit into any of the following categories, to ensure this process represented some hard-to-reach groups often not included in consultation and decision-making. Respondents were able to select more than one response or to write in their own.

Other considerations	#
I am a veteran	1
I live in or have lived in an institution	32
I am a refugee	
I have lived in Canada for less than 5 years	
I am or have been unhoused or precariously housed	
I am under the 2SLGBTQIA+ umbrella	
I am or have been incarcerated	
I live in a rural or remote place	52

Conversation hosts were encouraged to hold their conversation in whatever language best served the group. Debriefs from the conversation were submitted to the project team in English or French.

# 6. Analysis

Peer-to-peer hosts were each asked to complete an online debrief from their conversation to help synthesize the content of their discussions. They highlighted insights and areas of interest on what stood out to them most from the conversations they led, areas of agreement, areas of disagreement, thoughts on eligibility, the application process, the amount of the CDB, and the extra costs of disability.

### 1. What Stood Out from These Conversations?

- a. <u>The urgency of the need and significance of the financial struggles faced</u> by people with disabilities.
- b. The potential of disabled people and their right to live with dignity.
- c. The added costs of disability.
- d. The need for the CDB application to be simple and accessible.
- e. The need for the CDB to be flexible and adaptable.
- f. Equity and fairness.
- g. <u>Better communication about the CDB and inclusion of people with disabilities in policy making and implementation.</u>

Despite their diversity, participants in the peer-to-peer process consistently highlighted many of the same points throughout their conversations.

# a. The urgency of the need and significance of the financial struggles faced by people with disabilities.

Many participants expressed a sense of urgency for the government to act swiftly to improve disability benefits and support systems. The current situation is described as critical, with some facing extreme hardship and life-threatening challenges. Several participants expressed concerns that disabled people were choosing medical assistance in dying due to the living conditions or poverty they were experiencing. Participants often shared a sense of anger and disappointment at the pace of the government's action, which was compounded by the rising costs of living across the country.

One group of low-income white women in New Brunswick shared these emotional words: "We need this benefit now. They were able to put through CERB quickly, but nothing on this bill in years. People are dying, they are facing homelessness, they are starving and they are broken, WE need these funds NOW! ... This is BEYOND URGENT!"

### b. The potential of disabled people and their right to live with dignity.

Participants often expressed frustration with the lack of dignity afforded to disabled people. They advocate for support that does not simply allow survival but rather permits people with disabilities to reach their full potential. This includes financial independence and the opportunity to contribute to society in meaningful ways. It is recognized that if more support were available and if they could overcome poverty to access education and training, more disabled individuals could work and make further contributions to society. As noted by a group of low-income white women in BC, "People want dignity and to have the support they need to reach their full potential. Nothing more, nothing less."

The participants desire a system that helps "AS MANY PEOPLE AS POSSIBLE become not dependent on the system but interdependent with the system."

Respondents highlight the interest that disabled people have to actively participate in both the social and economic opportunities that Canadian society can offer. However, they identify the need for society to overcome existing biases and recognize the diverse ways people with disabilities can contribute. This includes acknowledging the skills, care, and thoughtfulness that come from living with a disability, which can enrich communities.

### c. The added costs of disability.

There's a call to appreciate the lived realities of disabled people. For most, the cost of living goes far beyond the basics of housing, food, and transportation. While respondents agree that the benefit should cover the necessities of life, they also advocate strongly for the benefit to include support for the many



additional costs that are unique to people with disabilities. This encompasses support for medical supplies, caregiving, and many other services and products that are essential for disabled people to live a dignified life. Participants also discussed opportunity costs including lost income from missing work due to illness or the lack of social networks. On this, one group from Manitoba that included two women between 24-44, one white and one Indigenous, noted, "these barriers are not a one time expense nor do they go away as you earn more money. People who are disabled will never be earning on par with their able bodied counterparts due to these added costs or expenses and repercussions from lost opportunities."

### d. The need for the CDB application to be simple and accessible.

Many respondents emphasized the importance of making the application process for disability benefits quick, easy, and accessible. This entails streamlining the process, reducing bureaucratic hurdles, and ensuring the application is understandable and available in multiple formats, including digital, paper, video, and sign languages.

Most participants also suggested that anyone already enrolled in a disability benefit program should be automatically eligible for new benefits like the Canada Disability Benefit, without needing to reapply and without any clawbacks to existing supports. This point was emphasized often.

As stated by one diverse group from New Brunswick that included two people who live in a rural and remote place, and a person who identifies within the 2SLGBTQIA+ umbrella and lives in New Brunswick Public Housing, "The assessment and evaluation process should [be] simple and completely transparent... and should not require onerous re-assessments annually, especially for chronic, disabling diseases."

There is a strong call for the system to be inclusive, taking into account the diverse needs of people with disabilities. Respondents urge the provision of



interpretation services and accessible facilities. They also ask the government and the agents responsible for providing direct support to applicants to consider and be mindful of the unique challenges faced by those with non-physical disabilities.

One group from BC shared the challenges of "having to repeat your circumstances so many times to a variety of different people & feeling like you're being grilled as if you're doing something wrong in seeking a benefit because of a disability."

### e. The need for the CDB to be flexible and adaptable.

Participants frequently identified that the experience of disability is unique and a one-size-fits-all approach cannot work for the CDB. The variation among disability including episodic, temporary, invisible and fluctuations in severity were often raised as significant reasons for the CDB to build flexibility into its criteria for eligibility.

Participants noted that the basic cost of living varies depending on location across the country, including substantial differences for those in rural, remote, and northern environments. Additionally, the extra costs faced by disabled people are highly individualized, further suggesting that the CDB must be adaptable in order to support the needs of those who require this assistance.

One group that included two low-income women from Ontario, one white, one Black, recounted a story of changing circumstances:

"Sometimes your disability can force you to have to change jobs. Sometimes they can force you out of a job. Right? Sometimes your employer will decide that they don't want to have you anymore because you're more of a liability instead of what they would deem to be useful. Right like and I just say that cuz I ran into a situation like that once but like I think that that's very important because if it was equally distributed as a one-size-fits-all. Life situations change and sometimes you need



more help and sometimes you don't need more help and I think that that's a fair assessment that if you are okay, and maybe you don't need that help, somebody else will. And so they should be allowed to."

### f. Equity and fairness.

A recurring theme is the need for equity and fairness in the distribution of the CDB. This includes ensuring that disability assessments are fair and accurate, benefits are not influenced by marital status or household income, and that there's no discrimination based on race, ethnicity, age, or gender.

Some participants shared concerns that those who face additional systemic and structural barriers such as newcomers, members of the 2SLGBTQIA+ community, Indigenous people, women and others are at greater risk. They ask that the CDB ensure that its policies regarding eligibility, application and amount offered consider the specific circumstances of these groups. One group from BC that included a transgender man and an Indigenous man living in a rural/remote area who identifies within the 2SLGBTQIA+ umbrella stated, "Queer and Indigenous people have extra barriers to assessments because of added discrimination in the health care system, and this discrimination is an added barrier towards receiving benefits."

# g. Better communication about the CDB and inclusion of people with disabilities in policy making and implementation.

Many participants expressed a lack of understanding and awareness about the CDB and other disability support programs. There's a need for better communication and education regarding these benefits that are targeted to people with disabilities and accessible to them in a variety of ways.

Several people felt that disability policies and programs do not adequately include or represent the voices of those directly affected. There is a perceived lack of understanding and empathy from policymakers and service providers

towards the challenges faced by people with disabilities. This includes not only financial challenges but also barriers to health care, employment, and social inclusion. As stated directly by the Manitoba group of two women between 24-44, one white and one Indigenous, "this needs to be run by someone with lived experience as a person with disabilities. Most able bodied people come from the bias of being able bodied and will not understand the minute to minute impact that disabilities have on a person."

Connected to this, some participants suggested the establishment of a Federal Office of Disability with service centres across Canada, staffed with disability advocates, to provide guidance and assistance to disabled individuals in accessing various programs and to facilitate application for supports.

### 2. Considerations on Eligibility

- a. It should not be overly burdensome to prove disability.
- b. <u>A flexible and wide-ranging definition of disability should be taken up for the CDB.</u>
- c. <u>Eligibility considerations should be inclusive, not placing limits based on employment status, income level or citizenship.</u>

Questions around who should be eligible and how eligibility should be determined were complex. Generally, participants highlighted their interest in a CDB that is accessible, comprehensive, and responsive to the varied needs of people with disabilities. However, they were also mindful of balancing the need for inclusiveness with practical considerations of policy implementation.

The question of eligibility produced the most divergence amongst respondents.

### a. It should not be overly burdensome to prove disability.

Several interviewees suggested that anyone who has already qualified for a federal, provincial, or territorial disability benefit should be automatically eligible



for the CDB and not need to complete additional application processes. A group consisting of two young women from Ontario who both live with mobility and pain related disability expressed: "being on ODSP is not a life; everyone who already is eligible for provincial disability benefits should automatically be eligible for a federal support program."

While participants had no interest in seeing the CDB program abused or misunderstood, there was some support for self-diagnosis as a means to determine eligibility. This was seen as particularly helpful for those whose disabilities are invisible or not immediately apparent, such as mental health issues or chronic pain. "Sometimes if you have invisible disabilities, it's harder to get out with applications for things like CDB because sometimes doctors or people helping you don't believe that you have disabilities," indicated a group of two lowincome young women in BC.

Part of the interest in self-diagnosis for eligibility is to help manage the overly bureaucratic processes that are challenging to navigate, especially for disabled people, and the added burden on the health care system. Regardless of whether self-diagnosis is permitted, the processes to determine eligibility and to apply for the CDB must be simple, clear, and easily accessible.

Many advocated for a balanced process that also relied on medical professionals to establish an individual's eligibility for the CDB. While medical professionals are largely seen to be able to provide a reliable and objective assessment of an individual's disability, concerns were raised that a purely medical perspective might not fully capture the lived experience of disability, particularly for conditions that are episodic or invisible. One diverse group from BC suggested that "People who self-identify with disabilities [must] go through an attestation process with a peer support worker" to become eligible.

Additionally, the costs and logistical difficulties of visits to a health care provider or having them provide a written form are barriers for many people with disabilities. "We shouldn't have to fill out more forms or have Doctors fill out yet

another form," specified a group from Alberta that included a woman who had been underhoused.

### b. A flexible and wide-ranging definition of disability should be taken up for the CDB.

Many responses highlighted the need for a flexible and inclusive definition of disability, taking into account the diverse and often changing nature of disabilities. One low-income group from BC comprising of a transgender man and an Indigenous man suggested that the CDB must consider "many more different types of disabilities than what is currently recognized."

The majority of interviewees hoped that the CDB would extend eligibility to people with non-permanent or episodic disabilities, recognizing that disability can fluctuate in severity and impact over time. Groups emphasized that all types of disabilities, including physical, mental, emotional and neurodiverse conditions, should be eligible for the CDB. This entails recognizing invisible disabilities. A group from Quebec that included three people who identify as non-binary and have experience with homelessness suggested that the CDB ought to be available to "everyone living in Canada under the poverty line that cannot work full time due to issues relating to health, trauma, injury, mental health, or neurodiversity." One low-income group from Ontario comprising a South Asian man and a Black woman took an even broader approach, suggesting that the CDB should be available to "people experiencing housing, food, income insecurity (using a social model of disability, in part so that the onus and the bureaucracy is not on the individual to prove they are disabled)."

# c. Eligibility considerations should be inclusive, not placing limits based on employment status, income level, or citizenship.

Most interviewees advocated for a comprehensive approach to determining eligibility for the CDB. Overwhelmingly people suggested that eligibility should be based on the individual's income rather than the family's income, highlighting



concerns about fairness, privacy, and the need to respect the autonomy and varied circumstances of individuals with disabilities. Several participants shared a fear of being forced to remain dependent on family or a spouse, as benefits are often tied to household income rather than individual needs. As stated directly by a group from Ontario consisting of a Latino-Indigenous family, "more help needs to be available especially for women who often bear the brunt of clawbacks due to spouse income. When in receipt of provincial benefits women often stay single because of the worry of having to depend on a spouse to support them." This was particularly important to help protect women and gender diverse people in abusive situations.

Many responses indicated that there should be no income cap for eligibility, as income can fluctuate, especially for those susceptible to job loss or unstable earnings due to their disability. Participants generally showed concerns about setting a strict income cap for the CDB, emphasizing the need to consider the high and varying costs associated with disabilities. The Manitoba group of two women proposed "no income cap because income can fluctuate a lot for people with disabilities as they are prone to being laid off." There was a call for a more nuanced approach that accounts for individual financial situations and the unique challenges faced by people with disabilities. That said, there was a recognition of the need to structure the program in a financially sustainable way, and a system of graduated benefits was mentioned by some.

Opinions on eligibility of non-citizens were varied. Some groups suggested that non-citizens, including refugees and immigrants, should be eligible for the CDB. The groups advocating for the eligibility of non-citizens and refugees expressed concerns about the potential marginalization of these populations. They highlighted the need for extensive support systems that recognize the challenges faced by non-citizens with disabilities. However, several groups thought that the CDB should only be available to Canadian citizens and permanent residents.



### 3. Considerations on the Application Process

- a. Simple, accessible and fast.
- b. Individualized and inclusive,
- c. <u>Automatic enrolment for those already on disability benefits and</u> coordination across benefits.

The conversations about the application process identified some of the same themes that arose in the discussion of eligibility. They often highlighted the notion that the process should be streamlined, respectful of the applicants' circumstances, and designed with the genuine intent of aiding those with disabilities. Participants continued to identify just how draining and challenging the process of application can be for someone with a disability, especially those who are living in poverty, facing additional forms of marginalization, or without help and support. They shared that the stigma associated with applying for disability benefits can be a barrier in itself, particularly in communities where there is a lack of understanding or acceptance of disabilities.

### a. Simple, accessible and fast.

Respondents overwhelmingly agreed that the application process must be simple, straightforward, and accessible. It should aim to assist rather than deter applicants, focusing on their needs rather than procedural hurdles. One Field Team Member shared that the people in their group, who were from Ontario, Quebec and BC, many of whom had invisible disabilities, "mentioned that disability applications in the past have not been inclusionary as in they try to look for reasons why not to give people with disability support. We all agreed this needs to change."

This includes having forms in simple language and available in multiple formats (paper, online, digital). The documents must be easy to comprehend, especially for people with reading or learning disabilities. There is a consensus that the process should not require extensive medical records or involve high costs for obtaining them, which can create unnecessary hurdles for many, including already strained health care professionals.



Respondents highlighted the importance of having a quick application and approval process to prevent further financial hardship and stress, especially for those at risk of losing their homes or facing other urgent needs. One group identified a specific concern that "some Doctors don't know what the program requirements are and they don't put enough information on the form. Applications get delayed or need to go through appeals due to this. People can lose their housing or not be able to eat because forms aren't filled out correctly and it delays them from getting money that they need to live."

The need for support during the application process, including help from advocates, social workers or community agencies, was emphasized. This support is particularly crucial for individuals who face barriers such as language, literacy, or cognitive challenges. Many participants identified ways in which they felt poorly treated or misunderstood by government employees and highlighted the need for government agents to be well-trained in the varying needs of people with disabilities.

One group from BC shared that "the process should be as easy & straightforward as possible taking into consideration people with the most barriers. That's the baseline. What currently exists is overwhelming in so many ways that we often end up re-traumatized or worse, give up!"

### b. Individualized and inclusive.

As with most questions addressed in this project, there was a strong emphasis on appreciating that disability is highly individualized and a one-size-fits-all system does not work.

The application process should be inclusive and non-discriminatory, accommodating various types of disabilities, including temporary, invisible, and episodic disabilities. It should also support non-native English speakers and those requiring interpreters.

As many of the potential applicants are already living in poverty, the process should consider and accommodate the unique challenges faced by prospective applicants, including those without permanent housing, who do not have a family doctor, or who face transportation barriers. A group from Quebec that included four people under the 2SLGBTQIA+ umbrella who are all unable to work due to disability suggested that "most people with chronic illnesses don't have a lot of energy for processes that need a lot of executive function and these processes tend to be difficult and require you to fax things and scan and print and remember a lot of details."

# c. Automatic enrolment for those already on disability benefits and coordination across benefits.

Many respondents believed that since the process of applying or proving eligibility can be difficult, painful and expensive, individuals already receiving federal or provincial/territorial disability benefits should be automatically enrolled in the CDB. This includes those receiving the Disability Tax Credit (DTC), CPP disability, or provincial/territorial disability benefits.

Respondents also thought there should be strong integration with existing federal and provincial/territorial systems to avoid conflicts and ensure that eligibility for one benefit does not disqualify from another or result in clawbacks. Many respondents expressed fear that applying for the CDB could make them ineligible for existing benefits or insurance coverage and lead to further bureaucratic challenges. A group from Saskatchewan that included a student who identifies as Indigenous and lives in a rural/remote area suggested that "the CDB needs to be consistent and guaranteed, not come with complicated ineligibilities (i.e. students are ineligible or workers get clawbacks). Consistency and stability of the income without fluctuations will help people live with dignity, autonomy and choice."

### **Outlier Comments**

One group of two women from Ontario, one white and one Black, suggested connecting the CDB application process with a variety of other social service providers, such as outreach workers, addiction services, victim services, counselors, and therapists, to be able to get the application to "marginalized groups that otherwise don't like to deal with some of the government offices that would help them get these benefits."

One pairing of two Ontario women, one Latina and one Afro-Indigenous, who are both full-time students, suggested that the application process could include an interview component "to make it more personal."

Whereas there was general consensus that being approved for a provincial disability benefit should allow a disabled person to be automatically approved for the CDB, one group from Alberta including one man and two women, all white, explicitly suggested that approval "should be independent of provincial benefit approval, keep the province as far away as possible."

Regarding reassessment, the group from BC that included a transgender man and an Indigenous man indicated that they thought that "people should have to disclose if their status changes" rather than reapply.



# 4. Considerations on the Amount of the CDB and the Cost of Disability

### **Top Themes:**

- a. An amount that allows for a dignified standard of living.
- b. Adaptable and flexible.
- c. No clawbacks or disincentives.
- d. Impact of disability on the cost of living.

Overall, respondents are seeking a CDB that is responsive to the realities of living with a disability, adequately addressing the higher cost of living, the challenges with employment, and the additional financial burdens that come with disabilities.

Participants expressed their hope that the CDB would enhance the quality of life of disabled people, not just ensure survival.

Amounts discussed varied between \$1000-\$5000 a month, with the majority landing in the \$2000-\$3000 range. Respondents once again highlighted the urgency of this money and how deeply needed it is by disabled people in this country.

### a. An amount that allows for a dignified standard of living.

Again and again participants emphasized the extra costs that are associated with disability such as medical expenses, assistive devices, transportation and personal care, and the need for the CDB to recognize that the cost of living is higher for a disabled person.

Respondents expressed the need for the CDB to bring people up above the poverty line and cover basic living expenses like housing, food and health care, while also providing some quality of life beyond mere survival. They also



identified a need to be able to prepare financially for potential emergencies and unanticipated expenses.

References were made to the Canadian Emergency Response Benefit (CERB) available during COVID, suggesting that if \$2,000 per month was deemed necessary during the pandemic, similar or higher amounts should apply to those with disabilities.

A diverse group of women from BC and Ontario shared: "The higher this amount is, the better; all of this money will go back into local economies, will be invested in improving recipients' health, and will reduce strain on other programs and resources. This money is not only an investment in disabled dignity and the wellbeing of Canadians; by reducing poverty, it will also reduce subjective experiences of disability."

### b. Adaptable and flexible

A recurring theme was that the CDB cannot be a one-size-fits-all solution. There's a consensus that disability needs and expenses vary significantly from person to person. This variation is due to different disability types, severity levels and individual circumstances including location, employment, family status, and many other factors. To illustrate this point, one pairing from BC of white women who are both parents shared that the CDB "should consider the whole picture including parenting a disabled child that needs home adaptations etc."

Most suggested that amounts should vary based on individual needs and regional cost of living differences. Some respondents discussed aligning the CDB with livable wage standards, which vary by region and take into account local living costs. However, some people argued for a uniform benefit across Canada, citing concerns about fairness and the complexity of administering variable rates.

Respondents agreed that the benefit must be indexed to inflation to ensure it maintains its usefulness as financial environments shift.



### c. No clawbacks or disincentives

There were concerns about provincial/territorial benefits being reduced when the federal CDB is introduced. Respondents advocated for the CDB to be in addition to provincial/territorial benefits without any clawbacks or reductions in financial support from insurance or other providers.

Some participants also suggested that the CDB should not disincentivize work, and income from employment should not lead to a reduction in benefits. The benefit should promote autonomy and independence, particularly in relation to marital status and living arrangements. As stated by a group of three women living in rural or remote areas of BC, the CDB "needs to lift people out of poverty and reduce struggle for basic needs so health and employment can be a focus."

On this note, one group with participants from Ontario, BC and Quebec shared the following specific concerns around clawback:

"We think the Canada disability benefit cannot be vulnerable to clawbacks by any other disability benefits providers, including long-term disability benefits providers, which would not only go directly against the Canada Disabilities' goal of "reducing poverty" and render it null and void, but in many cases, would strictly contribute to the record profits being recorded by multibillion dollar corporations such as private insurance companies. This must be included in the Canada Disability Benefit legislation....

We also agree that the fact that provinces are also expressing a desire to claw back the Canada disability supports the need for sustained and strong advocacy against claw backs. An example of this [is] ODSP clawing back payments if you have the CPPD."

### d. Impact of disability on the cost of living

Participants consistently mentioned the additional expenses that living with disability brings with it and how these extra costs must be considered when determining the amount of money that a disabled person needs on a monthly basis to pull out of poverty and support themselves.

A group of three from Alberta expressed the challenge of assessing all of the extra costs of disability: "How can we determine a cost of disability when we don't have the ability to pay for the additional costs, we just go without many times."

These expenses are wide-ranging and varied including but not limited to: medical supplies and equipment, transportation and vehicle modifications, medications and health care providers not covered by health insurance, special diets and food, housing and home modifications, care and personal support, mental health services, assistive technology, personal protective equipment, and many other forms of specialized needs.

Participants indicated that these 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. A group from Alberta shared this personal account: "Cost of living is becoming exorbitant, even living in city-housing, our rent went up, please let us have some breathing room. I really need new underwear."

### **Outlier Comments**

There were a few noteworthy points that diverge from the main consensus.

While most respondents advocated for a higher CDB amount, a small minority suggested a lower benefit, potentially due to concerns about government spending or the impact on other social programs.

One group of four people in Quebec who are all unable to work due to disability, including three who identify as non-binary, discussed how they wished that supports came from other systems such as accessible housing, free medication, and free transportation. They "think the system should look differently, but it doesn't and so right now we need to be able to cover [these costs in the CDB]."

One pairing of white full-time students in Ontario suggested that the CDB should be based on numbers direct from the CRA in order to "avoid any political tinkering."

Finally, one group of three from Alberta expressly shared their perspective that the CDB must include support for rest, explaining that many disabled people "exhaust ourselves just to get the basics and for some that means that a formal position or a career isn't an option because of how busy we are trying to take care of ourselves - rest is a privilege that so many don't even know that they have it's also a requisite for regulating energy and wellness."

### 5. Areas of Disagreement

In general, there was very little disagreement amongst the diverse participants in this project. All acknowledged the dire need for a benefit that lifts disabled people out of poverty as quickly as possible.

The disagreements that did occur were in the details. Some participants did not agree on the specific dollar amount of the benefit, though the range was generally between \$2000-\$3000 a month. Some participants felt the CDB should be open to anyone in Canada with a disability while others felt it should only be available to Canadian citizens. Some felt that there ought to be a reassessment process while most thought that permanent or long-term eligibility made more sense. Finally, there was some debate on whether one should be able to self-diagnose as disabled. Concerns were raised that this may lead to abuse of the system; however, access to a medical professional to confirm eligibility in our current health care crisis seemed unnecessary and burdensome to many.

# 7. Conclusion

Over 90 conversations including more than 200 people, the peer-to-peer process heard the stories, experiences, and perspectives of a diversity of disabled people in Canada. Through concerted recruitment and outreach efforts this process reached many of those whose voices are often excluded from policy-making including people who live in institutions, are experiencing or have experience with precarious housing, people who identify under the 2SLGBTQIA+, those who live in rural and remote areas, and people who identify as Black, racialized, and/or Indigenous.

Overwhelmingly there was consensus that the CDB is urgent and that the poverty that disabled people are experiencing is debilitating. Participants urged eligibility considerations that are inclusive of the breadth of disability and the various forms it can take and suggested that there ought not to be limitations based on income, employment or family status. While many thought that a health care provider could be involved in assessing disability, there was agreement that it should not be burdensome to prove. Participants advocate strongly for a simple, accessible, and fast application process that automatically enrolls anyone already receiving federal, provincial or territorial benefits. Finally, they ask for an amount, somewhere between \$2000-\$3000 a month, that helps to cover the necessities of life and all of the additional expenses related to disability. They strongly urge no clawbacks and no disincentives to work.

Participants were grateful to have the opportunity to contribute their thoughts and ideas through this process and were optimistic about the change that the CDB could bring to their lives. By removing some of the financial burdens of living with disabilities, the CDB would not only allow disabled people to more actively participate in society and the economy, it would afford them a life of dignity.

### **APPENDIX**

- Peer-to-Peer Conversation Guide
- P2P Debrief Questions
- P2P Training Video

### **SOURCES**

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

### **LINKS**

Please read the full report from the Shape the CDB Online Survey at <a href="https://www.disabilitywithoutpoverty.ca/shape-the-cdb-phase-1/">https://www.disabilitywithoutpoverty.ca/shape-the-cdb-phase-1/</a>

Please read the capstone report from the Shape the CDB project at <a href="https://www.disabilitywithoutpoverty.ca/shape-the-cdb-final-report">https://www.disabilitywithoutpoverty.ca/shape-the-cdb-final-report</a>

For more information about the Shape the CDB project by Disability Without Poverty please visit our website at <u>disabilitywithoutpoverty.ca</u> or follow us on social media.

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