Shaping Canada's Disability Inclusion Action Plan:

April 2023

Bridging the gap between lived experiences and policy through a community-led, capacity building and knowledge-exchange approach

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OF CANADA
PERSONNES
D'ABORD
DU CANADA

Inclusion
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Executive Summary and Recommendations

In 2020, the Government of Canada committed to creating a new Disability Inclusion Action Plan (DIAP), aimed at improving the lives of persons with disabilities. The objectives of DIAP are to:

- Improve the social and economic inclusion of people in Canada with disabilities
- Reduce poverty among people in Canada with disabilities
- Contribute to the realization of a barrier-free Canada by 2040
- Improve access to federal programs and services for persons with disabilities and ensure that disability inclusion is considered in all Government programs, policies, and services
- Foster a culture of inclusion and a shift away from attitudes of ableism and discrimination

The DIAP includes four thematic pillars:

- **Financial Security** (i.e., developing a Canada Disability Benefit),
- **Employment** (creating a national employment strategy for people with disabilities),
- **Disability Inclusive Spaces** (addressing barriers to public spaces), and,
- **Modernizing Approaches to Defining Disability** (ensuring a modern definition for disability and simpler process for accessing programs).

Canada's first Disability Inclusion Action Plan is a landmark approach aimed at promoting inclusion and accessibility for all Canadians with disabilities. The DIAP is a blueprint for a change: a comprehensive strategy developed to encourage disability inclusion through a set of interconnected and complementary actions. Essentially, the DIAP provides a framework for a holistic transformation towards greater disability inclusion. This plan ensures that disability considerations are taken into account in all of programs and services, while also providing targeted investments in key areas that aim to bring about positive change. The plan also builds upon previous measures that have been implemented to improve the inclusion of people with disabilities, while also introducing new and significant actions to further advance this cause. Community partners and persons with disabilities have been engaged in developing this plan. However, in line with the principle ***"Nothing Without Us,"*** the lived experiences of persons with disabilities and the valuable contributions, input and recommendations that persons with disabilities have on every part of the Action Plan are thoroughly explored through this community-based project: ***"Shaping Canada's Disability Inclusion Action Plan: Bridging the gap between lived experiences and policy through a community-led, capacity building and knowledge-exchange approach."***

This report aims to provide insights into how persons with disabilities can be socially and economically included, highlight the obstacles they encounter when accessing federal programs and benefits, and articulate the perspectives and requirements of persons with disabilities to ensure that the Government's policies and programs are inclusive and attend to their experiences. The data and insights provided in the report are intended to facilitate the implementation of the DIAP by enabling the development of novel and impactful measures and actions.

The project and its findings were guided by several principles: Firstly, there isn't a singular disability community, but instead, there are many communities that can be brought together through this process. Secondly, feedback from Canadians with a broad range of abilities was used to inform the DIAP, which supports its successful implementation. Thirdly, people with disabilities have the best understanding of the barriers and solutions to improve social inclusion, financial security, employment, inclusive spaces, access, and experiences related to disability programs and services. They are in the best position to speak about these areas. Fourthly, increased inclusion of people with disabilities in all aspects of society improves the quality of life for everyone by contributing to social and economic benefits. Lastly, increased collaboration and partnerships among organizations representing people with disabilities in Canada will significantly contribute to removing barriers to participation and advancing inclusion for all people.

The main driving force behind this work was to ensure that the diverse voices of people with disabilities who are ***"on the margins of the margins"*** of society are heard. Direct efforts were made to engage with individuals who are hard to reach or infrequently heard. Those "on the margins of the margins" include the stories and lived experiences that often go unrecognized and unseen. The project focuses on shaping, informing, and maximizing the impact of the plan through an inclusive approach that emphasizes participation and incorporates input from a diverse range of Canadians with disabilities, including those who are visible and non-visible, those from different regions and geographies, socioeconomic class, cultural backgrounds, ages, genders, those residing in institutions (e.g., incarcerated, in long-term care centers), and those without a residential address (e.g., homeless).

In this project, disability was defined based on the rights-based approaches outlined in national and international legal frameworks. These approaches recognize that disability is not solely caused by physical, mental, cognitive, intellectual, sensory, or developmental impairments. Instead, disability results from a combination of these impairments and societal barriers such as negative attitudes and inaccessible environments that limit the full and equal participation of people with disabilities in society. Disability also intersects with other aspects of identity, including race, immigrant status, ethnicity, Indigeneity, age, sexuality, gender, gender expression, financial status and class, creating unique experiences of disability and ableism.

Methodology

Through a series of consultations, surveys, and engagement activities, feedback and input on the barriers and challenges faced by individuals with disabilities, as well as potential solutions and strategies to promote inclusion and accessibility have been collected with **over 4000+ responses/interactions.**

The four pillar organizations connected with persons with disabilities and organizations who participated in critical discussions to inform the DIAP. Respondents represented persons with lived experiences, community members and other accessibility stakeholders. The initial consultation process included public sessions, focus groups, individual interviews, written submissions, email and phone/TTY calls. A consultation guide was developed in advance of the consultations to spark discussion. The opportunities and environments for collecting information were unique, online and offline, strategic/intentional (e.g., meeting with persons with disabilities from the 2SLGBTIQ community during Toronto Pride, seeking input from the unhoused/homeless in Vancouver's East side, consulting with Deafblind participants from Quebec.) The vast majority of respondents consulted have disabilities and considered themselves somewhat "on the margins" of the disability community. People from all provinces and territories were consulted and included in the different types of engagement on the DIAP. While the majority of consultations were held in the English language, interviews and consultations were conducted in French, American Sign Language (ASL), and Langue des signes québécoise (LSQ).

In addition to consultations that took shape in the form of short- and long-format interviews, 'kitchen-side' chats, focus groups, etc., an accessible and comprehensive 35-questions survey and four "What We Heard" Town Hall sessions were held to further gather input, perspectives and thoughts on solutions for the different aspects of implementing DIAP.

Learnings and Recommendations

Some of the views that emerged from the consultations and surveys indicate the following themes:

Pillar 1: Financial Security

- Living with a disability in Canada can be financially challenging, leading to poverty and compromising one's dignity, choice, and freedom. Many individuals with disabilities in Canada are struggling to meet their basic needs, faced with tough choices. These challenges are further compounded by the intersections of their identity, such as race, gender, Indigeneity, class, immigration status, family status, and language. This affects their access to government income programs and benefits, employment opportunities, housing, medical services, and support. For instance, some respondents who identified as racialized or queer and/or transgender, in addition to having a disability, experienced interpersonal, institutional, and systemic discrimination.
- Living in poverty with a disability can cause individuals to feel isolated and removed from society, both socially and physically. Access to accessible transportation is a significant challenge, which limits their opportunities for social connection, attending medical appointments, going to the food bank, and work. Family support and status can also impact how individuals with disabilities experience poverty. For some, their family support is essential in keeping them out of poverty, while for others, they lack such support due to historical trauma, such as those experienced by Indigenous peoples due to residential schools and colonialism.

Pillar 2: Employment

- Skills gaps became evident during the early onset of the pandemic. The current labour shortages experienced in multiple sectors across Canada are negatively impacting the amount of training provided by employers.
- Due to changing guidelines and travel restrictions, forging new professional or organizational relationships, especially interprovincial ones, has been particularly challenging during the pandemic.
- Persons with disabilities have perceived a lack of fairness in the income supports they receive compared to the financial supports (such as CERB) provided to Canadians who were laid off at the start of the pandemic. The low threshold to establish eligibility and the absence of a lengthy application process or wait-time before benefits were received in

contrast with the "claw-backs" imposed on workers with disabilities who earn income while working.

- The pandemic accelerated trends towards precarious work, the gig economy, and the growth of delivery services, as well as discrete work driven by remote or isolated living requirements.
- While remote work has been hyped as a benefit for people with disabilities, it has also ignored deeper challenges. Even when work was on-site during the pandemic, accommodation specialists could not visit workplaces for in-person assessments or build relationships.

Pillar 3: Inclusive Spaces

- Persons who have disabilities encounter various challenges when it comes to engaging in their communities. These challenges can be categorized as architectural or physical, informational or communicational, organizational, virtual or technological, systemic, policy, and attitudinal.
- These barriers are mainly caused by the failure of systems, services, and spaces to consider disability in their design. They do not fully understand the needs of individuals with disabilities or operate under false assumptions about disability, which leads to exclusion and difficulties for individuals with disabilities to participate fully in their communities.
- There needs to be a shift from only ensuring physical spaces are accessible and inclusive, but to also consider that experiences, accessing the right supports, and policies are in-reach, inclusive and accessible in its design and implementation.

Pillar 4: Modernizing Approaches to Defining Disability

- The inherent dignity of people with disabilities is important when redefining disability. There is desire and expectation that people with disabilities be treated with respect and as equals during any processes that determine the nature of their disability and their eligibility for programs and services.
- The principle of equality was a key concern when discussing the definition and scope of disability. Any definition of disability should not favour people with certain conditions, impairments, or functional limitations, while denying recognition of disability to others who experience different forms of difficulty.
- Despite their limitations, people with disabilities are capable of many things. The process of assessing disability should take into account what people can do, or what they could do with the right supports. The system should be designed to encourage this approach rather than the current approach, which tends to “pathologize” individuals based on what they cannot do.
- While some medical information may be necessary to assess the presence of disability, the information gathered should be limited to what is essential. The disability determination process should not be highly medicalized, as it often is at present.

Some of the views that emerged from the consultations and surveys indicate the following set of recommendations:

Pillar 1: Financial Security

→ Eligibility and enrollment for the Canada Disability Benefit should be automatic for people already receiving government disability support, with a separate application process for those who are not. The definition of disability should be broad and inclusive, based on how it affects people's daily lives rather than just medical diagnosis. Non-medical professionals should be allowed to assess disability. The benefit should not have an employment or asset test, and recipients should be legal residents. Income assistance programs should cover the cost of disability diagnosis.

- → Access to the benefit should be easy and flexible, with specially trained government representatives who are compassionate and inclusive. Independent "navigators" can help people navigate complex government systems and ensure the benefit reaches those who need it most. There should be a fair and independent appeals process.
- → There should be no reduction in existing government supports for people who receive the Canada Disability Benefit. There should be a generous earnings exemption, and the benefit should not be tied to the Disability Tax Credit or subject to income tax. Opinions are divided on whether the benefit should be income tested.
- → The Canada Disability Benefit should lift people with disabilities above the poverty line and acknowledge the extra costs they face. The minimum benefit should be between $2,200 and $2,400 per month, indexed to inflation, with potential for individualization based on needs and location.
- → Address other important factors include personal support, accessible housing, adaptive/assistive equipment, affordable and accessible communication, transportation, healthcare, education, food security, and employment.
- → There is a need for a specific strategy to address the unique challenges of financial insecurity in Canada's Northern regions.
- → Develop a publicly funded national disability insurance plan that would provide essential supports for persons with disabilities throughout their lifetime as an entitlement.

Pillar 2: Employment

- → To improve the exchange of information and best practices, it's necessary to establish structured mechanisms. Most employment programs are managed at the provincial level, which makes it challenging to learn about innovative developments happening across Canada.
- → There should be increased supports for both employers and jobseekers/employees with disabilities. Specifically, employer-focused practical resources and tailored assistance will be essential.
- → There is a need for a National Accommodation Fund, particularly for small to medium-sized employers. It should eliminate claw-backs when people with disabilities find employment and provide financial support that accounts for inflation.
- → It's crucial to adopt grassroots efforts that share ways of supporting jobseekers, especially during COVID-19 when onsite job coaches weren't available. Creating a forum to promote this knowledge exchange at multiple levels will be instrumental in ensuring future success. The process should be user-friendly and eliminate the need for lengthy reports or forms.

Pillar 3: Inclusive Spaces

- → The Canadian government needs to be more proactive and diligent in removing barriers within areas that fall under federal jurisdiction.
- → The Canadian government should increase efforts to redesign buildings, public spaces, and benefit programs so that they are more accessible.

- → To make all areas more inclusive, professional, and accessible for every stakeholder group, we need to prioritize sensitivity, respect, and cultural agility.
- → Retrofit buildings to make them accessible to everyone.
- → The built environment, emergency services, government offices, and virtual services should provide more support for the Deaf community.
- → To improve accessibility for the Deaf community, the government should provide more ASL/LSQ materials to help them use government services.
- → Emergency services and service-related messages should be available in many formats to ensure accessibility for everyone.
- → Government services should be accessible through many means, not just by phone or computer, to ensure inclusivity.
- → Virtual and digital spaces should be designed to be accessible by default, to improve accessibility for everyone.
- → Establishing a single Video Remote Interpreting Service for the public and federal employees would improve accessibility.
- → Policy-wide changes and education are necessary to remove barriers to accessibility.

Pillar 4: Modernizing Approaches to Defining Disability

- → There is a need for a new system that would:
  - Be based on an inclusive and evolving definition of disability that also recognizes people’s diverse other characteristics.
  - Be much better-harmonized, where individual programs may have their criteria but where the threshold of having a disability would be established more clearly, coherently, and fairly.
  - Establish the presence of disability through a variety of methods that do not rely so heavily as at present on medical doctors.
  - Ask most individuals that their disability be established once rather than repeatedly.
  - Be designed and managed to treat people fairly, with respect, as equals.
  - Have thorough and fully independent review and appeal processes.
  - Provide information and services in plain language in a variety of ways, including in person and online, and through straightforward print, audio, and video resources.
- → To measure the impacts of disability, it is important to consider the difficulties a person faces both with and without the support they require in various social contexts. This includes situations at home, school, work, during shopping or recreation, public events, while traveling, and in the healthcare system.
- → There is a need for new approaches to assess the impacts of socially imposed restrictions that result from the barriers individuals face in different contexts. These approaches should consider how these barriers affect a person's ability to participate fully in society and access services.
- → A measure of disability should take into account both episodic and continuous expressions for individuals who experience one or both. This means that the assessment should consider how a person's disability affects them over time, whether it is a temporary or ongoing condition.
- → The new approach should be designed to enable and support diverse people with disabilities to participate fully as equals in *all* the rights, benefits, responsibilities, and privileges that society makes available to its citizens.

In conclusion, the Disability Inclusion Action Plan project is a critical initiative that will help promote inclusion and accessibility for all Canadians with disabilities. This project's commitment to participation, collaboration, and co-creation has ensured that the voices of individuals with disabilities “on the margins of the margins” were heard and taken into account in the analyses. The project partners and pillar lead organizations are immensely thankful for the valued feedback and suggestions provided by persons with disabilities. The success of this project has largely depended on the active/trusted participation and constructive/transparent feedback from persons with disabilities, which has created a positive, valuable and insightful set of learnings and proposed solutions.

Although 98% of those that attended the *“Did We Get It Right?”* town hall sessions reported that the findings and recommendations align and ‘ring true’ to their own personal experiences and 92% reported information was not missing from the report, we encourage further consultation should happen with certain individuals such as those multiple chemical sensitivities and those with lived experiences of mental health issues.

The implementation of the Disability Inclusion Action Plan represents a critical step towards building a more inclusive and accessible society for all Canadians, but in order to be successful, the DIAP must be designed from an intersectional lens and the perspectives of a person with a disability should be factored through an iterative, meaningful and constant connection with persons with disabilities and community partners must follow.

The Executive Summary can be provided in any accessible format (plain language, French, ASL, and LSQ) upon request or can be accessed by visiting www.muscle.ca/diap.

Pillar 1: Financial Security

Inclusion
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Executive Summary of Themes

During the months of May and June 2022, Inclusion Canada and participating organizations held consultations with people with disabilities and the greater disability community on the proposed Canada Disability Benefit. The purpose of the consultation was to receive input on the design and implementation of the proposed Benefit, as well as to understand lived experiences and the challenges and limitations of current access to social and financial programs. This consultation will help inform the development of Canada's first Disability Inclusion Action Plan (DIAP), a plan to improve the lives of people with disabilities in Canada. Consultations were supported by DIAP project co-leads, **Muscular Dystrophy Canada,** and **Independent Living Canada,** and with financial support from Employment and Social Development Canada (ESDC).

The consultations engaged persons with disabilities and their families/supporters, disability organizations and their networks, and policy, legal, and financial experts in order to receive input on what the proposed Canada Disability Benefit should look like and how it should work. This report represents the views and opinions of the people with disabilities and organizations we spoke with and consists of what we heard. In total, we heard from 260 individuals, through 32 focus groups, 39 one-on-one key informant interviews, and 3 written submissions. Through the consultations, several key themes emerged:

1. Poverty makes life challenging, not disability

- Many people with disabilities in Canada are living in poverty and having to make tough choices between their basic needs. There are also people with disabilities fearful of the future and considering accessing Medical Assistance in Dying (MAiD) because they are living in abject poverty and unable to access adequate financial and social services, including safe, inclusive and affordable housing. The proposed Canada Disability Benefit would allow people with disabilities to live with more dignity, choice, and freedom.

2. Intersecting Identities

- The intersections of someone's identity further compounds the challenges they face as a person with a disability. Race, gender, Indigeneity, class, immigration status, family status, and language greatly impact how someone with a disability experiences and accesses current government income programs and benefits.

3. Eligibility Criteria

- Eligibility and enrollment for the proposed Canada Disability Benefit should be automatic for a person who already qualifies for other federal, provincial, or territorial disability supports, with a separate application for those not already on any government disability support. The definition of disability should be as broad and inclusive as possible, and based on a social model of disability, rather than a medical model, and one that considers what disability means in people's daily lives. Supporting a social model of disability should involve the reconsideration of who assesses for disability, allowing people other than medical doctors to assess for disability. We heard that income assistance programs, including the proposed Canada Disability Benefit should be paying for the disability diagnosis process. We heard other considerations including that there should be no employment test or asset testing to qualify for the proposed Canada Disability Benefit and that individuals should be legal residents to qualify for the Benefit, and the Benefit should be paid on an individual basis.

4. Access to the Benefit & The Application Process

- There should be a simple, accessible, and flexible application process for the proposed Canada Disability Benefit to be as inclusive as possible. Specially trained government representatives who show compassion, empathy, and inclusivity would make a huge difference in peoples experience in accessing government benefits. Independent "Navigators" would help people to navigate the complex systems currently in place to access government benefits and would help the proposed Canada Disability Benefit to reach the people with disabilities most in need. We also heard that there should be a fair and independent review and appeal process for people to challenge the decisions that are made on their eligibility and application.

5. Benefit Interaction

- The overwhelming majority said there should be absolutely no claw backs on peoples existing federal, provincial, or territorial government supports. There should be a generous earnings exemption to allow people to work and establish an asset base. The proposed Canada Disability Benefit should not be tied to the Disability Tax Credit and should be non-taxable. We heard differing opinions on whether the Canada Disability Benefit should be income tested; income testing could ensure people with the lowest incomes get more benefit or could see the policing of eligibility criteria and exclusion.

6. Amount of the Canada Disability Benefit

- The Canada Disability Benefit should raise the income of people with disabilities above the poverty line and acknowledge the costs often associated with having a disability. The Benefit should be between $2,200 and $2,400 per month at minimum, indexed to the cost of inflation, with the potential to be individualized based on someone's needs and geographic location.

7. Societal Value Shift

- We heard that we need to do better as a country to support people with disabilities and to provide accessibility as a human right.

8. Need for a Larger Agenda to Reduce Poverty Amongst People with Disabilities in Canada

- We heard that the proposed Canada Disability Benefit is just one piece of a larger puzzle to reduce poverty amongst people in Canada with disabilities, and this goal also requires access to personal supports, affordable and accessible housing, adaptive equipment, affordable and accessible internet and phone services, transportation, healthcare, education, food security, and employment.

- We heard from one of the national disability organizations who advocates for a complimentary program to be built alongside of a Canada Disability Benefit (CDB). They suggested that, while the CDB is needed it may still leave many without the essential supports they require. They have recommended the creation of a publicly funded national disability insurance plan that would provide essential supports for persons with disabilities throughout their lifetime as an entitlement. They have prepared a separate report which outlines the principles of such a plan and how it could be very complimentary to the CDB. This report will be included as a separate report and submitted to Employment and Social Development Canada as part of the environmental scan.

9. Other Issues Raised in Consultation

- With the proposed Canada Disability Benefit, we heard that it is important to collect data on how well the Benefit is supporting people once implemented, and who it is not reaching. We also heard a need for a specific Northern strategy to address the unique challenges of financial insecurity in the North.

Subsequent Survey

In addition to the consultations conducted, in October 2022, as part of the Disability Inclusion Action Plan (DIAP), all four DIAP Pillars created a joint national survey to build on the previous DIAP consultations as a supplement. The survey collected a broad range of information about the lived experiences of Canadians with disabilities. It included questions on all 4 pillars of the DIAP: Financial Security (The Canada Disability Benefit), Employment, Disability Inclusive Spaces, and Modernizing Federal Government Programs and Approaches to Disability.

The survey included a total of 9 questions on Pillar 1, Financial Security (The Canada Disability Benefit). Most questions were quantitative in nature; however, 2 questions were qualitative and asked survey participants to explain and describe their experiences. A thematic analysis of the

2 qualitative survey questions on Pillar 1, Financial Security is contained in an addendum to this report and can be found starting on p.70.

Introduction

Income Insecurity Amongst People with Disabilities

People in Canada with disabilities are more likely to be financially insecure and live in poverty than people in Canada without disabilities. This is unacceptable. In Canada, 22 percent of people have a disability, with more then 40 percent living in poverty.

People with disabilities in Canada face discrimination and barriers related to accessibility, employment, housing, healthcare, education, transportation, communication, personal supports and more, resulting in unequal health, social, and financial outcomes. In Canada, poverty is the most likely outcome for someone with a disability.

There is an overreliance on social assistance in this country; a system never designed to address the real income needs of people in Canada with a disability. Built as a system of last resort, our current systems of income support are failing to provide people with disabilities the income supports they need to live and prosper. Existing disability related financial supports are not enough to cover basic living expenses, let alone the extra cost of having a disability. People with disabilities are confronted with additional daily expenses including medical expenses, accessible housing and transportation needs, specialized equipment, personal supports and assistive devices.

Barriers to receiving quality inclusive education as well as exclusion from the labour market further contribute to the higher levels of poverty experienced by people with disabilities. Income security for people with disabilities is not simply about money. Poverty results not only from the absence of money but the absence of opportunity. People with disabilities living in poverty lack real choice and are stripped of their dignity.

No one living in Canada should have to live a life in poverty, especially as a result of having a disability. People with disabilities must have the income and resources they require to meet their personal support and income needs in order to secure a standard of life comparable to people without disabilities and fully participate in all aspects of community.

Disability Inclusion Action Plan

In 2020, the Government of Canada committed to creating a new Disability Inclusion Action Plan (DIAP), aimed at improving the lives of people with disabilities. The objectives of DIAP are to:

- Improve the social and economic inclusion of people in Canada with disabilities
- Reduce poverty among people in Canada with disabilities

- Contribute to the realization of a barrier-free Canada by 2040
- Improve access to federal programs and services for persons with disabilities and ensure that disability inclusion is considered in all Government programs, policies, and services
- Foster a culture of inclusion and a shift away from attitudes of ableism and discrimination

The DIAP includes four thematic pillars:

1. **Financial Security** (i.e., developing a Canada Disability Benefit),
2. **Employment** (creating a national employment strategy for people with disabilities),
3. **Disability Inclusive Spaces** (addressing barriers to public spaces), and,
4. **Modernizing Federal Government Programs and Approaches to Disability** (ensuring a modern definition for disability and simpler process for accessing programs like the Disability Tax Credit, the Canada Pension Plan disability benefit, etc.).

The Canada Disability Benefit

As part of the DIAP, the Government of Canada committed to introducing a new monthly Canada Disability Benefit (CDB) to address the immediate and long-term financial needs of people in Canada with disabilities. The intent is that adults with a disability in Canada would receive money from the Government to help with their daily living costs. Although the Benefit has not been created yet, the federal government indicated the new Canada Disability Benefit would:

- Be a new permanent income support program from the Canadian Government
- Focus on low to modest-income people with disabilities
- Support working-age people with disabilities (usually 18-64)
- Be added on top of the existing benefits people with disabilities can receive

The Government has not provided many details about the new benefit. They have not said who would get the benefit, how much money it would be, or when people with a disability would start receiving the benefit.

About the Consultations

Beginning in early 2022, DIAP project co-leads Muscular Dystrophy Canada and Independent Living Canada were selected by the federal government, through a Call for Proposal process, to partner to consult with the disability community and help inform the development of Canada's first DIAP. The 15-month collaboration began in early 2022, with plans to conclude in March 2023.

Inclusion Canada has led Pillar 1, the Financial Security Pillar of the Disability Inclusion Action Plan (DIAP), with support from the DIAP project co-leads, Muscular Dystrophy Canada and Independent Living Canada**,** with financial support from Employment and Social Development Canada (ESDC).

The purpose of the consultations was to understand lived experiences, the challenges and limitations of current social and financial programs, and to receive input on what the proposed Canada Disability Benefit should look like and how it should work.

The consultations under the Financial Security Pillar on the proposed Canada Disability Benefit took place throughout the months of May and June 2022 and included **small focus groups** and **one-on-one key informant interviews held virtually and in-person.** Inclusion Canada sought feedback from key stakeholders including:

1. Persons with disabilities and their families/supporters, including 'hardest to reach' lived experience populations;
2. Disability organizations and their networks, and;
3. Policy, legal & financial experts with experience in disability.

Approximately one hour was scheduled for each key informant interview and focus group. (See Annex B) for the list of consultation questions). Inclusion Canada engaged various disability organizations seeking their assistance to provide input to the consultations and to reach their communities. Organizations were asked to assist in a variety of ways: conduct their own focus group sessions on the design of the Canada Disability Benefit with their communities, host a focus group facilitated by Inclusion Canada, participate in a key informant interview, and/or attend a focus group roundtable held specifically for disability organizations. Inclusion Canada prepared a full consultation package in English and French for participating organizations to use in their consultations. (See Annex A) for the list of participating organizations).

Inclusion Canada would like to express our profound gratitude and appreciation to all the organizations and individuals who assisted in the process and took the time to provide us with excellent and thoughtful perspectives and their particular lived experience. Their words have been a powerful expression which will serve to inform the development and design of a proposed new national disability financial benefit.

Who We Heard From:

260 Participants

32
Focus Groups

39
Key Informant Interviews

2
Written Responses

Over the two-month period, we heard from 260 participants through consultations across the country that included 32 focus groups, 39 key informant interviews, and 2 written responses.

Demographics

During the consultations, each focus group and interview participant was asked to complete an optional demographic form, however not all participants chose to complete it. Additionally, some questions included on the demographic form were not mandatory and participants were given the option to share what they were comfortable with. This is important to remember when considering the demographics of participants.

Province/Territory of Participants

- 39% from Ontario
- 20.3% from British Columbia
- 9.9% from Nova Scotia
- 9.3% from Alberta
- 5.8% from Manitoba
- 4.7% from New Brunswick
- 4.1% from Quebec
- 1.7% from Saskatchewan

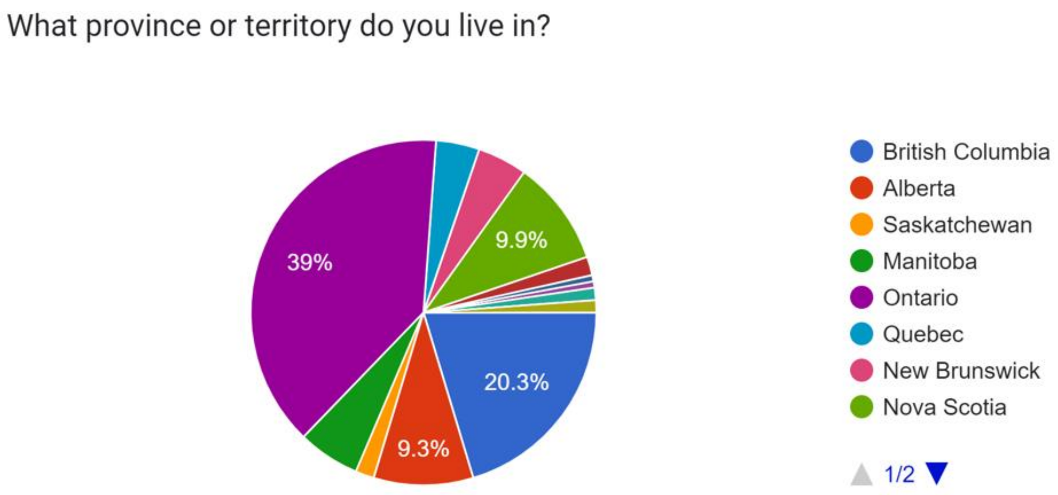
- 1.7% from Prince Edward Island

- 1.2 % from Nunavut

- 1.2% from the Northwest Territories

- 0.6% from Newfoundland and Labrador

- 0.6 % from the Yukon



What province or territory do you live in?

Gender Identity of Participants

- 57.6 % identified as women

- 38.4 % identified as men

- 2.9% identified as non-binary

- 1.2% preferred not to answer

Types of Communities of Participants

- 57.4 % of people live in a city with 100,000 people or more

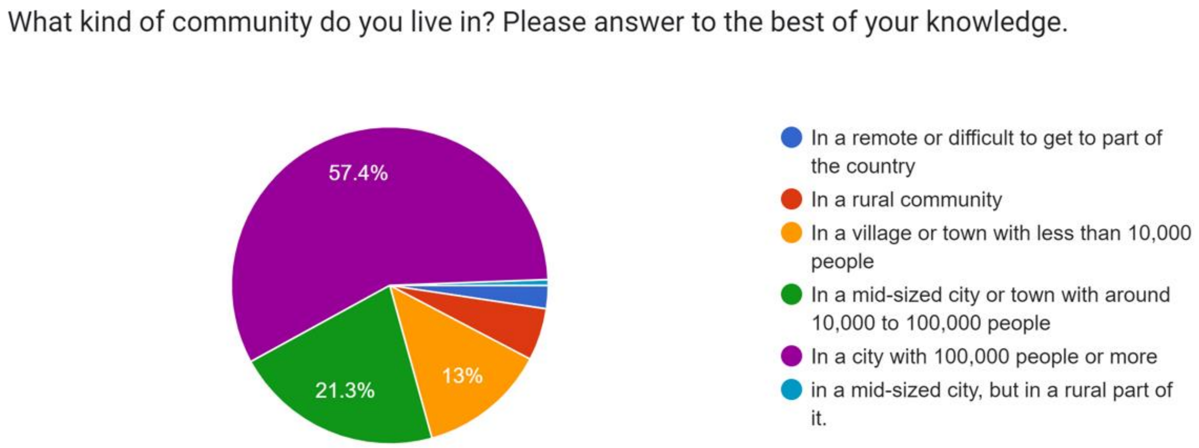
- 21.3 % of people live in mid-sized city or town with around 10,000 to 100,000 people

- 13% of people live in a village or town with less than 10,000 people

- 5.3% of people live in a rural community

- 2.4% of people live in a remote or difficult to get to part of the country

- 0.6 % of people living in a mid-sized city, but in a rural part of it



What kind of community do you live in? Please answer to the best of your knowledge.

Types of Living Arrangements of Participants

- 43.5 % live with family members

- 29.2% live alone

- 14.2% live with a partner

- 10% live with one or more roommates

- 1.4 % live in a congregate care setting

- 0.7% live in a supervised apartment

- 0.7% live alone with supervision

- 0.7% live in supportive housing

Main Source of Income of Participants

- 13.3% said they had multiple main sources of income (for example a combination of government benefits and work).
- 42 % of participants said their main source of income was government benefits
- 41% said their main source of income was work (full-time, part-time, seasonal, contract, and self-employment)
- 15.2 % said their main source of income is family support
- 7.2% said their main source of income is pension
- 2.1% said their main source of income is savings
- 2.8% of participants said they would rather not disclose

*Note: percentages are greater than 100% as some respondents reported more than one source of income.

Employment Status of Participants

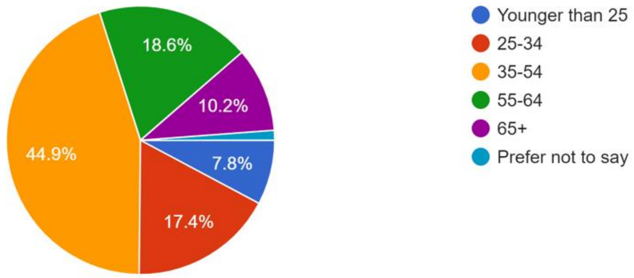
- 50.4% are employed in full-time or part-time work
- 42.7 % are not employed
- 5.6% are self-employed
- 1.4% did not want to disclose

Age of Participants

- 7.8% are younger than 25
- 17.4% are age 25-34
- 44.9% are age 35-54
- 18.6% are age 55-64
- 10.2% are age 65+

- 1.2% preferred not to say

How old are you?



Ethno-racial Identity of Participants

- 81.5% identified as Caucasian (white)
- 8.3% identified as Black or of African Decent
- 5.4% identified as Indigenous
- 1.8% identified as Arab
- 2.4% identified as Chinese
- 2.4% identified as South Asian (for example: East Indian, Pakistani, Sri Lankan)
- 0.6% identified as Filipino
- 1.2% identified as Southeast Asian (for example, Vietnam, Cambodia, Thailand)
- 0.6% identified as Japanese
- 1.2% identified as Latin American
- 3% identified as multi-racial (3%).

- 1.2% preferred not to answer

- 0.6% identified with another racialized or visible minority group

*Note: percentages are greater than 100% as some respondents reported more than one group they identified with

Citizenship of Participants

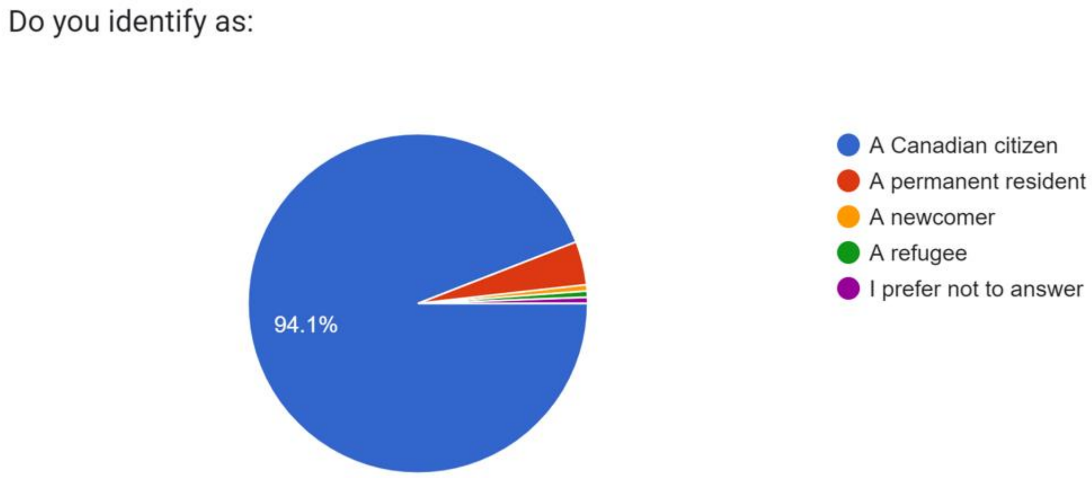
- 94.1% identified as Canadian citizens

- 4.1% identified as permanent residents

- 0.6% identified as refugees

- 0.6% identified as newcomers

- 0.6% preferred not to answer



Language of Participants

- 95.9% considered their main language to be English

- 1.2% considered French as their main language

- 5.3% identified as fluent in both English and French

- 3.6% identified another language as their main language

*Note: percentages are greater than 100% as some respondents reported more than one language spoken.

Types of Disability of Participants

- 47.6% identified as having a physical disability (for example: mobility, bending, reaching, grasping)

- 29% identified as having an intellectual or developmental disability

- 22.1% identified as having a learning disability

- 28.3% identified as having a psychosocial disability (for example: mental health)

- 13.1% identified as having a seeing disability

- 11% identifies as having aa communicating disability

- 9.7% identified as having a hearing disability

- 6.9% preferred not to say

- 10.5% of participants self-described as having other types of disabilities, including an acquired brain injury (1.4%), seizures (0.7%), Asperger's (2.1%), hypersomnia (0.7%), Autism (2.1%), a chronic illness (0.7%), a neurological disability (1.4%), an episodic disability (0.7%), and a severe autoimmune disease (0.7%). (See Annex C for visual representation of the full demographics of participants in the consultation).

*Note: percentages are greater than 100% as some respondents reported more than one kind of disability.

Limitations & Challenges

A major challenge identified early in the consultation development process was the lack of financial compensation or honorariums available for persons with lived experience participating in the interviews and focus groups. We recognize that consultations are meant to give a diverse range of individuals an opportunity for their opinions to be shared on important issues that have real life impact on theirs and others lives. Not including participant honorariums for consultations limits the opinions and perspectives that are shared, and often excludes hardest-to-reach communities.

As we began our consultation, this barrier was confirmed and limited the scope of who we were able to reach and engage with regarding the design of the Canada Disability Benefit. This challenge was ultimately corrected through budget reallocations, although late in the consultation process, which impacted the input we were able to receive from hardest-to-reach groups. For this and other reasons, including the expedient timeline required, some perspectives were missed from this consultation. Although we did reach some, we unfortunately did not adequately consult with various marginalized or hardest-to-reach communities, including targeted and meaningful outreach to persons with disabilities who also identify as 2ISLGBTQ+, racialized and Indigenous persons with disabilities, refugees with disabilities, people with disabilities experiencing houselessness, people with disabilities who are incarcerated or formerly incarcerated, veterans with disabilities, people with disabilities who are or have been institutionalized, or Northern communities. We remain hopeful that some of these individuals will be reached from a broader survey planned to be released by the lead organizations with the objective of having a wider circulation and reach.

Additionally, the lack of financial compensation presented a barrier to engaging smaller disability organizations that had limited resources to participate in the consultation but would have otherwise been interested in amplifying the voices from within their community. This limited the number of Black, Indigenous, and racialized perspectives we were able to obtain.

We recognize the perspectives that are missing from this report leave a gap. Persons with disabilities who have intersecting identities have a different and unique experience of disability and poverty, and it is important that these perspectives are included in government consultations and reporting, while consulting in ethical and safe ways.

What We Heard – Key Themes

1. Poverty makes life challenging, not disability

Many people with disabilities are living in poverty, struggling to make ends meet. People are having to make **tough choices between their basic needs** and necessities. In our consultations we heard that people are choosing between paying rent or buying groceries; they are living in unsafe living arrangements; they are taking risks with their health and safety; they are taking expired medication; they are using food banks; they are repairing old shoes with duct tape and glue; they are unable to afford new boots for their kids; they are wearing glasses with a 10-year-old prescription; they are unable to afford a new battery for their hearing aid; they are not able to save; they cannot maintain repairs of their accessibility devices; and they are isolated. People with disabilities are going without everyday.

> **“*Right now I basically eat one meal a day. With the new Canada Disability Benefit, people like me would be able to eat more than one meal a day, and this would be a luxury*”**

We heard from many people that poverty makes disability worse. For people with disabilities, living in poverty quickly becomes all consuming. Enormous amounts of time and energy is devoted to basic survival. Living in poverty without access to basic needs creates social isolation, increases stress, anxiety, and depression, and worsens mental health challenges for people. We heard from one participant who works with people with disabilities who said, “*I have one patient who has had a broken scooter for years and cannot afford to fix it, so they can’t get around and are stuck at home. They are alone and isolated and not socializing.”* We heard that social isolation is debilitating and gives people with disabilities a sense that they are alone, with no support, community, or societal value.

> **“*It’s sad that in Canada you can die with dignity, but cannot live with dignity*”**

We heard that many people with disabilities have **considered accessing Medical Assistance in Dying (MAiD)** because they are living in poverty and social isolation, unable to get access to adequate financial and social services. When speaking about the urgency of a Canada Disability Benefit, one participant said, “*This is something that needs to be out now. We have people actually signing up for MAiD because they can’t afford their monthly costs.”*

We heard that people with disabilities in Canada are thinking about accessing MAiD, not because of their disabilities, but because they face overwhelming barriers in accessing the essential disability support services that would allow someone to live a dignified life. This should never be a reason to access MAiD, however, recent changes by the federal government now permits MAiD on the grounds of one having a disability. Sadly, since these changes we have seen many people being permitted to access MAiD instead of being offered equitable access to services and supports and safe and affordable housing. This was referenced frequently by participants. We also heard about many people's daily struggles and **fears of the future**. Many participants said they have stopped planning for the future entirely. One person with a disability said, "*One of my solutions for the future is to take every medication that I have right now, and I think about that every night."*

We heard that a Canada Disability Benefit would help to lift people with disabilities out of deep cycles of poverty and allow them to participate more fully in their communities. It would allow people to live with more **dignity, choice, and freedom**, increasing social connection and reducing isolation. People with disabilities <u>want</u> financial security.

<u>Positive Effects of a Canada Disability Benefit</u>

Throughout the consultations we spoke to people with disabilities about what they would be able to do if they had more money to meet their needs, and their wants. We heard that people with disabilities would have increased social connections, an improved quality of life, healthier lifestyles and reduced health issues, increased life expectancy, and more involvement in their communities.

We heard that people would be able to afford to participate in physical activities that could help ease some disability or improve mental health; they could eat healthier, more nutritious food; they could volunteer, donate, and contribute to society more fully; they could buy new clothes; they could visit friends and family; they could pay off debts; they could travel outside of their houses and neighbourhoods; they could go back to school.

> ***"Goals and wants aren't in the picture here, right now people can't even cover their basic needs. People should be able to have joy in their lives – go to a concert, educate themselves. More money would mean people wouldn't have to choose between eating and paying their bills."***

We heard from one participant who spoke about not being able to access funding for a needed mobility device in their hometown, but who had the opportunity to rent one through their union. They said, "*I was in Vancouver two weeks ago. And I rented a scooter. Our hotel was right on the water, right on the harbor. So I actually went out by myself, which I've never done before in my life. And I was out on my scooter, and I just went around the waterfront. And that was beautiful."* After speaking more about having access to an accessible transportation device, they said, "*I'm 40 and I've been disabled since I was six. I have never been out either walking around or anything by myself ever."*

We heard that with a Canada Disability Benefit and increased financial security, people with disabilities could have **freedom, choice, and independence**. One participant said, "*With the money we receive now, we are stuck in a cycle."* In addition to increased financial security to cover basic needs, people with disabilities deserve to be able to cover some wants - just like people without disabilities. We heard that poverty is exhausting and all consuming, and that people with disabilities can't think about their wants and goals when they're living in poverty.

Life is about more than basic survival and covering basic human needs. People with disabilities want to go out and treat themselves; they want to travel and see the world; they want to go to the movies. **We heard that people with disabilities want to enjoy their lives in the same way that people without disabilities do. The CDB would help make this possible.**

2. Intersecting Identities

People live with multiple identities. We heard that the intersections of someone's identity **further compounds** the challenges they face as a person with a disability. Various identity markers, such as race, gender, Indigeneity, class, immigration status, family status, and language greatly impact how someone with a disability experiences and accesses current government income programs and benefits. This is essential to consider when designing a new Canada Disability Benefit. Marginalized and hard-to-reach people with disabilities often face additional compounded barriers, such as systemic racism and discomfort or mistrust of government authorities and bureaucracies, medical racism and misdiagnoses, language barriers, culturally specific disability stigmas, and other barriers.

We heard that people with disabilities and other intersecting identities, particularly queer, trans, Black, Indigenous, and racialized, face having to navigate systems of oppression that were founded on concepts of colonialism and racism that continue to perpetuate ableist and discriminatory systems, institutions, and societies.

Additional Barriers Faced by People with Disabilities and Other Intersecting Identities

While we know that all people with disabilities experience discrimination, people with disabilities and other intersecting identities face additional barriers including institutional barriers, community barriers, individual-level barriers, and systemic barriers. Some of the barriers we heard through our consultation of which the Government must consider when designing a Canada Disability Benefit include:

1. **Stigma**

    - Many marginalized communities with disabilities face additional stigmas and misconceptions about disabilities. For example, we heard that for Black, Indigenous, and racialized people who are on government support, they are often viewed as lazy "welfare seekers". We heard that people with disabilities from racialized communities have "always been seen as welfare seekers". When speaking about Black people with disabilities, who have some of the lowest rates of poverty and unemployment in Canada, we heard from one participant, "*The Canada Disability Benefit would allow us as Black people with disabilities to feel some dignity in our own communities, and to feel some dignity around people who already look at us a takers and welfare cases."*

2. Diagnosis & Misdiagnosis

- We heard that marginalized people with disabilities experience intensified forms of oppression due to the combination of ableism and racism. For example, in our current system, a medical diagnosis of disability is often needed as a first step to accessing government disability support programs. We heard in our consultations that for a racialized person with a disability, this may present an even larger barrier, as most doctors diagnosing disability do not have the lived experience of being racialized or marginalized. This often leads to misdiagnosis, dismissal, and other forms of medical racism. We heard from one person who spoke of the difficulty of finding a Black doctor, or psychologist or psychiatrist who would understand and believe their disability, "*This means we have less access to every service and every resource, including these benefits."* We heard from another person with a disability who said, "W*hen it comes to us Indigenous folks, it's more about misdiagnosis. So, they attribute a lot to "oh that person is just drunk or non-compliant", instead of saying "oh that person has a brain injury".*

3. Immigration Status

- Im/migrants, refugees, and newcomers with disabilities in Canada face additional barriers and stigmas. People may fear identifying themselves or a family member as a person with a disability for fear of not receiving permanent residency status, or of being deported. They often have limited access to information and resources, including doctors needed for disability diagnosis; they may have a language barrier and be unable to navigate the required forms and websites to apply for disability assistance or access translation services; they may have immigrated alone and have no network to draw on for support, leading to social isolation. We heard that another major disadvantage for im/migrants, refugees, and newcomers to Canada is that they can often get "stuck" in their initial landing destination. Due to restrictions from immigration laws and/or policies on family sponsorship, im/migrants, refugees, and newcomers with disabilities may be directed to a specific Canadian city. They are often limited in choice on where they live, where they pursue education, and where they can work, and aren't able to move between cities with their family if their family chooses to move. This is a particularly restrictive inequity for im/migrants, refugees, and newcomers with disabilities. Additionally, we heard that im/migrants, refugees, and newcomers to Canada are also vulnerable to acquiring both visible and invisible disabilities, as they are often only able to secure labour intensive jobs. Additionally, many experience feelings of isolation and community disconnect that often result in mental health stressors and psychosocial disabilities.

4. Mistrust of the Government

- We heard that communities of persons with disabilities have a mistrust of the Government due to the historic mistreatment of their communities by the Government of Canada or the Government of the country from which they immigrated. We heard that im/migrants, refugees, and newcomers may distrust the government and fear being deported or having their children with disabilities taken away, making them less likely to disclose disability status and seek out appropriate support. We heard that a similar barrier exists for many Indigenous people with disabilities, as historically Indigenous people who identify as women who reported their children through the tax system would have their children taken away.

The manifestations of having multiple marginalizing identities as a person with a disability are critical to the equitable development of a Canada Disability Benefit. We heard from participants that other federal, provincial, and territorial benefit programs have illustrated that the take-up in these programs by people with disabilities and other intersecting identities is not as high as it should or could be. There are potentially large groups of people who could qualify for the proposed Canada Disability Benefit and might not take advantage of it for reasons related to the intersections of identity noted above. In addition to disability, a person may face systemic barriers related to their race, sex or gender, socio-economic status, immigration status, sexuality, or language that prevent them from taking full advantage of the income assistance programs available. While not all intersecting experiences of disability are captured here, we heard from participants that it is imperative for the Government of Canada to recognize that a person’s experience of disability varies depending on their other intersecting identities, and the design of the Canada Disability Benefit must be as “low barrier” as possible as well as designed through an intersectional lens.

3. Eligibility Criteria

In terms of who should qualify for the Canada Disability Benefit, many participants believe that eligibility and enrollment for the proposed Benefit should be **automatic**. If a person already qualifies for another federal, provincial, or territorial disability program or receives disability income assistance, they should not have to go through an additional or new medical assessment or application to determine eligibility for the proposed Canada Disability Benefit. We heard from many participants about the frustrating process of re-application over many years and having to prove repeatedly that their disability still exists. For participants who do not already receive government income programs or assistance via the (deemed problematic) Disability Tax Credit, a new simple and easy application process would be required.

Defining Disability

Participants told us there must be a **broad definition of disability** that is informed by the UN (United Nations) Convention on the Rights of Persons with Disabilities. We also heard that the current definitions of disability used by various government programs should be reviewed, with the recognition that there should be constant review and updating to the definition as we learn more about disability. We heard from policy professionals that the current definitions of disability under the Disability Tax Credit, the Canada Pension Plan - Disability, and provincial programs like Ontario Disability Support Program (ODSP), are problematic. We heard from the community that the Government should use a hybrid of the current definitions of disability to provide the most expansive definition that puts an emphasis on understanding what disability means in people's daily lives, and that looks at how their disability affects them in multiple spheres. We heard that the definition should be based on a **social model of disability** that also recognizes episodic, cyclical, and invisible disabilities, especially mental health illnesses and psychosocial disabilities.

> ***"Any definition of disability needs to be one that is generated from the community – from people living with disabilities themselves".***

We heard concern from people with disabilities about qualifying for the proposed Canada Disability Benefit, as they view doctors as gatekeepers. We heard that the discussion of eligibility criteria is deeply rooted in a medical model of disability. One individual said, ***"We're trying to separate the deserving poor from the undeserving poor, and 500 years later, why are we still asking disabled people to prove how they're eligible for benefits."*** We also heard concern about getting the correct documentation to qualify for government benefits. If a medical doctor is necessary for a diagnosis and to sign off on certain paperwork needed to access disability support, they must be educated on the complexities of what having a disability means. We heard from one community member who assists people with disabilities in accessing government support programs who said, "*I find in my role, a lot of time, I have to accompany my clients to the doctor's office to explain their disability, because the doctor might not be aware or might not have worked with a lot of individuals with this type of disability. Some of them say no, this is not considered a disability."*

In line with shifting from a medical definition of disability to a social definition of disability, we heard that **we must consider the question of who is assessing for disability**. Once the eligibility criteria for the proposed Canada Disability Benefit are determined, is it still appropriate that we have a medical based model for determining program eligibility? The assessment of disability for eligibility purposes could be opened more broadly to engage alternative options to collaborate to assess and certify for disability. We heard that it isn't just medical doctors who hold that knowledge, and we should begin to think about other people that could assess for disability, including Indigenous healers or other culturally appropriate individuals, counsellors, therapists, psychologist, and others who are more embedded in the relevant community. We heard that this could be especially helpful considering the current shortage of family doctors available. We heard an example from one person who works on policy related to disability and immigration that for a person who is coming from a refugee camp, there is trauma, depression, anxiety, isolation, and a sense of displacement that might be present. Many newcomers with disabilities might not be able to articulate what they are feeling yet. Whoever is assessing for disability must understand both visible and invisible disabilities through an intersectional lens. All disability assessments should have a broad understanding of who someone is and look at physical and mental health, as well as overall social conditions and social positioning. Current eligibility assessments medicalize the system and exclude large groups of people from accessing financial benefits.

We heard that income assistance programs, including for the proposed Canada Disability Benefit program, should be **paying for the diagnosis process**.

> ***"You're talking about somebody who is trying to go on income assistance, and then asking them to pay hundreds of dollars for the paperwork to be completed. They can't afford to pay that."***

Other Qualifying Considerations

We heard that there should be **no employment test**. People with disabilities should not have to be required to demonstrate a certain history or record of labour-force attachment. The proposed Canada Disability Benefit is meant to lift people with disabilities in Canada out of poverty and should not be based on employment status or someone's ability to work.

We heard that there should be **little, if any, asset testing**, like we see in social assistance, where people are required to dispense of their assets before they are eligible to receive assistance. We heard that people should be encouraged to accumulate assets and foster resilience for themselves and their families and this should not affect their ability to qualify for receiving the Canada Disability Benefit.

We heard that individuals should be **legal residents** to qualify for the proposed Canada Disability Benefit, but that there should not be a test of citizenship. Throughout the consultations we heard from people with disabilities that the proposed Canada Disability Benefit should not be tied to a particular provincial or territorial area. The Canada Disability Benefit should be portable and mobile across the country, allowing people receiving the benefit to move freely across the country without fear of the Benefit changing based on the province or territory in which they choose to reside. We heard from one participant who said, "*I have a family member living in Alberta and he's stuck. He can't afford to live here, and if he leaves, he'll get a huge cut to his benefits."*

We heard that the Canada Disability Benefit should be paid on an **individual basis** and based on an individual's income, <u>not household or family income</u>.

"There have been times that my partner and I have talked about legally separating so that I could maybe get disability supports."

People with disabilities should have the choice of living alone or living with family or a partner and not have it affect the level of income assistance they receive. We heard from one person with a disability who said, "*The way it is right now, you are punished when you are in a relationship or live with a family member, even if that's a better option for you."* We heard that currently, if you are in a relationship with someone who's income level is over a certain financial threshold, you will not qualify for disability supports. This disadvantage also has disproportionate implications for people who come from more collective cultural backgrounds. Many other cultures uphold a collective culture, focused on holistic ideas of community, and punishing this ideal is discriminatory towards the diverse population of people living in Canada. Additionally, we heard that distributing the Canada Disability Benefit based on a family/relationship unit assumes that **every household has intra household sharing, cooperation, and bargaining**. This is not the case for many, and an individual based Benefit would allow people with disabilities, particularly people who identify as women, to have autonomy, independence, and dignity, and allow them to feel financially secure to leave unsafe situations or abusive relationships. Lastly, we heard that if a person with a disability cannot qualify for individual disability support and must rely financially on their family, partners, or guardians, they can oftentimes feel like a burden. We heard from an individual who works with people with disabilities who shared the following about someone they support: "*I will never remarry. I will never have the opportunity to remarry, because I will lose all of my benefits. And then I will become a burden to whoever it is that I decide to partner with in the future. And that's just not something I'm willing to do so. So I will be single for the rest of my life. Because I am in poverty."*

4. Access to The Benefit & The Application Process

We heard that the administration processes and service delivery infrastructure that aid in accessing and applying for the Canada Disability Benefit are important. Even the best designed income program will not be of assistance if people face barriers in accessing it. We heard from people with disabilities that the current application processes for accessing government benefits are long and complex, presenting significant challenges for many. We heard from one person who said, "Y*ou need a lot of perseverance to navigate the system".* For the Canada Disability Benefit, there should be a **simple application process** that is consistent across the country, that is easily understandable, in plain language, and can be filled out and processed quickly. We heard that many people need either an advocate to help them navigate the complex system or plenty of time and personal resources to try to navigate it alone. Not everyone has access to this support. One person with a disability said, "*I'm afraid to even apply. There are so many barriers".*

We also heard that when designing the entryway to accessing the Canada Disability Benefit, a starting point should be providing **one simple entryway** to all potential government disability support programs. One person said, "W*hen it comes to accessing benefits across the country, people with disabilities have to knock on 20 different doors*." We heard that it is disheartening for people with disabilities to have to repeatedly discuss and explain their disabilities. We heard from one person with a disability that, "*the application process needs to be designed from the perspective of a disabled person, not through the perspective of some ministry system".*

Flexible Application Process

We heard that there should be numerous and flexible ways to apply for the proposed Canada Disability Benefit. People with disabilities said that the application for the proposed Benefit should be accessible to people with all types of disabilities. Similarly, we heard that the application for the Canada Disability Benefit should be available in various formats, including online, in person, and by phone, as not everyone has the option to access the internet.

Additionally, we heard that there should be potential for a flexible application process, based on the identified needs of specific groups. We heard from an individual who works with unhoused and unsheltered individuals who often have undiagnosed disabilities, who spoke of the barriers individuals face when trying to access government income benefits. Barriers such as a lack of identification (e.g., birth certificates, health cards, status cards, or social insurance cards) needed to complete applications, or having no permanent address. This barrier would also impact people with disabilities who are incarcerated or have been formerly incarcerated who would be eligible for the Canada Disability Benefit. We heard that since the Canada Disability Benefit is meant to lift those in the deepest poverty out of poverty, the design of the application process must be flexible and innovative to allow more people to easily access the benefit.

Compassionate Government Service & Community Engagement

We heard that call centres, with specially trained government representatives, who are trained in providing **compassionate, empathic, and inclusive assistance** to people would make a huge difference in people with disabilities experience in accessing government benefit programs. Many people expressed frustration in dealing with the current systems, expressing that they felt most government staff have a limited knowledge of disability, and stereotypical, ableist, or stigmatized views of who people with disabilities are. We also heard there needs to be consistency within the government, as many people shared experiences of receiving different answers from each person in the government they spoke to. We heard from one participant that we need a more compassionate way of administering our benefit systems.

"I refuse to believe that we can't teach systems to be kind and compassionate, because we create those systems."

We heard that for the Canada Disability Benefit, the Government should explore funding independent "**Navigators**" who could assist people to navigate the complex systems currently in place. For the Canada Disability Benefit to reach people with disabilities most in need, there needs to be very specific and targeted outreach to hardest-to-reach communities. We heard that the Government of Canada should engage with community organizations that could assist people with knowledge and awareness of the available government financial benefit landscape. We heard from one community service worker that community organizations can establish "warm connections" between hardest-to-reach people with disabilities and government departments to assist in with accessing and applying for government programs; they said, "W*e need to make sure that this new Benefit program* ***is not just something that somebody has to go find, but to some extent, it finds you****."* Additionally, we heard that this system of compassion and community support would help to eliminate the companies that target vulnerable populations and offer assistance in navigating the complex application process for a steep (and unethical) fee.

We heard from participants that there must be very clear and fair **review and appeal processes** for people to be able to challenge the decisions that are made regarding eligibility and applications. It is important for the Government of Canada to provide avenues for re-course for applicants, particularly if the Government is considering one single avenue for entry to the Canada Disability Benefit.

Finally, we heard that there is a **lack of knowledge and awareness** amongst people with disabilities about what benefits currently exist and how to access them. We heard that information about the new Canada Disability Benefit must be well publicized and promoted, and made available in various languages, including sign language, and in an easy-to-understand format in order to be accessible to as many people as possible. To lift people with disabilities out of poverty, we must ensure that the community is aware of the Benefit and can easily access it if they are eligible.

5. Benefit Interaction

We heard great concern from many people about how the new Canada Disability Benefit would interact with other existing federal, provincial, and territorial supports. We heard that there should be absolutely **no claw backs** with this new Benefit and that there should be strong legislation and/or regulations in place to disallow provinces and territories from clawing back benefits from other existing programs. For the Canada Disability Benefit to be effective in lifting people with disabilities out of poverty, it needs to be complimentary and build on to existing benefits, not replace them.

> ***"Right now nobody is allowed to stack benefits – this is legislated poverty because it keeps people below the poverty line. People with disabilities are scared that bringing in this new Canada Disability Benefit is going to take away what they already have."***

We heard from the disability community that this new Benefit should not be used by provincial and territorial governments as their own cost saving mechanism to reduce payouts to their own programs. People need to be able to maintain their existing health benefits, transportation allowances, adaptive equipment, employment supports and other in-kind benefits available from provincial and territorial government. The Canada Disability Benefit needs to be a top-up program and established as a floor, not a ceiling for combined assistance.

Throughout the consultations we heard that it is extremely important that the federal government work with the provinces and territories to ensure a positive interaction between different benefit programs. We heard that to avoid claw backs and other negative unintended impacts, the relationship between federal and provincial/territorial governments should be mapped out in detail to outline a strategy for creating a more coherent benefit landscape.

In addition, we heard that part of a coherent benefit landscape with no claw backs includes not just the protection of essential provincial and territorial programs, but federal social services and programs as well. We heard concern that the cost of the proposed national Canada Disability Benefit program may tempt the federal government to cost save on other vital social service programs, leaving many people with disabilities with no benefit as they gain financial security in one area and lose it in another. We heard that the federal government must also be held accountable for looking internally to ensure they are not taking resources from one important program to pay for another.

I am concerned that the proposed Canada Disability Benefit will draw money away from other vital needs such as housing and yet not end up making a big difference for people with disabilities. I think that provincial governments will respond by not increasing funding for community living. Families and individuals will end up using the Canada Disability Benefit to pay for programs.

Employment Income

We heard that the Benefit should include a **generous earnings exemption**; larger than what we have now. We heard that people with disabilities want to work – they just don't have the opportunity and are penalized financially if they do. Someone's desire to work and improve their quality of life should not have a negative impact on their Benefit amount.

"Under no situation, under no circumstance, in any province or territory, can someone be worse off by going to work."

We heard concern that the Canada Disability Benefit cannot have earning exemption rules that cause people to not want to work or be motivated to leave work to gain better access to government supports. Allowing people with disabilities to continue working allows them to establish an asset base, which helps support the added cost of disability. We also know that employment is not just about wages - employment builds self-esteem, self-value, and a sense of contribution. We heard from one participant that said, "*You want to make sure that you support people in working. It is not about cheating the system or getting more money, it's about allowing people to amass a financial base."*

Other Considerations

We heard that the proposed Canada Disability Benefit should not be tied to the **Disability Tax Credit**. We heard throughout the consultation that the Canada Disability Benefit should be detached from the income tax system and not dependent on filing a tax return. Many people do not file taxes, and this creates a barrier to accessing income support through this route. Additional barriers include the forms being too long and complex, with many people needing assistance to fill them out; the forms only being available in two languages (English and French); the exclusionary criteria and difficulty of diagnosis; as well as the need to reprove your disability over and over to continue qualifying. We heard from one participant who said, “***We in no way shape or form should have a tax auditor auditing a medical condition***.” Another individual said, “***The Canada Revenue Agency is a tax collection agency, and their ethos and value is about catching tax cheats, and that is totally antithetical to delivering benefits to vulnerable groups***.” Additionally, we also heard that the Benefit should be **non-taxable**. We heard that the new Canada Disability Benefit needs to be defined as benefit income, so that it is not taxable. It should be treated like the Canada Child Benefit, or the Guaranteed Income Supplement, and not delivered through the tax system.

We heard many differing opinions on the issue of **income testing**. Some participants said the Canada Disability Benefit *should* be income tested. Supporters of income testing the Benefit said that including an income testing component would allow for more poverty reduction by ensuring that people with the lowest incomes receive more benefit and that if you have sufficient support from other places, you do not receive the Benefit. We also heard from participants who supported the idea of a universal Canada Disability Benefit, *without* income testing. This perspective said that income testing the Benefit would be problematic, as many people with disabilities have variable work experiences and abilities, and this would see the policing of eligibility criteria, leaving people out, disempowering people, and forcing people to make a case for themselves, ultimately leading to exclusion.

6. Amount of the Canada Disability Benefit

We heard that the Canada Disability Benefit should ultimately raise the income of people with disabilities in Canada **above the poverty line**.

“The poverty line should be the floor, not the ceiling.”

Throughout the consultations, we heard that the first hurdle that we must get across in determining the amount of a Canada Disability Benefit is understanding Canada’s official poverty line. There are numerous different poverty lines across the country, each accounting for regional differences. During the consultations we heard debate on which of the various measures of poverty should be used to calculate the poverty line that the Canada Disability Benefit should strive to lift people with disabilities above, including a Living Wage, the Market Basket Measure, and the Low-Income Measure. We heard that with a federal benefit, you cannot have a one size fits all benefit that will be sufficient in every province and territory.

There was also debate surrounding whether the Canada Disability Benefit should account for the extra cost of disability, or not. One perspective we heard was that the amount of the Canada Disability Benefit should give people a living wage but should also consider providing a percentage above the living wage to **account for the extra cost of having a disability**. Another perspective we heard was that while the Canada Disability Benefit could provide a percentage above the living wage to account for the extra cost of disability, this percentage should not replace the special recognition of technical aids, adaptive equipment, assistance, medication, services, and other disability supports. This perspective shared that the extra cost of disability is impossible to evaluate at a standard level. We heard from one disability policy professional who said, "*We can't make the mistake of saying we'll throw in an extra $5000 and that will cover everybody's special needs. That is not the case."* We heard from another person who spoke of the importance of having income support and separate programming for the additional costs of disability supports; they said, "A *one size fits all program fails to acknowledge that heterogeneity is vital to ensuring that people get the supports they need; you don't just need income."*

In terms of the amount of the Canada Disability Benefit, we heard many individuals refer to Canada Emergency Response Benefit (CERB) as a benchmark for how much the Government of Canada has already recognized is necessary to cover basic expenses, at $2,000 per person per month. Although the proposed amount of the Canada Disability Benefit varied greatly throughout the consultation, we heard that if the amount of the Canada Disability Benefit accounted for and acknowledged **the additional cost associated with disability,** it should fall in the range of $2,200 to $2,400 per month and be **indexed to the cost of living/inflation**. We heard that due to inflation, people with disabilities receive a *reduction* in disability income assistance each year if the benefit amounts aren't indexed to inflation and the increasing cost of living.

Throughout the consultation, some participants were hesitant to suggest a set amount for the Canada Disability Benefit. We heard that there should be a provision within a Canada Disability Benefit that allows for it to be individualized and flexible (or adjusted), based on someone's particular needs and geographic location. We heard that a person's geographic location will create major differences in the amount they would need monthly. A person with a disability living in a city versus a rural community versus the Northern Territories will have vastly different expenses. There is no one person with disabilities; every person with a disability is unique and has unique needs. We heard that if we want to have an effective disability support program, it needs to be responsive to peoples' particular needs and situations.

7. Societal Value Shift

Throughout our consultation, we heard from people that the general population is not aware of how people with disabilities in Canada are treated. **We need to do better as a country to support people with disabilities**. We should aspire to be the best country in the world to live in for people with disabilities. The new Canada Disability Benefit could be a national point of pride; a program that illustrates our dedication as a country to support people with disabilities and our progressive realization of the UN (United Nations) Convention on the Rights of People with Disabilities, which Canada has signed and ratified.

We heard that we need to work to counteract the impacts of ableism, to address inaccessibility, and to take responsibility for the way we view and assign worth to people with disabilities in our society. We heard that people with disabilities are not considered contributors to our economies or communities, and so are not given value or worth. People described the negative stereotypes, attitudes, and misconceptions that exist about people with disabilities in our society, and how these manifests in shame and isolation. We heard that we need to shift the way we view disability in our society and provide **accessibility as a human right**.

We heard that in our society the Government of Canada interacts with people with disabilities as their gatekeepers, policing people with disabilities from the beginning of the process of trying to access disability support. People are made to prove that they're telling the truth about their disability needs, to prove their disability and prove that they're not "taking advantage of the system". We heard from one person who said, "***They are not set up to help you qualify. They are set up to police for integrity***." We heard from another individual who said, "***There's always people who will try to cheat the system, but you can't define the system and design it based on the cheaters – you can't punish 99% for the actions of 1%.***"

We heard that the Canada Disability Benefit needs to be a **value driven program**. A new Canada Disability Benefit could give people with disabilities a sense of self-determination. People would be better supported to choose their own path in life.

> ***"These are not values of pity, or values of taking care of people, these are values of removing barriers that we have created as a society to allow people to be able to live lives of dignity, and we should stand behind that."***

8. Need for a Larger Agenda to Reduce Poverty Amongst People with Disabilities in Canada

Throughout the consultation, we heard that the Canada Disability Benefit is just one piece of a larger agenda needed to reduce poverty among people with disabilities in Canada. We heard that poverty is not just about money. People with disabilities in Canada need access to resources, supports, and opportunities to fully participate in every aspect of their communities.

We heard that an agenda that will truly reduce poverty amongst people with disabilities in Canada will need to include systemic level transformation in various areas. Real change will be sustainable long-term and include a comprehensive approach. We heard that a larger agenda to reduce poverty amongst people with disabilities would include access to treatment, personal supports, affordable and accessible housing, as well as internet and phone services, transportation, healthcare, education, food security, and employment.

We heard from a national disability organization that an essential pre-requisite for effective poverty reduction could be a publicly funded national disability insurance plan that provides essential supports for persons with disabilities throughout their lifetime as an entitlement. This long-term, sustained provision of essential supports and services would work to fill the disability supports gap in Canada's social safety net. They indicated this type of program would supplement the much-needed Canada Disability Benefit (CDB) and address gaps that the CDB may not provide relief to. They prepared a separate report outlining the principles of such a plan and how it could be very complimentary to the CDB. This report will be included as a separate document and submitted to Employment and Social Development Canada (ESDC) for consideration as part of the environmental scan of the DIAP project. The organization has recommended that ESDC consider future work, or a larger literature review directed toward examining the feasibility of a complimentary national disability insurance plan.

We also heard that increased cross-movement collaboration for disability justice will amplify advocacy surrounding the human rights of people with disabilities in Canada. In relation to the importance of the Canada Disability Benefit for reducing poverty, we heard from one individual who said, "*It is not just a benefit, it is an infrastructure piece."*

9. Other Issues Raised in Consultation

Throughout the consultation, we heard about other issues related to income security, poverty, and the proposed Canada Disability Benefit.

Data Collection

Numerous participants throughout the consultation spoke about the importance of data collection and the need for better disaggregated data to understand how accessible the proposed Canada Disability Benefit is, how well it is supporting people, and who it is not reaching once implemented. This collection of data is especially important for ensuring the inclusion of hardest-to-reach people with disabilities in accessing and benefitting from the Canada Disability Benefit. We heard that we also need to collect data from everyone who experiences disability, not just those who are receiving the program, and then ensure resources are in place to remove barriers for those who are not receiving the program, particularly those who are socially isolated.

A Northern Strategy

We heard that a Northern strategy needs to be developed to specifically address the unique challenges of financial insecurity that exist in Northern, remote areas of the country. We heard that this strategy should be led by Indigenous leaders and disability organizations in the North. We heard from people working in a disability organization in the Northwest Territories who echoed the idea that the amount of the Canada Disability Benefit should consider someone's geographic location. The cost of living in the Northwest Territories is one of the highest in the country, exponentially increasing as one moves further from the city centre. In many Northern, remote communities, unique barriers exist such as a lack of infrastructure, high levels of unemployment, food insecurity, and housing insecurity. Additionally, specific challenges related to healthcare disproportionately exist. One person called it a health crisis, saying, "*There are not enough doctors and nurses; a community may have a nurse who flies in from time to time, but if you need a hospital, they have to medivac you, and you need special coverage to access this."* This creates a barrier for people with disabilities to access a basic or emergency healthcare, as well as a disability diagnosis and access to government programs and support. We heard that the unique circumstances that exist in the Northern regions of the country create additional and disproportionate barriers for people with disabilities and must be addressed through a Northern Strategy.

The Benefit Age Requirement

We heard concern about the age requirements to be eligible for the Canada Disability Benefit and scrutiny of why the Benefit would stop at age 65. We heard that at the age of 65, your disability doesn't magically disappear, and the additional costs of disability are still present. We heard that there would need to be some negotiation of how the Canada Disability Benefit transitions to other income security options that are available when your reach the age of 65. Government must be mindful to ensure financial programs for 65+ have a similar disability component funded at the same level as the Canada Disability Benefit. Individuals should be no worse off than when they were 64.

Next Steps

These consultations have provided valuable insight and perspectives into understanding the lived experience and financial insecurity among people with disabilities in Canada, as well as views on how the proposed Canada Disability Benefit should be designed and implemented. **We heard that poverty makes life challenging, not disability,** and that the proposed Canada Disability Benefit must be designed from an intersectional lens and from the perspective of a person with a disability. We heard that the disability community wants broad eligibility, with a simple application process, no claw backs from their existing benefits, and a benefit amount that brings people above the poverty line. We heard that we need an attitudinal shift as a society to provide accessibility and financial security as a human right. The Canada Disability Benefit will start to give people with disabilities the opportunity to live more fully, more comfortably, and with more dignity.

This consultation was an important first step in considering the design and development of a proposed Canada Disability Benefit aimed at improving the lives of people with disabilities. It will be important that the federal government takes these views and perspectives into consideration as it drafts regulations on program criteria, eligibility, and the administration of this new benefit.

Annexes

Annex A – Participating Organizations (who held focus group or participated in a key informant interview or focus group)

Organization who provided responses to consultation questions provided their own views or that of their disability organization.

Pillar 1 Participating Organizations included:

- Accessibility for All
- Alliance for Equality of Blind Canadians
- ASE Community Foundation for Black Canadians with Disabilities
- British Columbia Aboriginal Network on Disability Society (BCANDS)
- Burnaby Association for Community Inclusion
- Canadian Association of the Deaf
- Canadian Food Centres Canada
- Canadian Autism Spectrum Disorder Alliance (CASDA)
- Canadian Mental Health Association
- Canadian Multicultural Disability Centre
- Canadian National Institute for the Blind (CNIB)
- Centre for Research on Work Disability Policy (CRWDP)
- The Cerebral Palsy Association of Manitoba
- Council of Community Living Ontario
- Disability Without Poverty
- DisAbled Women’s Network Canada (DAWN)
- Down Syndrome Association of York Region
- Every Canadian Counts
- Eviance
- Human Rights Department of the Canadian Labour Congress – Disability Rights Working Group
- Inclusion BC
- Inclusion Canada

- Inclusion Nova Scotia
- Income Security Advocacy Centre (ISAC)
- INÉÉI-PSH National Institute for Equity, Equality and Inclusion
- Institute for Research and Development on Inclusion and Society (IRIS)
- L'Arche Canada
- LiveWorkPlay
- March of Dimes
- Mount Paul Community Food Centre – Interior Community Services
- Multiple Sclerosis Society of Canada
- Muscular Dystrophy Canada
- Northwest Territories (NWT) Disabilities Council
- Ontario Council of Agencies Serving Immigrations (OCASI)
- Ontario Disability Support Program (ODSP) Action Coalition
- People First of Canada
- Plan Institute
- Project Pal
- Realize Canada
- Supporting Employment & Economic Development (SEED) Winnipeg
- Sinneave Foundation
- Social Planning Council of Winnipeg
- Spinal Cord Injury Canada
- Staying Connected Network
- Welcome Hall Mission

Annex B – Focus Group & Key Informant Interview Questions

1. Do you feel like you have enough money to meet your needs and goals? What could you afford to do if you had more money that you can't do today?

2. What do you think are the most important things to think about when designing the new Canada Disability Benefit?

Some examples could be:

   a. Allow people to keep some of their earnings from work (*Earning exemptions*)
   b. Keep all existing benefits, including health benefits, transportation allowances, adaptive equipment, employment supports and other benefits available from provincial and territorial governments or other federal benefits (*No claw backs*)
   c. Allow people to live with who they want or with their family and still receive the benefit (*Individual income-based, not family income -based*)
   d. The amount of the Canada Disability Benefit

3. Do you have concerns about what this benefit might mean for you? Some examples could be:
   a. Affecting your current benefits and disability supports
   b. Not being eligible
   c. Not being the same depending on where you live across the country
   d. Your family or relationship income affecting the amount of the benefit
   e. The length of time it will take to get the benefit started
4. What barriers do you currently experience in accessing government income benefits?
5. Who do you think should receive this new benefit?
   a. How should that be determined?
6. What do you think would be the easiest way to access this benefit?
   a. Some examples could be:
      i. Everyone currently receiving disability benefits (through any government program) is automatically eligible for the new benefit
      ii. Everyone needs to apply through a new and separate application
      iii. People currently receiving benefits automatically get the new benefit, and people who do not currently receive any benefits need to apply for the new benefit
7. A living wage is the hourly wage which reflects what people need to earn to cover the actual costs of living in their community (food, clothing, rent, childcare, transportation, small

savings etc.) An average living wage (for a family of 4) has been estimated at $3,017/month. Another organization estimates the living wage for an individual to be $2052/month by 2023.

   a. In Canada, current disability rates range from a high of $1685 per month in Alberta to a low of $697 per month in New Brunswick, with most provinces and territories offering about $900-$1100/month. How much funding per month do you think people with disabilities should receive in a disability financial support to meet their needs or goals?

8. Is there anything we didn't ask about creating the Canada Disability Benefit that you feel is important and want us to know?

In addition to the focus group questions, we asked additional questions in our key informant interviews, including:

1. How do certain identity markers (race, gender, Indigeneity, class, immigration status, family status, and language) impact or add another layer to the barriers that people with disabilities face?
2. What are the potential positive effects of a Canada Disability Benefit for __________ (particular population)?
3. What are the potential unintended impacts regarding a Canada Disability Benefit for __________ (particular population)?
4. What are some daily/weekly/monthly things you are doing to compensate for any financial challenges, if any?
5. The Canada Disability Benefit is just one piece of a larger agenda to reduce poverty among People in Canada with disabilities. What else has to be part of the agenda?

Annex C – Demographics of Participants

Table 1.1: Province/Territory of participants

Provinces/territories	Percent
British Columbia	20.3%
Alberta	9.3%
Saskatchewan	1.7%
Manitoba	5.8%
Ontario	39%
Quebec	4.1%
New Brunswick	4.7%
Nova Scotia	9.9%
Prince Edward Island	1.7%
Newfoundland and Labrador	0.6%
Yukon	0.6%
Northwest Territories	1.2%
Nunavut	1.2%
Total	**100%**

Table 1.2: Gender Identity of Participants

Gender Identities	Percent
Women	57.6%
Men	38.4%
Non-Binary	2.9%
Preferred Not to Answer	1.2%
Total	**100%**

Table 1.3: Types of Communities of Participants

Community Types	Percent
People living in a city with 100,000 people or more	57.4%
People living in mid-sized city or town with around 10,000 to 100,000 people	21.3%
People living in a village or town with less than 10,000 people	13%
People living in a rural community	5.3%
People living in a remote or difficult to get to part of the country	2.4%
People living in a mid-sized city, but in a rural part of it	0.6%
Total	**100%**

Table 1.4: Living Arrangements of Participants

Types of Living Arrangements	Percent
Family members	43.5%
Alone	29.2%
Partner	14.2%
One or more roommates	10%
Congregate care setting	1.4%
Supervised apartment	0.7%
Alone with Supervision	0.7%
Supportive housing	0.7%
Total	**100%**

Table 1.5: Main Source of Income of Participants

Types of Income	Percent
Government Benefits	42%

Types of Income	**Percent**
Work (full-time, part-time, seasonal, contract, and self-employment)	41%
Family Support	15.2%
Pension	7.2%
Savings	2.1%
Rather not disclose	2.8%
Total	**Variable***

*Some respondents reported more than one source of income, therefore totals equal more than 100%

Table 1.6: Employment Status of Participants

Employment Status	**Percent**
Employed in Full-Time or Part-Time work	50.4%
Not Employed	42.7%
Self-Employed	5.6%
Rather not disclose	1.4%
Total	**100%**

Table 1.7: Age of Participants

Age	**Percent**
Younger than 25	7.8 %
25-34	17.4%
35-54	44.9%
55-64	18.6%
65+	10.2%

Age	Percent
Preferred not to say	1.2%
Total	**100%**

Table 1.8: Ethno-racial Identity of Participants

Ethno-racial groups	Percent*
Caucasian (white)	81.5%
Black or of African Decent	8.3%
Indigenous	5.4%
Arab	1.8%
Chinese	2.4%
South Asian (for example: East Indian, Pakistani, Sri Lankan)	2.4%
Filipino	0.6%
Southeast Asian (for example, Vietnam, Cambodia, Thailand)	1.2%
Japanese	0.6%
Latin American	1.2%
Multiracial	3%
Another racialized or visible minority group	1.2
Preferred not to say	1.2
Total	**Variable***
*****Some respondents reported more than one group that they identified with, therefore totals equal more than 100%	

Table 1.9: Citizenship of Participants

Citizenship	Percent
Canadian citizens	94.1%
Permanent residents	4.1%
Refugee	0.6%
Newcomers	0.6%
Preferred not to say	0.6%
Total	**100%**

Table 1.10: Language of Participants

Language	Percent
English	95.9%
French	1.2%
Fluent in both English and French	5.3%
Another Language	3.6%
Total	**Variable***

*Some respondents reported more than one language spoken, therefore totals equal more than 100%.

Table 1.11: Types of Disabilities of Participants

Types of Disability	Percent*
Physical disability (for example: mobility, bending, reaching, grasping)	47.6%
Intellectual or development disability	29%
Learning disability	22.1%
Psychosocial disability (for example: mental health	28.3%
Seeing disability	13.1%

Types of Disability	**Percent***
Communicating disability	11%
Hearing disability	9.7%
Preferred not to say	6.9%
Other disability	10.5%
Total	**Variable***

*Some respondents reported more than one kind of disability, therefore totals equal more than 100%.

Addendum to Inclusion Canada’s What We Heard Report: Thematic Survey Analysis

Disability Inclusion Action Plan (DIAP) Pillar 1:

Financial Security – The Canada Disability Benefit

March 2023

Introduction

In October 2022, as part of the Disability Inclusion Action Plan (DIAP), all four DIAP Pillars created a joint national survey to build on the previous DIAP consultations. The survey collected a broad range of information about the lived experiences of Canadians with disabilities. It included questions on all 4 pillars of the DIAP: Financial Security (The Canada Disability Benefit), Employment, Disability Inclusive Spaces, and Modernizing Federal Government Programs and Approaches to Disability.

The survey included a total of 9 questions on Pillar 1, Financial Security (The Canada Disability Benefit). Most questions were quantitative in nature; however, 2 questions were qualitative and asked survey participants to explain and describe their experiences. Below is a thematic analysis of the 2 qualitative survey questions on Pillar 1, Financial Security. The analysis outlines some of the major themes that emerged from the survey responses.

Important Considerations

While considering the results of this survey, as well as the rest of the broader consultation, it is important to keep in mind who would have had access to this survey and the barriers and challenges that exist for some to participate in an online survey. This includes barriers and challenges such as: time, survey fatigue, internet access due to remote location or cost, access to technology and/or assistive technology devices, technological literacy/digital capabilities, language, communication challenges, and other barriers. It is important to keep this in mind while considering the experiences being shared. It’s vitally important to consider what perspectives are missing through these particular survey results.

Q 34: Have you experienced poverty? Please tell us what it is like to be a person with a disability living in poverty.

- **Yes**: 539 (68%)
- **No**: 246 (31%)

Survey respondents were not required to complete every question on the survey. They were given the option to share what they were comfortable with. 785 participants chose to answer this question, while 471 did not answer. 68% of respondents said that they have experienced poverty, and 31% said that they have not.

“No, I Haven’t Experienced Poverty, But…”

Through the survey results we heard that peoples’ experiences of poverty were not black and white; many people expressed that they had dealt with poverty to some degree at some point in their life thus far.

Many of the survey respondents who answered no, they did not experience poverty, went on to explain that while they weren’t currently living in poverty, they felt they were just “one thing” away from living in poverty, and that it could happen at any moment. Many people anticipated poverty in their future.

Many survey respondents who answered no, they were not living in poverty, said that while they didn’t consider themselves in poverty, they were unable to access the medical and assistive devices that they needed to maintain a good quality of life.

Many survey respondents who answered no, they were not living in poverty, said that the only reason they weren’t living in poverty was because they were living with their parents/family/partner/spouse who supported them and covered their cost of living. Many respondents expressed fear around what would happen when their parents/family/partner/spouse weren’t here anymore. One survey respondent said, “I have to live with my parents, and I won’t be able to live on my own when they die. I will seek out medical assistance in dying (MAiD) when they pass”. Another survey respondent said, “If I didn’t have the benefit of being married to a very supportive women, I would be living on the streets”.

Key Themes

The qualitative survey results confirmed many themes from the broader consultation on the Canada Disability Benefit. The *top 5 themes* of this survey question on respondents’ experiences with poverty included: isolation, stress and exacerbation of mental health issues, basic needs not being met, dependability and lack of financial autonomy, and feelings of shame, embarrassment, and dehumanization.

1. Isolation

Many survey respondents expressed that living in poverty with a disability made them feel isolated, removed or withdrawn from society, forgotten, or alone with no sense of community or societal value. One survey respondent said “poverty is more than being without money.

Emotional poverty is even worse because you become isolated and feel worthless because society doesn't value you as a person.” Survey respondents said that they felt like going out of the house would cost them money, and so they had to stay home, making if difficult to make or maintain friendships, relationships and other social connections. Another survey respondent said, “poverty limits your participation in all aspects of life: education, fun, social, art, just getting a coffee with friends is out of reach”. Furthering the feeling of isolation, some survey respondents said that living in poverty with a disability meant some months they had to cancel their phone/internet plans to save money, leaving them feeling even more isolated from their communities and the rest of the world.

Survey respondents also expressed feelings of not only social isolation, but physical isolation. Respondents said that access to accessible transportation was a huge challenge and further isolated them as they were unable to afford repairs to their broken mobility devices, unable to afford accessible public transportation, or unable to afford a retrofitted personal vehicle. In addition to affecting peoples’ opportunities for social connection, respondents expressed that a lack of affordable accessible transportation also limited their ability to attend their medical appointments, travel to the food bank, or travel to work, limiting their opportunities for employment.

2. Increased Stress & Exacerbated Mental Health Challenges

Another key theme expressed within the survey responses was that being a person with a disability living in poverty greatly increased stressed and exacerbated mental health challenges. Many survey respondents expressed that the daily stress of living in poverty compounded their health issues, both physically and mentally, increasing anxiety, depression, and worsening their overall mental health. Respondents said that living in poverty made them feel that they had no control over their own lives, making them feel vulnerable, unsafe, and fearful of the future. One survey respondent said, “knowing that I can apply for Medical Assistance in Dying (MAiD) is a dangerous slope as I am regularly considering assisted suicide, especially when my survival resources run out”.

3. Basic Needs Aren’t Being Met

Throughout the survey responses, people with disabilities living in poverty overwhelmingly said that they did not have enough income or support, and their basic needs weren’t being met. Respondents expressed that they were living paycheque to paycheque, unable to afford safe accessible housing, food, clothes, medication, or therapies. Respondents said that they had to find ways to cut costs by turning their heat off even in the winter, not purchasing the proper clothes for the season (for example not buying winter boots and a winter coat), only eating one meal a day, using food banks, or staying in subsidized housing even if it was unsafe. Survey respondents expressed that they could barely meet their basic needs and were unable to do anything outside of basic survival, with no possibility of saving. One survey respondent said, “with most supports not being indexed to inflation, people are barely getting by, and it’s getting worse”. Respondents expressed having to max out credit cards to make up the difference and cover their basic necessities.

Many respondents reported that they were experiencing nutritional deficiencies and malnutrition due to not having enough money to purchase nutritious foods or maintain a healthy diet, only being able to eat once a day, or relying on food banks where they had no control over their food choices. They said that this was worsening their disability and overall health.

4. Lack of Financial Autonomy & Dependability

Another major theme expressed by people with disabilities living in poverty was that they felt dependent on others and lacked financial autonomy. Many respondents shared that they were forced to stay in abusive relationships or unsafe living arrangements because they didn't have enough money to leave and had no other option. One respondent said, "I am happily married but even if I weren't I would be unable to leave my husband. If my husband ever got tired of carrying the whole financial load for our family I would be homeless". Another survey respondent expressed that they would have liked to leave their abusive relationship, but they had no money to escape and shelters would not accommodate their complex health and disability needs, leaving them with nowhere to go. Many respondents said that because of a lack of government income support for persons with disabilities, employment discrimination and government clawbacks, they were totally dependant on others to survive, giving them no autonomy or choice in their lives and often making them feel like a burden.

5. Feelings of Shame, Embarrassment, and Dehumanization

The final theme that came up through the survey responses was that people with disabilities living in poverty often felt shame, embarrassment and dehumanization. Many respondents said that they were treated as less than human in our society and by our government and felt worthless. One survey respondent said, "people look at you differently and then you look at yourself differently". Respondents expressed that this depleted their self-worth and increased feelings of isolation and mental health challenges. Respondents said that they often felt embarrassed that they couldn't afford to maintain getting regular haircuts, buying new clothes, or getting their nails done. Or that they couldn't afford to attend their loved one's weddings or buy gifts for their families. One survey respondent said that they aren't able to make any fun memories because their life involves just trying to survive day to day.

Additionally, some survey respondents said that living in poverty made them feel shame and embarrassment, especially within their personal relationships. One survey respondent expressed that they were embarrassed to have to always rely on their family and felt no sense of independence. Another respondent said, "there is constant stress and humiliation of feeling like I have to beg others for help".

Many survey respondents expressed that the proposed Canada Disability Benefit must be based on a human-rights focused framework that doesn't dehumanize people with disabilities for "taking advantage of the system". Many respondents said that they felt criminalized because they had a disability and were seeking government supports. One respondent said, "I am a non-person to my government. Not important enough to care for. Disabled people are invisible in Canada".

Q 35: Different people experience poverty differently. Things like race, sexual orientation, gender, or personal identity can affect poverty. Do you have any personal experiences with this you would like to share?

Important Considerations

Survey respondents were not required to complete every question on the survey. They were given the option to share what they were comfortable with. Of the survey respondents who chose to share their experiences with the intersections of their identity and disability poverty, common themes included: sex, gender, gender identity or expression & sexual orientation, family status and support, race, immigration status, and weight.

People live with intersecting identities. Someone's sex, age, gender identity or expression, sexual orientation, race or ethnicity, Indigeneity, class, immigration status or place of origin, family status or composition, and/or language can further compound how someone experiences disability poverty.

Although some themes emerged from the survey responses, these themes are not extensive. Some individuals can experience some of these barriers, all these barriers, or additional barriers not mentioned here. While considering the results of this survey question, it is important to keep in mind what perspectives and experiences we might be missing through these particular survey results.

Key Themes

1. Sex, Gender, Gender Identity or Expression & Sexual Orientation

One theme that was identified through the survey responses was that someone's sex, gender, gender identity or expression, or sexual orientation can affect the way they experience disability and/or poverty, and access to employment opportunities, housing, medical services and support.

Some survey respondents who identified as women expressed that they often found it extra difficult to get by as a woman with a disability, especially when it came to things like shared housing. We heard from some survey respondents who identified as women with a disability living in poverty who said that they were at an increased risk for gender-based violence, and some said they were stuck living with their abusers because they were unable to afford to leave.

Some survey respondents who identified as queer and/or transgender expressed that the intersections of their identity compounded the barriers they already faced as a person with a disability. One survey respondent said, "being queer and disabled can be very scary. There are stigmas still attached to both facets of my lived experience". Some survey respondents who identified as queer and/or transgender said that they experienced additional fears and barriers within the medical system or when trying to access social services such as housing. One respondent said, "homelessness would be really bad for me. I'm nonbinary and shelters are very gendered. My family is homophobic so that's not an option but my identity complicates things and makes it so housing is a scary thing for me that I anticipate [becoming poor] and feels like it always might happen". Another respondent said, "being disabled and queer is a scary experience – it comes with a lot of fear and avoidance of trying to access social service supports for additional fear of being treated poorly for gender identity”.

2. Family Status & Support

Another theme that came up through the survey responses was that someone’s family status or level of family support may affect how someone with a disability experiences poverty. As was mentioned in previous survey question, for some people with disabilities, the only thing keeping them from living in poverty or experiencing houselessness is the support of their family. We heard through this survey question that some people with disabilities may not benefit from this family structure or level of support. For example, some Indigenous survey respondents said that they didn’t have generations of family support due to the impacts of residential schools, colonialism, and intergenerational family trauma. Additionally, some survey respondents who identified as queer and/or transgender said that because of identity-rejection from their family they were unable to rely on them for social or economic support.

3. Race

An additional theme that emerged through the survey responses was that people who were racialized experienced additional compounded barriers and discrimination that intensified the forms of oppression that they experienced as a person with a disability. Some survey respondents who identified as racialized expressed that in addition to their disability, they experienced interpersonal, institutional, and systemic racism. One respondent said, “when it comes to seeking accommodations or help by social systems, I'm often confronted with racist staff that think I'm trying to lie or take advantage of the system”. Another survey respondent said, “I am a female person of colour (POC) who is also LGBTQ. I can’t access unbiased basic health care, let alone any further care. I feel that being who I am makes everything harder. Because it does. Systemic racism, generational trauma, record high inflation, the pandemic - all these things hit me harder”.

Some survey respondents identified that because of their race and/or gender identities, they were at odds with the white, patriarchal, and heterosexual norms that are still pervasive in today's society. They expressed that this had negative consequences on their ability to access important systems such as healthcare, social services, educational opportunities, professional development, and employment opportunities.

4. Immigration Status

Another theme that emerged through the survey responses was that people with disabilities who had immigrated to Canada experienced additional barriers and forms of oppression. Some of the survey respondents who identified as immigrants reported feeling lonely, with no support system to fall back on, experiencing additional discrimination within the job market, having difficulty accessing health care, and experiencing language barriers. One respondent said, “I am a cis [gender] racialized immigrant woman. I have some privilege over other women like me, for example, I can speak both official languages, I have post secondary education, I have status. I know many in my community who don't have the same privileges and their experience of disability is far more dire than mine. They cannot even speak of their experiences and every consultation and survey excludes them as they cannot read/speak English or French”.

5. Weight

We heard from a few survey respondents who expressed that their body weight was used as an additional factor of oppression and basis of discrimination. One survey respondent said, “as a plus size woman with a disability, I get judged by doctors, employers, and the general public [. . .] my extra weight gets blamed for my mobility issues. Its not the weight, [. . .] its very frustrating and humiliating. I've been told I overreact and that it can’t be that bad”. Another survey respondent expressed that weight is not often identified or recognized as an additional barrier that people with disabilities might face, but that as a plus size person with a disability they are constantly discriminated against and not taken seriously, especially within the medical system.

Pillar 2: Employment

CCRW | CCRT

Methodology

Between April and June 2022, Pillar 2 (Employment) hosted five online focus group consultations on May 17, May 20, May 24, June 7, and June 13 with a total of 26 contributors representing frontline workers with people with disabilities, individuals with lived experience, union representatives, and stakeholders who were instrumental in developing the Pan-Canadian Strategy on Disability and Work. The gathered responses were summarized in the previous progress report, and we were quite pleased with the garnered results and information.

The subsequent focus of our pillar involved following up on would-be focus group participants whose schedules did not permit online attendance for one of the five scheduled focus group sessions. As a result, our goal was to further engage with participants by encouraging written submissions concerning the focus group questions over the summer, which could be done at participants' leisure and in whatever language they preferred.

Similar to the online focus group sessions held in May and June, all focus group participants were invited to request accommodations prior to submitting their written responses. All questions and materials were emailed to participants and in multiple formats (English/French, Word, PDF, and plain text formats) to allow participants ample time to review the materials and compose pertinent notes. Participants were given time to submit their responses and were encouraged to use any suitable format (point form, paragraph responses) and response length of their choosing. Participants were also advised that responding to all questions was not mandatory. Similar to our previous Progress Report, the overarching aim of the written submissions for Pillar 2 (Employment) was to build upon the extensive and robust consultations conducted in 2019 for the development of the Pan-Canadian Strategy on Disability and Work (*https://ccrw.org/dwc-initiative/dwc-strategy/*). Our goal was to determine what areas, if any, require review and possible revision given the global events (the COVID-19 pandemic and attendant labour market effects) that have transpired over the last three years.

Key Themes

Pillar 2 (Employment)'s written submission request centred on the Pan-Canadian Strategy for Disability and Work and featured the eight open-ended questions previously used from the online focus groups designed to gather participants' thoughts and reactions but slightly modified to reflect an individual (rather than focus group) experience. We have categorized the data collected from these written submissions to align and complement the themes previously addressed by the focus group participants:

1. Needs and lived experiences of Canadians with disabilities in terms of skills training and other employment supports

Focus group participants had identified that skills gaps became evident during the early onset of the pandemic; where jobs or positions that easily facilitated a Work From Home (WFH) transition such as office-based positions required a quick upskilling in terms of using newer software that facilitated remote work (and ensuring proper accommodations were in place); whereas frontline positions (for example, cashier, cleaner, etc.) that did not require any technical accommodations remained unchanged except for a large growth in the number of positions suddenly available (for example, extra cleaners required to ensure proper disinfection procedures were followed within a particular workplace). Written submission respondents further commented on the current labour shortages experienced in multiple sectors across Canada as negatively impacting the amount of training provided by employers, noting:

“The pandemic and current labour shortage have impacted employers’ ability to spend more time training persons with disabilities. Where before most workplaces were robustly staffed and there could be mentors in the workplace to assist with training, many places now are so short staffed that they simply cannot properly onboard and train inclusively (or choose not to based on other urgent priorities).”

2. Addressing programing gaps and challenges

Focus group participants remarked how the pandemic made forging new professional or organizational relationships (especially new interprovincial relationships) particularly difficult due to changing guidelines and travel restrictions. Participants also highlighted the need to establish mechanisms for more structured information and best practices exchange. Most employment programs are governed and administered on a provincial level making it difficult to learn of innovative developments happening across Canada. Written submission respondents emphasized these themes while noting the impact of current labour shortages within the non-profit sector and its impact on service delivery:

“Honestly, we need more funding and bodies to do job coaching. As a non-profit we are constantly losing workers to higher paying government jobs, and the demand for job-coaching has only increased as more workers with disabilities enter the workforce … They cannot expect us to serve more and more people without increasing our funding.”

3. Risks, and impacts of participation in skills training and other employment programming on eligibility for benefits and other supports

Focus group participants remarked at the perceived unfairness with regards to income supports for people with disabilities when compared to the financial supports (CERB) received by Canadians who were laid off at the beginning of the pandemic (for example, the very low threshold to establish that benefits were needed, no lengthy application process or wait-time before benefits were received). “Claw-backs” (where workers with disabilities are penalized through a reduction of disability income supports for working) were discussed as particularly unfair and distressing to prospective employees with disabilities. Written submission respondents additionally commented on the added challenge of trying to coordinate wraparound supports in a post-pandemic environment, as noted by one respondent, “For people who need to book their transportation, or take the bus regularly it’s a challenge … signing up for weekly shifts and then trying to time everything isn’t great.”

4. Labour market trends during Covid 19 as they impact persons with disabilities

Arguably, the pandemic accelerated trends towards precarious work (the “gig economy”), growth in delivery services as well as in “discrete” work (work that is often one task or one project) driven by the necessity of remote or isolated living. One written submission respondent highlighted the strong preference for a simplified employment experience noting, “I look forward to a paid job - and I want A job, not 5 or 6 little jobs.” Another respondent noted the perceived increase in complexity for employment, remarking "…having to sign up for weekly shifts - I want a routine that is a regular schedule. I don't want to go on the internet every week".

Another participant noted that employers might not want to bother with individual accommodations in a precarious work relationship and creating inclusive workplaces is tied to having longer employment relationships.

It was further noted that the hype surrounding remote work benefitting people with disabilities often ignored deeper challenging issues, as remarked by a participant: "The people who need the most help, they already have challenges with the digital world...individual, face-to-face support works best for many people, but the pandemic created a barrier to that". They noted that, even when work was on site during the pandemic, accommodation specialists couldn't visit workplaces for in-person accommodation assessments and build relationships. "[The pandemic] has decreased the willingness of management to talk to [employment support workers]. People who work on accommodation couldn't go into workplaces".

5. Common barriers faced by organizations when trying to encourage employers with respect to disability inclusion

Focus group participants made the distinction between employers supporting employees with visible disabilities in comparison to invisible disabilities (including mental health issues); with the former being more easily accepted (even desirable from a DEI perspective) and therefore more readily accommodated in a workplace setting. However, one written submission respondent noted the impact of the COVID pandemic on the prevalence of disability which may help to combat workplace stigma, an oft-mentioned barrier to disability inclusion, remarking, "many individuals discovered or encountered experience with a disability during the pandemic (e.g. mental health issues that affected their ability to work) … I see a lot more acceptance in the younger generations than when I was in school."

Frontline community agency workers relayed employers' concerns around performance management and/or integrating employees with invisible disabilities into their workplaces. As well, written submission respondents noted the challenge in promoting inclusive hiring practices, as one respondent remarked, "many employers are not willing to truly change their hiring or interview processes, and although they often share job descriptions … I will later see their postings online when they have not shared them with me."

Some participants noted that service providers need to find ways to make employers not feel shame when they, as one written respondent described, "walk back" their support of accommodating employees with disabilities. Written respondents further mentioned the benefits of the current labour shortages as "forcing" employers to explore hiring employees with disabilities which may have a positive impact depending on the employment outcome and overall hiring experience.

Written submission respondents agreed with focus group participants that while some progress has been made there is still much work to be done to ensure full and authentic workplace accessibility. As one respondent noted, "More work needs to be done with employers to ensure they are not just 'talking the talk' about being inclusive."

6. Identify promising practises/policies with respect to increasing the inclusion of persons with disabilities in the workforce

Like the focus group participants, written submission respondents shared their grassroots approaches to maintaining communication with other agencies and employers as the pandemic evolved; remarking that most employers were keen to maintain their respective workforces and worked in tandem with community organizations to minimize layoffs.

Similar to focus group participants, some written submission respondents were unaware of the Pan-Canadian Strategy's existence; promoting the Strategy as a tool to community organizations will encourage creative and focused inclusion of people with disabilities in the workforce. With the current labour shortage in Canada, written submission respondents noted a growing interest in helping employers and recruiters develop simplified interview standards and processes that address the specific skills needed for on-the-job success as well as simplified training processes, as opposed to interview questions and processes that feature high-tech online meeting software and passive questions about a candidate's general strengths and weaknesses.

Pillar 2 Survey Questions

Q 17: Inclusive Workspaces are accessible to workers with disabilities. It means the design of the workplace is accessible. It means the workplace culture is accessible. It means that employers and businesses are supported.

Do you think the workplaces have become more inclusive since 2019?

Answer Choices:

a) Yes: some workplaces are more inclusive: 13.77%

b) Somewhat: workplaces are a little more inclusive: 34.18%

c) No: workplaces are not more inclusive: 27.69%

d) I prefer not to say: 6.33%

Highlighted Comments:

- Certain respondents remarked that COVID amplified the inclusiveness of employers who were already inclusive prior to 2019 while reducing the inclusiveness of employers who were not previously inclusive.
- Some respondents indicated that one employer can be both inclusive and exclusive from the perspective of various departments and willingness to accommodate.
- The role of technology in the ability to Work From Home (WFH) was cited by several respondents as being a key factor concerning workplace inclusiveness from an employer's perspective.

Q 18: Employers need to be "disability confident." This means they need to commit to hiring people with disabilities. It means they need to be confident in their ability to hire people with disabilities. They need to know how to hire, manage, accommodate, support, and keep workers with disabilities.

Do you think employers have become more confident in their ability to be inclusive since 2019?

Answer Choices:

a) Yes: employers' confidence has improved: 5.89%

b) Somewhat: employers' confidence has improved a little: 29.65%

c) No: employers' confidence has not improved: 40.06%

d) I prefer not to say: 8.35%

Other (please specify): 16.06%

Highlighted Comments:

- Some respondents mentioned that employers in certain sectors prioritized managing and implementing the guidelines and restrictions associated with the COVID 19 pandemic, leaving little room for disability confidence in the workplace.
- Several respondents mentioned that disability confidence varies depending on an employer’s size, sector, costs (for example, costs associated with modifying building codes) and incentives (for example, subsidies to cover accommodation costs) to encourage disability confidence.

Q 19: What supports would help job seekers with disabilities to find good jobs and grow their careers?

Over 800 suggestions were collected and categorized along the following themes:

- Attitudinal supports: encouraging employers to approach hiring with a person-centred approach with flexibility concerning job tasks, hours worked, flexible scheduling, and the essentiality of work tasks as opposed to a role-centred approach and trying to find the perfect candidate to perform specific duties.
- Legal supports: Mandatory hiring requirements with associated reporting and punitive fines if not completed (as evidenced in other countries).
- Accommodation supports: creation of an independent, external, certified position (similar to an SSW) to coordinate logistical and financial accommodations and ensure accommodation burdens do not fall on jobseekers nor employers
- Training supports for jobseekers with disabilities: More upskilling/retraining available to jobseekers with disabilities who may not have current or valid educational credentials
- Training supports for employers: Training support for hiring managers and human resources with a practical focus towards employment and accommodation.

- Educational supports: Transitional support for high school students with disabilities into post-secondary settings; support to ensure post-secondary students with disabilities reach graduation
- Wraparound job search supports: i.e. access to reliable internet for Zoom interviews, professional attire for job interviews, affordable phone plans
- Additional wraparound supports: subsidized childcare, attendant care, access to affordable housing

Q 20: What supports do employers need to help people with disabilities to get better jobs and grow their careers?

Approximately 775 responses were collected that have categorized along the following themes:

- Education and training supports: provide regular information sessions, webinars, media campaigns and printed information providing concrete suggestions while allowing for information exchange across employers
- Financial supports: Offer employer incentives such as accommodation subsidies as well as wage subsidies during the training/probationary period and for small to medium-sized employers
- Promote an attitudinal shift from viewing employees with disabilities as liabilities to understanding the business case for hiring and accommodating employees with disabilities

Q 21: Do you have any other comments or feedback?

Approximately 352 responses were collected; some highlighted responses and themes include:

- Progress has been made but there is more work to be done.
- The importance and need for continued education, patience, and tolerance for employers, human resources, and employees with disabilities; case-by-case approach to disability management in the workplace will ensure success rather than trying to use the “one size fits all” approach
- Accommodations should be inherent in the workplace with accommodation supports, plans, and staff readily and easily available to implement (for example, no long reports to complete) with the federal government promoting the advantages of hiring people with disabilities through media campaigns as well as through subsidies and readily accessible accommodation funding.
- The importance of receiving a living wage for employment in recognition of fluctuating disability costs

Pillar 3: Disability Inclusive Spaces

Canadian
Association of the Deaf

Association
des Sourds du Canada

Introduction to the Survey Consultations Reports, Literary Review & Analysis

In the 2020 Throne Speech, the Government of Canada committed to creating a new Disability Inclusion Action Plan (DIAP). The objectives of the DIAP are to:

- Improve the social and economic inclusion of Canadians with disabilities.
- Reduce poverty among Canadians with disabilities.
- Contribute to the realization of a barrier-free Canada by 2040.
- Improve access to federal programs and services for persons with disabilities and ensure that disability inclusion is considered in all Government programs, policies, and services; and
- Foster a culture of inclusion and a shift away from attitudes of ableism and discrimination.

The overarching aim of the focus group consultations for Pillar 3 (Inclusive Spaces) was to consult with peoples directly affected in order to provide recommendations to the federal government on how to enact their action plan.

A strong partnership was forged between the Canadian Association of the Deaf – Association des Sourds du Canada (ASC-CAD), Rick Hansen Foundation (RHF) and Spinal Cord Injury (SCI) Canada in the design and analysis of our survey. As a result of this community outreach, we are presenting our policy and process recommendations to improve accessibility and inclusion in various domains.

Appreciation

As the Executive Director of the Canadian Association of the Deaf – Association des Sourds du Canada (CAD-ASC), I would like to express the profound appreciation of the CAD-ASC Board of Directors to the participants from the disability community who generously shared their insights and experiences for this report. Your contributions have been instrumental in ensuring that this report accurately reflects the needs and perspectives of a wide array of persons with disabilities who live in Canada.

Indeed, your feedback and suggestions have been critical in shaping the report's approach and ensuring that it is inclusive and accessible to all members of the community. Your voices have been heard, and your perspectives have been reflected in this report.

The Board also wishes to express their gratitude to Anne MacRae, the National Executive Director of Independent Living Canada for the chance and support you have offered to CAD-ASC in leading the Disability Inclusive Action Plan (DIAP) – Inclusive Design Pillar.

I add my thanks to Bill Adair, the Executive Director of Spinal Cord Injury Canada, Doramy Ehling, the Chief Executive Officer of the Rick Hansen Foundation, Janet Mou Pataky, the Director, Accountability, Evaluation, and Impact, at RHF. I am deeply grateful for their invaluable input and support throughout the report's development and success.

On a personal note, I wish to thank Jim Roots, the former Executive Director of CAD-ASC whose extraordinary leadership brought us together and launched us onto this journey.

And finally, to Pavel Koval, the holder of the pen on this report. Without his tenacity, prose, and uncanny ability to surmise all this data, this report would not exist.

Thank you again to all involved for your contributions and support.

Richard Belzile

Executive Director, CAD-ASC

Methodology

The research and outreach phases that were used to solicit the required information revolved around engaging with persons with disabilities, Deaf people, Hard of Hearing people, and people with disabilities from marginalized and hard-to-reach communities. Our purpose was to obtain feedback, knowledge, and expertise of those community members to inform our research, and to outline the community's concerns, hopes, and aspiration with respect to the DIAP's objectives.

Our work followed the principle of an intersectional engagement with persons with diverse social groups. For example, we conducted interviews with people with various disabilities, genders, age, Indigenous peoples, people from a variety of cultural backgrounds including racialized people, people who were employed and those who were not, people with lower, middle, and higher incomes, people with no educational certification, high school graduates, people with some postsecondary education, and college and university graduates. Such a diverse outreach allowed us to receive information from various perspectives and viewpoints.

Partners

This work was done in cooperation with Spinal Cord Injury Canada, and outreach was conducted primarily in the provinces of Ontario and British Columbia. CAD-ASC, and SCI Canada had many project meetings throughout this initiative to discuss ongoing issues, to ensure alignment, and to share community outreach efforts throughout Canada. CAD-ASC is deeply grateful to and SCI for their hard work, dedication, and professional excellence.

Materials

Prior to engaging with the community members, several materials were created: Inclusive Spaces Focus Group questions, an Interview Guide, and PowerPoint presentations to match the DIAP discussion subject for each separate session. All materials were made available in American Sign Language (ASL) and Langue des Signes du Quebec (LSQ), and participants were offered required accessibility accommodations. Additionally, all sessions were recorded and translated in various languages to match the requirements of all audiences. Moreover, advertisement campaigns were initiated prior to each event, with focus group materials, announcements, and descriptions distributed via a wide array of social media elements.

Presentation materials used throughout the sessions were also created in an accessible format with plain and simple language.

Participants

After developing the survey questions, a facilitation guide, and a consultation schedule, the four-pillar survey was produced, translated in French, ASL (AMERICAN SIGN LANGUAGE) and LSQ (Langue des Signes Québécoise) and distributed online.

CAD-ASC, for Pillar 3 section, continued to explore the hard-to-reach candidate offline, seeking input from the homeless, in Vancouver's East side, the 2SLGBTIQ community during Toronto Pride, and Deafblind participants from Quebec.

In all over 1000 contributors being people with disabilities, individuals with lived and living experience, community members, and other accessibility stakeholders shared their feedback on the four pillars: 1) Financial Security, 2) Employment, 3) Inclusive and Accessible Spaces and 4) a Modern Approach on Disability.

About 85 contributors in total representing people with disabilities, individuals with lived and living experience, community members, and other accessibility stakeholders shared their feedback on inclusive spaces. All focus group participants were offered or provided with accommodations prior to attending their focus group session. Each online session featured ASL/LSQ interpretation as well as CART1 live transcription services as applicable. The Toronto Pride festival had a Sign language interpreter on site, and bilingual CAD-ASC personnel was present. Focus group questions and materials were emailed to participants and in multiple formats (English/French, Word, PDF, and plain text formats) prior to the session to allow participants ample time to review the materials and compose pertinent notes.

In total, the Pillar 3 group hosted twelve (14) focus group consultations in ASL/LSQ/English/French, which were conducted on the following dates:
- a virtual session on May 20, 2022 in English;
- a virtual session on June 7, 2022 in English;
- a virtual session on June 2, 2022 in English;
- two virtual sessions on June 14, 2022 in ASL;
- a virtual session on June 15, 2022 in English;
- a virtual session on June 22, 2022 in English;
- a virtual session on June 28, 2022 in English;
- an in-person "on the street" interview session during the June 25-26th Toronto PRIDE festival weekend, which was conducted in English, French, and ASL;
- a virtual meeting on July 5 in LSQ;

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1 CART Service means Communication Access Realtime Translation Service, which provides instantaneous translation of what is being said into visual print display so that it can be read (instead of heard).

- a virtual meeting on July 7 in English;
- a virtual meeting on July 12 in French;
- a virtual meeting on July 13 in English;
- a virtual meeting on July 24 in ASL.

Several interview sessions were also arranged in BC on these dates:
- four virtual sessions on September 17;
- a virtual session on September 20;
- two virtual sessions on September 31.

CB Linguistic Services a deaf owned business from Quebec conducted 5 interviews of participants win the LSQ Deafblind community.

For all sessions, participants were asked to reserve 90 minutes for focus group participation for a discussion moderated by representatives of CAD-ASC, Spinal Cord Injury (SCI), and/or the Rick Hansen Foundation (RHF). Sessions were recorded, and detailed notes were taken. To preserve the participants' privacy, no identifying information was recorded or transcribed.

Outreach

It should be noted that CAD-ASC, RHF, and SCI worked on focus groups with that were cross-disability in focus. Below is the core group of partners and participants we reached out to in this project.

Partner	Representative
Canadian Association of the Deaf – Association des Sourds du Canada	Richard Belzile
Supporting Partners – Partenaire de soutien	**Representative**
Abilities Center	Stuart McReynolds
Active Living Alliance	Jane Arkell
Alliance for Equity of Blind Canadians	Marcia Yale
Autism Speaks Canada	Jill Farber
BC Aboriginal Network on Disability Society (BCANDS)	Neil Bélanger
Brain Injury Canada	Suzanne McKenna Michelle McDonald Rachel Newcombe
Canadian Cultural Society of the Deaf	Vincent Chauvet
CASDA	Johnathan Lai
Confédération des organismes de personnes handicapées du Québec (COPHAN)	Véronique Vézina
CRWDP	Emile Tompa Ellen MacEachen
DAWN	Bonnie Brayton
Eviance	Susan Hardie
Inclusion Canada	Krista Carr
L’Arche Canada	Louis Pilotte
Learning Disabilities Association of Canada	Mark Buzan

LiveWorkPlay	Keenan Wellar
Muscular Dystrophy Canada	Stacey Lintern Homira Osman
National Network for Mental Health	Julie Flatt Ellen Cohen
Neil Squire Society	Gary Birch
Race and Disability Canada	Rabia Khedr
Realize	Tammy Yates
Réseau Québécois pour l'inclusion sociale des personnes sourdes et malentendantes	Anne-Marie Paradis
Rick Hansen Foundation (Project partner)	Doramy Ehling
Spinal Cord Injury Canada (Project partner)	Bill Adair

The project team wanted to ensure that people with disabilities who are in the margins were consulted. Over 50 organizations across Canada were contacted, representing a range of people with various racial, ethnic, socioeconomic, cultural, and accessibility backgrounds. Additionally, community outreach attempts were made via social media such as Facebook. As a result of that outreach, over 30 individuals expressed their desire to participate in the Pillar 3 survey, yet repeated attempts to obtain responses from those individuals were not successful. Lastly, it should be stated that the community outreach at Pride Toronto by definition represented the multi-dimensional aspect of diversity, including disability, sexual orientation, and the matter of genders as well – we are glad that a great number of intersectional and diverse representation was present during that event.

Pillar 3 Consultations

Since this Pillar's focus groups centred on Inclusive Spaces, its outreach featured eight questions designed to gather participants' thoughts and reactions. We have categorized the data collected from these focus groups into the main themes shown in sections below.

1. The respondents want the Government of Canada to be more proactive and diligent in removing barriers within areas of federal jurisdictions.

2. The overwhelming majority of respondents believe that the Government of Canada wants to change the way building, public spaces and benefit programs are designed and

built, so that all barriers to people with disabilities are removed. Both verbal and written feedback data collection indicated that practically all respondents shared the Government of Canada's desire to redesign buildings, public spaces, and benefit programs to ensure a greater degree of accessibility, and expressed their desire for the Government to continue its efforts.

3. Participants noted that despite recent efforts by the Government of Canada to promote and expand accessibility, many areas within the federal jurisdictions continue to present physical and environmental barriers, particularly those buildings that had been designed at a time when accessibility was not given proper attention, and this should be changed. Some people also noted that there was a lack of specific activities that the government had in mind: milestones, benchmarks, and desired outcomes were often missing – those specific activities should be added.

4. Respondents also stated that the Government of Canada should re-examine the respondents' previous expertise, opinion, and thoughts that had already been solicited by Canada.

5. It was underscored that more sensitivity, respect, and cultural agility were needed to make every area more inclusive, professional, and accessible for each stakeholder group.

6. Lastly, participants shared that the most impactful and beneficial change that they would welcome entails facilitating and expanding access to various benefit programs – both federal and provincial. Nearly everyone stated that a greater financial freedom would mean reduced barriers in various areas.

Overall Categories

Several observations in various categories could be made from that outreach:

1. Organizational or/and Systemic Barriers:

The existing piece meal and partial provision of accessibility accommodations is not sufficient, and such accommodations should be provided in full by the federal government.

Participants shared that various jurisdictions provided accessibility accommodations to match the needs of some, but not all, groups. For instance, if a museum offers an audio guide for a Deaf person, and no other materials are available for Deaf persons, that lack of accommodation presents a barrier to Deaf persons. This situation was repeated at different levels across the country.

There should be more transparency in government services.

Participants noted that there is a lack of clarity about benefits across the country, and how much money they are entitled to. It was said that the Canadian government should provide varied incomes based on each province so to ensure that in the end there will be a fairly similar income from benefits across the country. The benefits system needs to be standardized across Canada else a Canadians freedom of movement is curtailed.

The federal government should take measures to alleviate support personnel shortage.

For example, many participants complained that there was a lack of Sign language interpreters in government facilities; Consider funding post-secondary college or university that would provide a fully immersive learning environment for Deaf people and interpreters. This is especially needed for LSQ

More services should be provided in Sign language.

For example, compared to France, Quebec has very few LSQ providers and material creators. Essentially, Cinéall2 is the sole provider, which leaves a lot of gaps due to high demand. Respondents noted that hospitals should have Sign languages available upon request, or have staff on site who are Deaf who can respond immediately to Sign language requests.

Persons with disabilities should be more included in the design process in policy and processes.

Such exclusion would often lead to disability perspectives being forgotten, left behind, or not given proper attention, especially in matters of emergency situations planning, health, and safety.

Organizations should be considering accessibility for clients and customers, and employees.

For instance, in many banks, counters and client tables are inaccessible for persons with physical accessibility needs, including communication.

Universities should provide proper supports for Deaf students.

In the absence of such support, such as Deaf students ASL/LSQ interpreter delays, they are often forced to stay longer in their educational programs without compensation for the delay in their studies or their professional careers.

The government should make it easier for people to submit their accessibility requests.

For example, lots of participants had to fill out forms and applications to confirm their disability needs, look for relevant information, ask customer service providers for the information and accommodation they need, repeatedly, which can be a difficult and onerous prospect for some people. There is a need for the government to make that application process more accessible in itself.

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2 Cinéall is a Quebec-based organization that provides translation, video creation, video recording, training, and counselling services in American Sign Language (ASL), Langue des Signes Québécoise l'(LSQ), English, and French.

2. Policy Barriers

Some disability support programs should be re-designed to provide value to those using them.

For instance, a federal disability tax credit does nothing for people with disabilities without income, or with limited income. Additionally, current financial assistance on both federal and provincial levels is very limited and does almost nothing to elevate people with disabilities' quality of life, which should be changed.

Restrictions on income support should be lifted.

Participants voiced their concerns about welfare "clawback" the moment they generate any income. Such a restrictive approach is said to promote poverty, income insecurity, and stress. Welfare supports should be tied to inflation, and revised at least annually.

Government support should apply to personal accessibility expenses. Several responders noted that they have to pay for their own accessibility accommodations out of their own pockets to be fully included at work or in private life affairs, yet they do not get any financial assistance to cover such expenses. This lack of assistance hampers their financial stability.

Federal disability benefits should apply to academic expenses for Deaf people.

Since Canada does not have post-secondary education facilities like Gallaudet University for Deaf people, the federal government should institute financial support to enable Deaf people to get the education of their choice, including the cost of a foreign education and the establishment of a Deaf University in Canada.

Inclusive policy updates should be introduced at many levels.

Governmental policies and procedures need to be re-written to ensure a greater degree of equity, diversity, inclusion, and accessibility considerations included in them. Participants noted that government acts in accordance to its own policies, which are not promptly or/and often updated. Making these updates would ensure that no member of the disability community is left behind.

Governments should engage in proactive consultations with the community to maintain shared understanding of the accessibility issues.

At times, what the government thought was accessible, was, in fact, deemed to be inaccessible by the community members.

People with disabilities should have more equal opportunities in employment.

There was a general recognition that special programs should be in place to hire more persons with disabilities. This needs to be done in both governmental and private sectors at all levels. Respondents said that Deaf people should be hired by the government so that they would be able to provide accessible and Deaf-appropriate customer service to Deaf citizens. In other words, accommodations for Deaf citizens to access government, should be recognized as necessary accommodations to allow Deaf employees to provide government services or assistance to persons living in Canada.

Accessibility compliance mechanisms by the government should be supported by proper funding.

It was shared that the government does not always have enough staff to monitor, inspect, and enforce accessibility compliance.

3. Financial Barriers

Direct financial support mechanisms should be introduced to help people.

Participants noted that their financial insecurity prevents them from full participation in society, hampering their personal and professional development efforts, and reducing their efforts to simply getting by financially without being able to have savings or any financial freedom. This financial issue could be resolved by the federal government introducing a more streamlined mechanism of providing direct financial support to those who need it.

The government should change its policies to avoid penalizing people who decide to get married and have their income status changed as a result.

Several participants indicated that the fear of losing financial support from the government prevented them from getting married and thus changing their income status. Respondents indicated that individual benefits should not be revoked if a person decides to get married.

4. Architectural or Physical Barriers

Old buildings and facilities should be retrofitted with updated accessibility features.

Hospitals, office buildings, parking centres, and other facilities can be very accessible at times depending on how recently that particulate building was built or renovated. Unfortunately, over half of all respondents noted that they regularly faced accessibility barriers at all stages at each of those facilities due to old architecture and lack of technology inside the buildings.

Physical barriers should be removed at all levels within a building, as opposed to removing them on some levels only.

For instance, a building may have an accessible washroom on some floors, but not on all floors. In other cases, building or business owners have only focuses on public areas, leaving employee areas inaccessible to current and future staff.

Healthcare facilities should have funding allocated to provide accessibility services to their patients.

Respondents noted that many hospitals were not physically accessible for them due to lack of accessibility improvements, which could have been achieved with more funding allocated to these purposes.”

Airplanes should be made accessible for wheelchair users.

Respondents noted that airplanes were not physically accessible for wheelchair users due to lack of accessibility improvements, which could have been achieved with more funding allocated e purposes.

5. Information or Communications Barriers

More materials in ASL/LSQ should be provided that would help Deaf people navigate through the process of using governmental services.

That lack of linguistic accommodations renders them unable to get full understanding of what they are reading. Government also requires a lot of documents to be filled out, which is a barrier in itself, and these forms do not meet accessibility requirements. Automatic application processes in enrolling into these programs and services would be useful.

Emergency services and service-related announcements should be provided in various formats, as opposed to being done via audio communication means only.

Deaf and Hard of Hearing people are often unable to comprehend the information shared with them as members of the general public due to that information provided verbally. The lack of in-flight announcements on airplanes was a glaring example of this lack of communication.

Security facilities and other facilities that serve a great number of people should offer more accessibility accommodations and supports.

For instance, Deaf people in correctional facilities are not provided with Sign language support; they do not have VRS[3], or any other appropriate means of communication.

For the physical environment, especially for Deaf people, more visual supports, screens, more Sign language materials, and a remote interpreter service should be made available.

For example, in case of Passport Canada, there is an office where an interpretation service is available, but Deaf people do not know which one. Better job should be done to promote the existence and awareness of these services and their availability.

Government should work with the passport providers, Custom Canada and VRS Canada to identify ASL and LSQ users.

The difficulties that Deaf travellers face at domestic and foreign customs must be addressed. An official notice to call VRS from any location should the need for ASL or LSQ interpretation arise would ease the burden on Deaf people trying to identify themselves and get interpreters in a foreign land.

6. Technology Barriers

Government services can should be made available via different means, not just through phone only.

For example, a chat window that allow access to a Deaf government employee to assist in navigating the government's web page for people who are Deaf. This change would ensure that Deaf, Deaf-Blind, Hard of Hearing, and other people with hearing disabilities will not be cut off

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[3] Video Relay Service (VRS) is a form of Telecommunications Relay Service that enables Deaf people and persons with hearing disabilities who use American Sign Language to communicate with voice telephone users through video equipment, rather than through typed text.

using those services due to access barriers and ensure employment of Deaf people within the government.

Virtual/digital spaces should be made accessible by default.

At times, organizations use non-standard applications, or approaches, with which persons with disabilities are not familiar. There needs to be a more universal adherence to recognized software solutions, such as Zoom. For the solutions themselves, there needs to be better captioning. Government services should at least have a virtual chat option to reach a customer.

Telephone services need to be updated.

Respondents shared that TTY[4] was not really usable to the Deaf community that signs anymore. Government business should have VRS numbers to allow Deaf people to access government services and employees directly.

The IP relay service[5] should be promoted more.

People tend to use it mostly for important calls, making it unknown and awkward to use with people who aren't use to it.

The Video Relay Service (VRS)[6] should be accepted as a communication choice for Deaf people at all times.

Currently many issues exists with VRS: 1) it is not a 24/7 survey, 2) the interpreters chosen via the VRS are randomly chosen (first come first served) Deaf people don't know who they will end up with. 3) People from institutions (banks, governments, etc.) often refuse to talk to interpreters for security reasons, and it takes time and energy to explain to them how VRS works and that it is safe to share information with a third party and that the Deaf person is the right person who needs information or services. This is an extra burden for Deaf people. The use of third parties (or not) to share passwords or permissions on behalf a Deaf user should be respected 4) the limited use of VRS to interpret phone calls only and not face to face situations is a barrier to full accessibility. Although expensive, it is a cost that should be borne by all

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[4] A Teletypewriter (TTY) is a special device that lets people who are Deaf, hard of hearing, or speech-impaired use the telephone to communicate, by allowing them to type text messages. A TTY is required at both ends of the conversation in order to communicate. Unlike text messaging, it is designed for synchronous conversation, like a text version of a phone call.

[5] Internet Protocol (IP) Relay Service allows persons with a hearing or speech disability to use Telecommunications Relay Service (TRS) through a computer or web-enabled device to communicate through the telephone system with hearing persons.

[6] Video Relay Service (VRS) is a form of Telecommunications Relay Service that enables Deaf people and persons with hearing disabilities who use American Sign Language to communicate with voice telephone users through video equipment, rather than through typed text.

peoples living in Canada so that Deaf people can reap the equality benefits of our laws and Charter of Rights.B7. Attitudinal barriers:

Attitudinal barriers remain an issue, and policy-wide changes and education are required to remove them.

Respondents shared that attitude barriers continue to serve as one of the most significant issues affecting almost all areas. Instances of prejudice, erroneous assumptions, mistreatment, refusal to accommodate, and refusal to provide mandatory supports continue to be experienced by virtually every stakeholder. Policy and attitude adjustments can be made and achieved through educational media campaigns.

More accessibility changes are required for museums, schools and municipalities.

Not only are more and more museums becoming accessible, but there are also a number of museums that allow a person to be accompanied by another person if they have an accompanying sticker behind their health insurance card. In schools, there are services to help students with special needs, and they work in collaboration with an interpretation service. For the Deaf parents of hearing children, there is a big gap in service, because school boards focus on the child rather than the parents needs. As for municipalities, depending on their province, more counter service, information sharing, and programming, need to consider the needs of their citizens, including people with disabilities and especially Deaf people.

Organizations should not be reluctant to provide Deaf people with client-facing work. ti

At banks, airports, and Service Canada counters, it is always hearing people who deal with customers, and never Deaf employees. For the sake of equality, and to change minds and attitudes, this attitudinal barrier should be challenged.

Organizational policies should include all, and not exclude people who may not have disabilities, but still face barriers in other ways.

For instance, a building may not have a breastfeeding room, or floor plans may be noisy, which would be disturbing for neurodivergent people.

Organizations should provide sufficient accessibility accommodations in different environments and circumstances.

For instance, a Deaf person may be offered a TTY system in the environment where no phone calls can be made, or VRS where there are no opportunities to get an Internet connection.

There should be more captions/subtitles available in movie theatres.

Even though captions can be useful for non-Deaf people, as well, movie theatres should be mandated to enable open captioning for all films.

Four Pillar Consultations

As part of the overall consultations, the four pillars of the project combined their questions into one survey, that was distributed across the country. Below are the questions, used in the Pillar

3 consultations and the Four Pillar consultations. They were identical. The analysis of the four-pillar consultation can be found below.

DIAP Four Pillar Survey Analysis

CAD-ASC provided an analysis of the participants' responses to the DIAP survey which closed in November 2022.

Question 227: "The Government of Canada wants to change the way buildings, public spaces and benefit programs are designed and built. They want to remove all barriers for people with disabilities. Do you agree with the statement above? If not, what would change?"

Based on the responses shared, it is clear that the majority of people agree with the goal made by the Government of Canada regarding removing all barriers for people with disabilities in buildings, public spaces, and benefit programs. Many of the respondents emphasized the importance of including disabled people in the planning process and incorporating Universal Design to ensure equal access for all. Additionally, some respondents pointed out the need for removing not only physical barriers but also attitudinal barriers that limit and devalue disabled individuals.

However, some respondents expressed concerns about the feasibility of removing all barriers for everyone. For instance, some mentioned that it may not be possible to remove all sensory barriers in public spaces like grocery stores, government buildings, and hospitals. Additionally, some pointed out the issue of people misusing disability programs, and the need for measures to prevent such abuse.

Despite these challenges, many respondents emphasized the need for the government to take concrete steps towards removing barriers for people with disabilities. Some suggested that the government should enforce laws for new buildings to be accessible, and for older buildings to be retrofitted to meet accessibility standards. Additionally, some respondents mentioned the need for financial support and compensation for people with disabilities to access necessary equipment and participate in society.

To sum up, the responses shared for this question highlight the importance of removing barriers for people with disabilities in buildings, public spaces, and benefit programs. While there are challenges to removing all barriers, the majority of respondents agreed on the need for the government to take concrete steps towards improving accessibility for disabled individuals. This includes involving disabled individuals in the planning process, enforcing accessibility laws, providing financial support, and addressing attitudinal barriers.

Question 23: "What public spaces, programs and services are accessible to you? This includes services that are both in person and virtual. Below is a list of public spaces, programs and services. Please rate how accessible each one is for you."

The responses provided in this part indicate several areas in which accessibility can be improved for people with disabilities. One of the most prominent areas is the workplace. Many

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7 As the Four Pillar survey included the questions from all four pillars, the numbering for the questions submitted by Pillar 3 begins at question 22.

respondents reported facing bullying and discrimination in the workplace, and some mentioned that they had trouble finding employment due to their disabilities. This suggests that more efforts are needed to create inclusive and respectful work environments for people with disabilities.

Another issue that came up frequently is the lack of accessibility in public spaces, programs, and services. Respondents mentioned that many public transit systems still need improvements to make them accessible, and that sidewalks and crosswalks are often unsafe for people who are visually impaired or use wheelchairs. Respondents also reported difficulty accessing health and medical programs, particularly those designed for people with autism or who learn differently.

Respondents also highlighted the importance of washroom accessibility, which was described as critical for people with physical disabilities. They also mentioned the need for virtual services to be fully accessible, rather than just an option, in order to include people who are still in full isolation due to their disabilities.

In conclusion, several respondents mentioned the impact of the COVID-19 pandemic on their accessibility. Some reported that the use of masks has made it harder for them to communicate, as they are unable to see facial expressions or lip-read. Others mentioned that they have had to cancel virtual appointments as soon as things started to reopen, which has excluded them from services they rely on. This highlights the importance of ensuring that the needs of people with disabilities are considered when making decisions during the pandemic.

Question 24: “How does being able to access these spaces and services affect you? Does it affect your ability to work, live, or engage with your family or community?”

Based on the information shared, it is evident that access to services and spaces is a major concern for individuals with disabilities. The lack of accessibility affects various aspects of their lives, including work, daily activities, and engagement with their family and community.

Many respondents reported difficulties in accessing essential services, such as healthcare and government assistance, due to the lack of adaptations for people with disabilities. This often results in a need for extra support from family members and a sense of dependence and frustration. The absence of ramps, elevators, and well-adapted toilets in public spaces also creates barriers to accessing leisure activities and participating in society.

The difficulties faced by individuals with disabilities go beyond just physical barriers. Many respondents reported negative experiences with service providers and a lack of understanding and empathy from the people around them. This often results in a sense of exclusion and the need to avoid interactions with others. Moreover, the process of obtaining accommodations and support services is often cumbersome and requires a lot of effort, which adds to the stress and frustration faced by individuals with disabilities.

It is clear that access to services and spaces is a critical issue for individuals with disabilities, and that changes are needed to address these challenges. The government needs to take a more proactive approach in ensuring that public spaces and services are adapted and accessible to all, regardless of ability. This will not only improve the quality of life for individuals with disabilities but also promote inclusiveness and a more inclusive society.

Question 25: “What kind of barriers have you had when trying to access public spaces and government programs or services?”

The information provided for this question indicates that it is clear that individuals with disabilities face numerous barriers when trying to access public spaces and government programs or services. These barriers can be physical, financial, informational, and attitudinal in nature, and can greatly impact the daily lives and independence of individuals with disabilities.

One of the most commonly cited physical barriers is the lack of accessibility in buildings and public spaces. Many individuals with disabilities reported difficulty accessing buildings due to a lack of ramps, elevators, or automatic doors, making it difficult for them to enter and navigate these spaces. Additionally, there were also reports of poor accessibility in bathrooms, with many lacking adequate facilities or being difficult to access for those with mobility issues. These physical barriers can greatly limit the ability of individuals with disabilities to participate in daily activities and access important services.

Another barrier reported by individuals with disabilities was a lack of access to financial support and resources. Many reported having trouble accessing specific materials or equipment that they needed for school or work, as well as not having access to additional financial aid to help cover these costs. This lack of support can make it difficult for individuals with disabilities to fully participate in these activities and further exacerbates the impact of physical barriers.

Moreover, there were also reports of attitudinal barriers and a lack of understanding from employees and others in the community. Many individuals with disabilities reported feeling that their needs were not understood or taken into account, and that they were often met with miscommunication and misunderstanding. This can lead to feelings of frustration and discouragement, and can further limit the ability of individuals with disabilities to access the services and support they need.

In conclusion, individuals with disabilities face numerous barriers when trying to access public spaces and government programs or services. These barriers can greatly impact their daily lives and independence, and should be addressed in order to ensure equal access and opportunity for all people with disabilities.

Question 26: “What is the first barrier the Government of Canada should remove? How should they do it?”

The majority of respondents believe that the first barrier the Government of Canada should remove is physical accessibility, including the accessibility of public places, buildings, sidewalks, and public transportation. The main barriers identified include physical accessibility, financial insecurity, lack of knowledge and understanding among staff and service providers, and bureaucratic red tape. They suggest that the government should enforce laws requiring businesses to facilitate access to wheelchairs, elevators, ramps, and other necessary equipment. Additionally, they suggest that all new construction should be built with consideration for people with different needs.

Financial insecurity was also identified as a major barrier faced by people with disabilities in Canada. Respondents suggest that the government should provide financial freedom, which they see as the first step towards achieving dignity. They also recommend that the government provide more financial help to disabled people and their families and that it should inform them of all the services available. Respondents also mention the complexity of obtaining a disability tax credit, which they believe should be simplified.

A lack of knowledge and understanding among staff and service providers was also identified as a barrier. Respondents suggest that the government should educate and train staff on how to approach and assist people with disabilities and that services should be formulated in plain language. They also recommend that all websites and online applications be fully screen reader accessible. Additionally, they suggest that physicians or healthcare professionals should be assigned to meet and assess people who believe they have a disability.

What is more, bureaucratic red tape and the slowness of the system were also identified as barriers. Respondents suggest that the government should eliminate red tape and simplify processes, particularly in accessing support services. They also recommend that the government should assign a government employee to assist people with disabilities with all written communications, rather than sending written materials directly. They believe that the government should work towards the implementation of an accessible construction obligation and accessible renovations, making it possible for people with disabilities to live with dignity and quality of life.

In conclusion, the majority of respondents believe that physical accessibility should be the first barrier the government should remove, followed by financial insecurity, lack of knowledge and understanding among staff, and bureaucratic red tape. They suggest that the government should enforce laws, educate and train staff, simplify processes, and provide financial assistance to people with disabilities.

Summary of What We Heard

1. Removal of Organizational and/or Systemic Barriers:

- The existing piece meal and partial provision of accessibility accommodations is not sufficient, and such accommodations should be provided in full by the federal government.
- The federal government should alleviate support personnel shortage. (such as, Sign language interpreters, Visual/Tactile Interpreters, and personal attendants)
- There should be more transparency in government services.
- All government services should include an active offer of accommodation and be ready to offer Sign language interpreters ASAP upon request.
- Persons with disabilities should be more included in the design process of legislative proposals, policies, programs, renovations and new architectural builds.
- Organizations must consider accessibility for clients and customers, employees and management.
- Universities, and all post-secondary schools, should provide proper supports for all students with disabilities, but especially for high needs students (especially high needs student – such as Deaf students).

- The government should make it easier for people to submit their accessibility requests. (i.e., single identity cards that identifies a person's accommodation needs, one window chat box for people with disabilities, visual 1-800 options for people who can't use the phone).

2. Removal of Policy Barriers:

- Some disability support programs should be re-designed to provide value and aim to:
    - achieve economic independence from disability supports.
    - Remove restrictions on income support.
    - Support personal accessibility expenses.
    - relieve academic expenses related to accommodations.
- Systemic inclusive policy reviews and updates should be introduced at all levels.
- Governments should engage in proactive consultations with people with disabilities to maintain shared understanding of accessibility issues.
- People with disabilities should have equal opportunities in employment that can only be achieved by legislated quota on hiring.
- Accessibility compliance mechanisms by the government should be supported by proper funding and legislated changes that allow disability organizations and individuals access to the complaint mechanism.

3. Removal of Financial Barriers:

- Direct financial support mechanisms should be introduced to help people.
- The government should change its policies to avoid penalizing people who decide to get married and have their income status changed as a result. The government should review and change policies that penalize people. (i.e., people who decide to get married or lose a spouse to divorce or death may have their income status changed as a result.)

4. Removal of Architectural or Physical Barriers:

- Older federal buildings and facilities should be retrofitted with updated accessibility features. (such as., government should certify all their buildings for accessibility, budget accordingly to update all buildings and sites, establish a minimum building code standards for provincial implementation.)
- Healthcare facilities should have funding allocated to provide accessibility services to their patients, including mandatory Video Remote interpreting (VRI) for all employees, patients and visitors. (See Eldrige).

5. Removal of Information or Communications Barriers:

- More materials in ASL/LSQ should be provided that would help Deaf people navigate through the process of using governmental services. (Consider virtual chat window staffed by Federal Deaf employees)
- Physical and virtual (lack of captions on screens) barriers should be removed at all levels within a building.

- Emergency services and service-related announcements should be provided in various formats, as opposed to being done via audio communication means only.
- Security facilities and other facilities that are funded by the government (i.e., schools, shelters, entertainment venues, should have funding contingent upon the offering of accessibility accommodations and supports.
- For the built environment, especially for Deaf people, more visual supports, screens, more Sign language materials, and a remote interpreter service should be made available, and interactive wayfinding with audio/ text guidance for the blind.
- Government should work with the travel industry, Canada Border Services Agency and VRS Canada to identify ASL and LSQ users and provide 1-800 face-to-face interpreting services at international airports and border crossings.

6. Removal of Technology Barriers:

- Government services can should be made available via different means, not just through phone or computers only.
- Virtual/digital spaces should be made accessible by default.
- Telephone services need to be updated.
    - The IP relay service8 should be promoted more.
    - The Video Relay Service (VRS)9 should be always accepted as an accessible communication choice for Deaf people in all places and its “not at the workplace”, “not face-to-face” and “not for the hearing” limitations removed.

7. Removal of Attitudinal Barriers:

- Attitudinal barriers against people with disabilities remain an issue, and policy-wide changes and education are required to remove them.
- More accessibility changes are required for museums, entertainment venues and parks.
- Organizations should not be reluctant to provide client-facing work (Customer Service Reps, Bank Tellers) to employees with disabilities.
- Organizational policies should not exclude the needs of people who may not have disabilities, but who still face barriers in many areas (i.e., persons who experience homelessness).
- Organizations should provide sufficient accessibility accommodations in different environments and circumstances.
- There should be open captions/subtitles available in theatres.

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8 Internet Protocol (IP) Relay Service allows persons with a hearing or speech disability to use Telecommunications Relay Service (TRS) through a computer or web-enabled device to communicate through the telephone system with hearing persons.

9 Video Relay Service (VRS) is a form of Telecommunications Relay Service that enables Deaf people and persons with hearing disabilities who use American Sign Language to communicate with voice telephone users through video equipment, rather than through typed text.

Policy Review & Analysis

The Accessible Canada Act (ACA) is a key national disability legislation that aims to prohibit discrimination against individuals with disabilities. It builds upon the existing Canadian Human Rights Act and was presented for its final reading by Carla Qualtrough on June 21, 2019, before receiving Royal Assent.

The ACA applies to the federal public sector, Crown Corporations, and all federally regulated organizations, including industries such as railways, airplanes, inter-provincial buses, banks, mining companies, trucking, television and radio.

Accessibility Standards Canada (ASC) is responsible for developing the accessibility standards required under the ACA. The priority areas for these standards include employment, emergency measures, the built environment (including parks and outdoor recreation facilities), information and communication technologies, Indigenous accessibility, and accessible communications.

The ACA also established the positions of an Accessibility Commissioner and Chief Accessibility Officer. The Accessibility Commissioner has the authority to fine organizations up to $250,000 per violation and has broad powers to conduct investigations of complaints. If a complaint is substantiated, the commissioner has the power to order appropriate corrective measures and provide compensation to the complainant.

While the ACA, without doubt, is a powerful tool in making Canada a more accessible and inclusive country, some challenges remain. From the standpoint of implementing and enforcing the ACA, these issues could include a lack of resources or funding for accessibility initiatives, resistance or lack of compliance from some organizations, and a lack of awareness or understanding of the ACA among members of the public and some organizations.

Additionally, based on the previous community outreach conducted in similar circumstances, CAD-ASC offers further policy considerations and recommendations below that complement and build on the research done in this particular project. These practical recommendations represent “real life” solutions and sound advice to help the federal government improve its accessibility reforms for our common benefit.

Our recommendations have a simple structure. There are several different topics: poverty, healthcare, technology, human rights, civil rights, civic participation, and transportation.

Each recommendation has 4 sections: 1) Current federal legislation; 2) Current UN Convention on the Rights of Persons with Disabilities (CRPD) status; 3) Strengths and weaknesses of the current Federal situation; 4) Possible recommendations the Government of Canada.

We hope that these additional recommendations will further build on the suggestions that have been proposed in the first half of this report.

Poverty and Disability Policy Recommendations

Current legislation:

The federal government enacted several measures to reduce the poverty and increase income security needs of disabled persons who live in Canada. It has been done through:

- Employment Insurance (provides Regular Benefits to individuals who lose their jobs through no fault of their own (for example, due to shortage of work, seasonal or mass lay-offs) and are available for and able to work, but can't find a job);
- CPP/QPP (earnings-related *social insurance* program);
- Old Age Security (monthly *social security* payment available to most people 65 years of age or older);
- Guaranteed Income Supplement (gives a monthly non-taxable benefit to Old Age Security pension recipients who have a low income and are living in Canada);
- Income Assistance measures (general social assistance programs such as Bill C-22;
- The National Child Benefit;
- Child Disability Benefit;
- Disability tax credit, such as *Registered Disability Savings Plans*.

Positions Outlined in The Convention On The Rights Of Persons With Disabilities And in International Acts

The CRPD's positions on poverty reduction are written in the **Article 28**. It says that persons with disabilities have an equal right to necessary standards of living, such as food, clothing, housing, water, social protection, poverty reduction programs, and retirement benefits.

Strengths And Weaknesses of The Current Situation in Canada

According to the *2017 Canadian Survey on Disability report,* most persons with disabilities live at or below the poverty line. Approximately one in five people have a disability and among working age adults with severe disabilities, almost 1/3 are living in poverty.

The term "poverty" means that people spend approximately 60 per cent of their income on food, shelter and clothing. With an income below or at the poverty line, there is no room in the budget to invest in quality of life, savings, transportation and educational opportunities.

Overall, persons with disabilities had lower personal income compared to those without disabilities and it varied depending on sex, severity of disability, and household living arrangements.

For example, women aged 25 to 64 years with milder disabilities had median after-tax personal income that was 24% less than their male counterparts and 13% less than women without disabilities.

Among working age adults, personal income was strongly related to the severity of disability. Those with no disabilities had a higher median after-tax personal income ($39,000) than those with milder disabilities ($34,300) and those with more severe disabilities ($19,200).

In addition, among working age adults, 28% of those with more severe disabilities were living below Canada's official poverty line (based on the Market Basket Measure), compared with 14% of those with milder disabilities and 10% of those without disabilities.

The highest rates of poverty (for those aged 15 to 64 years) were among those with more severe disabilities who were living alone or were lone parents. For those living alone, 6 in 10 were below the poverty line, as were 4 in 10 of lone parents. Regardless of disability, 8 in 10 lone parents were women.

Possible Policy Recommendations

There are several various proposals to address the problem of poverty among the people with disabilities. *Bill C-22,* "An Act to reduce poverty and to support the financial security of persons with disabilities by establishing the Canada Disability Benefit and making a consequential amendment to the Income Tax Act", was introduced, if passed, this Bill would create a new Canada Disability Benefit to reduce poverty and improve the financial security of working-age persons with disabilities

The Caledon Institute10 proposed that the federal government should invest in a new initiative called "the Basic Income Program." The purpose of such program is to best provide the support that people from disadvantaged and/or underprivileged communities need.

Canadian Centre for Policy Alternatives described a vision of a widely-discussed **guaranteed income** to reduce the poverty levels among the disabled people. It is a form of a welfare payment in which the state regularly provides a minimum level of basic income to every adult. These payments are made regardless of a person`s economic circumstances or need, and there are no or very few conditions.

While these plans may be too far-fetched at this moment, the *Centre* also offered a few more politically achievable solutions:

- **Improved social assistance**: more investments in education, health care, child care to prevent poverty in the first place. It would give people a strong initial ground to firmly stand on;
- **Labour market reform**: higher minimum wage, flexible hours of work, better paid parental and maternity leave support;
- **Universal and affordable childhood education and childcare**: it would benefit women`s equality and will enable many of the poor people to leave their poverty behind.

Every Canadian Counts offered its own economic vision of improving the situation, such as:

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10 Founded in 1992, the Caledon Institute of Social Policy, also known as Caledon Institute, is a private Canadian think tank focused on social policy.

- **A national disability program**: the creation of a new separate national program designed to meet the needs of the disabled people. This program would introduce new financial resources coming from the federal government to help every province and territory to provide better services to its disabled citizens;

- **Disability information sharing**: a separate national program would allow provinces to share and coordinate their efforts about policies and delivery methods;

- **National data collection system:** it could provide a clear picture of provincial/territorial performance. It would allow the federal and provincial programs to direct resources to identified areas of need.

Tony Dolan, the then-chairperson of the Council of Canadians with Disabilities, summed up 3 *central solutions to improve the situation:*

- **The need to create new initiatives to address poverty**, including improving the Registered Disability Savings Plan and Canada Pension Plan Disability Benefit. That means removing barriers for those with intellectual disability wishing to open RSDP Plans, expanding the Disability Tax Credit Definition and making the CPPD benefit non-taxable.
- **New initiatives to improve employment access**. It includes setting specific targets for the employment of persons with disabilities in Labour Market Agreements with the provinces and expanding EI Sick Benefit.

- **New initiatives to improve access**, including the regulation of new information technologies to ensure it, and the creation of a Centre of Excellence that would provide best practice information to employers, businesses, etc. on innovative universal design options.

Health Care And Disability Policy Recommendations

Current legislation

Canada has a national healthcare program composed of thirteen provincial and territorial health insurance plans. They operate under the Canada Health Act and are governed by the Canadian Health Care System.

Federal and Provincial-Territorial Governments share the responsibilities and roles for Canada's health care system. Provinces must meet a lot of conditions to receive funding (Canada Health Transfer) from the federal government. Provincial and territorial governments bear the responsibility for organizing, delivering and managing health services provided to all their residents.

The *1997 Eldridge Case by the Supreme Court* plays an important role in the disability rights.

The Supreme Court ruled that sign-language interpreters must be provided in provincial hospitals in order to comply with equality rights guarantees in section 15(1) of the Canadian Charter of Rights and Freedoms. It was also established that all federal health care funding recipients must make their services accessible to disabled people. However, a lot of medical and mental health services are not provided in hospital settings, and access to interpreters is often lacking in these situations. Clarity on the obligation and the funds is required to offer such accommodations, and they should be made available - especially to small and medium sized providers of health services.

Positions Outlined in The Convention on The Rights Of Persons With Disabilities And in International Acts

The right of the disabled persons to health care is outlined in the ***Article 25***. It says that the people with disabilities have the right to equal quality and kinds of health services, including early intervention, sexual health, and health insurance.

Health professionals must provide equal quality of health care. Health care workers must receive training about the human rights, dignity, independence, and needs of persons with disabilities

Strengths And Weaknesses of The Current Situation in Canada

The difficulties that all persons who live in Canada have to deal with in finding a family physician are much more serious for people with disabilities. According to the Canadian Disability Policy Alliance, persons with disabilities have less access to healthcare. In addition, their health needs are less met than those of non-disabled people. There are 4 groups of barriers that people with disabilities in Canada face:

1) **Physical barriers**: inaccessible entrances to doctors’ office, inaccessible examining areas, lack of transportation to appointments; inaccessible office space, examining equipment and washing rooms.

2) **Barriers created by attitude**: negative perceptions about disability that influence the health care quality. Lack of willingness to accommodate the needs of the disabled patients, and lack of respect for the human rights of people with disabilities.

3) **Expertise barriers**: lack of understanding of disability, and of the health issues and complications that come with it. Often, doctors over-attribute health problems to the patients’ disability. Similarly, they often under-attribute health problems for the same reason. In general, doctors must do a better job understanding disability-related and non-disability-related health problems.

4) **Systemic barriers**: people with disabilities find they cannot get insurance to cover costs for

physiotherapy, medical equipment and mental health services. Disabled people have longer waiting times, and they have more difficulties getting an appointment.

5) **Financial barriers**: costs of transportation to appointments. Costs of disability supports are often too high and they are not always refundable. For example, the costs of hearing aids for hard of hearing persons can be too expensive to afford. When the government provides financial help, it is never enough, it is not always refundable and it does not cover both hearing aids in some cases).

Possible Policy Recommendations

1) **Updated rules**: review intake hospital and healthcare facility procedures to ensure that disability is identified and prioritized among registered patients;

2) **Physical accessibility**: ensure that all medical practices are accessible to disabled patients;

3) **Federal oversight**: establish a new department that would assist with placing disabled patients with family physicians in their regions. Encourage and provide the necessary resources so that the sole-practitioner physicians can take more disabled patients in their care.

4) **Raising awareness**: better inform the public and the disabled people about the availability of doctors in their vicinity with media campaigns prepared by people with disabilities.

5) **Better funding:** provide either direct accommodations, such as transportation services, support persons or interpreters to the disabled patients or cover the cost of the accommodations.

Education and Disability Policy Recommendations

Current legislation

On the federal level, the rights of the disabled people to an accessible education without discrimination are reflected in 2 documents:

- *Canadian Charter of Rights and Freedoms, 1982 (Section 15);*
- *The Canadian Human Rights Act, 1977* (prohibits discrimination based upon physical or mental disability).

In the United States, there are more federal laws regulating education for the disabled people than there are in Canada. *The Individuals with Disabilities Education Act* (IDEA), along with other legislation such as *the Americans with Disabilities Act (ADA),* and *the Rehabilitation Act*

(Section 504), form a national US strategy aimed to increase assess to assistive technology in education.

In Canada, the provinces and territories control the delivery of educational services. The provinces also establish their own systems. There is no pan-Canadian centralized educational strategy on how to deliver assistive technology for special needs students.

Positions Outlined in The Convention on The Rights Of Persons With Disabilities And in International Acts

Canada was one of the original signatories to the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD). The UN Convention recognizes the right of Deaf people to equal access to education, and upholds their right to be educated in Sign language. The Convention also supports the specialized schools (for example, Deaf schools) and it supports inclusive education at the same time.

This position is reflected in the ***Article 24 of the UNCPRD****.*

Article 24 says that governments must make sure that persons with disabilities have equal access to quality, free education with the support and assistance that they need. This means education at all levels: elementary, high school, university, training school, adult learning.

The article clearly states that the government must facilitate the learning of sign language and the promotion of the linguistic identity of the deaf community

It also includes learning Braille, Sign language, and any other form of communication that the person needs or wants. The educational facilities must support and enable the best academic and social development of children with disabilities. Teachers must be given appropriate training, and teachers with disabilities must be hired.

Strengths And Weaknesses of The Current Situation in Canada

The most frustrating fact is that Canada lacks a centralized federal system that would regulate educational concerns of the people with disabilities. These rules are set by the provinces. However, the federal government has and does offer a range of programs to help the disabled citizens to get a better education, but they are often inadequate:

1) ***Grant for Students with Permanent Disabilities:***

With this grant, students with permanent disabilities can receive $4,000 per academic year to help cover the costs of accommodation, tuition, and books.

2) ***Grant for Services and Equipment for Students with Permanent Disabilities:***

This grant provides up to $20,000 in assistance per academic year for students with permanent disabilities who need exceptional education-related services or equipment. It can be tutors, note-takers, interpreters, Braille interpreters, or technical aids. It should be noted that $20,000 would only cover full-time interpreting costs for approximately 4 weeks.

3) ***Canada Student Loans Program - Permanent Disability Benefit:***

This benefit gives people with disabilities means to repay their student loan to the government but not their debt.

4) ***Opportunities Fund for Persons with Disabilities:***

This benefit gives funding for national, regional and local projects that assist people with disabilities to find a job, become self-employed or get necessary working skills.

5) ***Canada Pension Plan Disability Vocational Rehabilitation Program:***

This program offers vocational counselling, financial support for training, and job search services to recipients of Canada Pension Plan (CPP) Disability Benefits to help them return to work.

6) ***Literature for the Blind:***

This service allows people to send materials such as Braille, audio tapes, and printing plates that will benefit visually impaired persons learning for free.

7) **Employment and Social Development Canada:**

This department offers several employment programs to help unemployed and underemployed persons, including those with disabilities.

8) **Lifelong Learning Plan (LLP):**

This plan allows a person to withdraw funds from their registered retirement savings plans to finance training or education. It can be done for themselves or their spouse or common-law partner.

On the other hand, there are also some concerns about the educational system:

1) **Lack of Individualization:** the schools do not always provide the “most enabling environment” for students with disabilities. Often, schools cannot give these students enough special attention and communication because of the number of students in class

and because of the curriculum’s structure.

2) **Accommodation Process:** Tutoring in ASL/LSQ in never provided for the deaf students. Special education programs, support and services are often confusing and time-consuming. The right to privacy is not always respected.

3) **Inadequate funding: the funding structure is overly-complicated, setting many restrictions and rules that make it difficult to get proper assistance. Very often, funding is given to accommodate the budgetary rules and not the needs of disabled students.**

4) **Physical Inaccessibility: lack of ramps, elevators, easy-to-open-doors, accessible washrooms and home-to-school transportation raise concerns about the rights of the disabled students.**

5) **Ineffective Conflict Resolution Mechanisms:** if a disabled student decides to address his concerns in the Human Rights Commission or in a court, the process is often too long, complicated, expensive and stressful.

6) **Negative Attitudes and Stereotypes:** students with disabilities often face negative attitudes and stereotypes in the education system. Educators, staff and students can make it difficult for students with disabilities to access educational services equally because of the lack of sensitivity training and disability awareness.

Possible policy recommendations

1) **Promoting public understanding and awareness**: students and teachers alike should be aware of the needs of the disabled students, and the government should encourage the efforts to change any negative perceptions;

2) **Increased funding**: the federal government should create a centralized system to provide additional funds to meet the needs of the special students, both technical and educational;

3) **Developing educational tools**: the special needs of every disabled student are different. Schools and educational facilities should work to make their programs more individualized and less generic.

4) **Enforcing the law**: the law requires educational facilities to provide equal services and proper accommodation to the disabled students. It should be strictly enforced, with corrections being made promptly and without being stressful for a student.

5) **A separate government agency**: to make sure the needs of the disabled students are

met. In Ontario, there have been calls for a provincial wide “Special Education School Board” that would guide administrators in implementing and delivering resources across the province for all students identified under an Individualized Education Plan.

Technology and Communications Policy Recommendations

Current legislation

The Canadian government is required to provide accessible information that meets the needs of the disabled people. These obligations are expressed in three documents:

- *the Convention on the Rights of Persons with Disabilities;*
- *the Canadian Charter of Rights and Freedoms*;
- *The Canadian Human Rights Act;*
- *The Telecommunications Act.* The Canadian Radio-Television and Telecommunications Commission (CRTC) serves as a regulatory body for broadcastings and telecommunications.

These legal documents require the Government of Canada to deliver accessible web information that is inclusive of the needs of disabled persons.

Additionally, some provinces have gone ahead of the federal government and implement legislation that will support Canada’s implementation of the UNCPRD within areas of their jurisdiction. The Ontario’s Accessibility for Ontarians with Disabilities Act (AODA) has set forth robust regulations that mandate minimum accessibility standards for Customer Service, Employment, Transportation and Information and Communications, including websites. Specifically mandating the adherence to the Web Content Accessibility Guidelines (WCAG) 2.0 level AA. These guidelines play a crucial role in ensuring that digital content is inclusive and accessible to individuals with varying abilities, including those with visual, auditory, cognitive, and motor impairments.

By adopting the currently recommended *World Wide Web Consortium Web Compliance Accessibility Guideline (WCAG) 2.1 level AA* as the federal standard, governments and organizations could create a more equitable digital landscape, promoting equal access to information and services for all citizens. Indeed, embracing such a comprehensive approach at the federal level would not only eliminate many barriers for people with disabilities but also foster a culture of inclusivity and social responsibility nationwide.

Positions Outlined in The Convention on The Rights Of Persons With Disabilities And in International Acts

The Convention's positions on the use and promotion of accessible technology are shown in **Article 4, Article 9**, **Article 21** and **Article 29** reproduced below.

Article 4 obliges the government to provide assistive technology and cooperate with organizations of people with disabilities to promote it;

Article 9 says that the government must set standards and good practices for accessibility;

Article 21 explains that the government should provide information in accessible formats and technologies in a timely manner and without additional costs;

Article 29 sets it as a requirement that the government must facilitate the use of assisting technologies to ensure the full participation of disabled persons in political and public life.

Strengths And Weaknesses of The Current Situation in Canada

New telecommunications technology must always be accessible to the persons with disabilities. But it can only be achieved if disabled citizens are involved in every aspect of technology: development, regulation, and distribution.

Unfortunately, new technology continues to be developed, regulated, and distributed without any involvement of the disabled community. Making changes for a greater accessibility is difficult and expensive. Inclusion should begin from the start, and early involvement of Deaf, Blind and other disabled persons is essential.

Another concern is the quality of telecom services. The lack of disabled consultants prevents businesses from enforcing high standards of service (or, in many cases, any service) for the disabled customers. Often, wireless services are inaccessible products for disabled people. Services and prices do not acknowledge how people with disabilities use data, and service personnel are not aware of their own company's disability discounts.

Canada is a world leader in closed captioning services, but refuses to require it for online videos, even where it licenses the provider (for example, broadcasters). The actions must be taken to ensure that online telecommunication services also have closed captioning.

Possible Policy Recommendations

In 2008, the Council of Canadians with Disabilities, on behalf of the Community Coalition (the Alliance for Equality of Blind Canadians, CNIB, Canadian Association of the Deaf, Canadian Hard of Hearing Association, Canadian Council of the Blind, Neil Squire Society, University of Toronto Adaptive Technology Centre, ARCH, Roeher Institute, Dis-IT, Media Access Canada), submitted *a report to the Canadian Radio-Television and Telecommunications Commission*.

In that document, the Coalition provided several recommendations on how to make telecommunications and technology more assessable to the disabled persons:

- **Federal regulation**: access and equality can only be achieved through government regulation;
- **Inclusiveness**: telecommunications architecture should always strive to be as inclusive and accessibility-friendly as possible;
- **Help from corporations**: corporate public services should include and support accessibility accommodations;
- **No new barriers**: any new policies must not create new difficulties to the disabled citizens;
- **National strategy**: an all-Canadian approach must be adopted to meet the needs of disabled people on the national level;
- **Follow the rules**: the Canadian Radio-Television and Telecommunications Commission must ensure that its actions meet the requirements of the Charter of Rights and Freedoms and the Canadian Human Rights Act;
- **Disability consultations**: a constant involvement of the people with disabilities in the policy decision-making is important.

Human Rights, Civil Rights, Civic Participation Policy Recommendations

Current legislation

The 1977 Canadian Human Rights Act prohibits discrimination against persons with disabilities when they are employed by or receive services from:

- The federal government and its regulatory agencies;
- First Nations governments;
- Private companies that are regulated by the federal government like banks, trucking companies, broadcasters and telecommunications companies;
- Crown corporations.

The Equality Rights Section (15) of the *1982 Canadian Charter of Rights and Freedoms* guarantees people with disabilities equal benefit and protection before and under the law.

It makes clear that every individual in Canada – regardless of race, religion, national or ethnic origin, colour, sex, age or physical or mental disability – is considered equal. This means that governments must not discriminate on any of these grounds in its laws or programs.

Positions Outlined in The Convention on The Rights Of Persons With Disabilities And in International Acts

The Convention's position on human and civil rights, and civic participation are outlined in several articles. These rights include:

- the right to food, clothing and shelter;
- the right to dignity and respect;
- the right to quality education to the highest level desired;
- the right to communication and information;
- the right to the language of their choice, including Braille and Sign language;
- the right to freedom and justice;
- the right to equality and access.

Five Articles reflect these rights in particular:

Article 4 ensures that the government will support the full equal rights and freedoms of people with disabilities. The government must remove barriers, stop discrimination, and provide information and assistive technology;

Article 6 and **Article 7** say that women and children have equal rights and freedoms;

Article 14 explains that people with disabilities have the right to liberty and security like everyone else;

Article 33 requires the government to make sure that the human rights of the people of disabilities are properly observed.

Strengths And Weaknesses of The Current Situation in Canada

Many disability organizations are aware that in Canada most violations of the human rights of disabled people are not deliberate and intentional but result from systemic discrimination, inappropriate priorities, and simple ignorance.

The consequences; however, are the same: discrimination against disabled people because of their disability. Any type of discrimination is inexcusable.

Possible Policy Recommendations

There are several structural barriers that prevent the disabled citizens from enjoying their full human and civil rights, and participating in the public life of Canada. The Council of Canadians with Disabilities sought commitments from Canada's major political parties on initiatives focused on enabling full citizenship. Still, lots of barriers persist. To remove these barriers, the federal government should:

- **Encourage captioning and/or interpretation** of information and entertainment;
- **Provide technical and human assistance** to access telecommunication services and systems;
- **Provide education in the most enabling environment**. The language and methods of education must be best suited to the disabled person's needs, skills, and preferences. For the Deaf community, preferably in a Canadian post-secondary setting or campus that recognizes, promotes and celebrates that language.
- **Ensure the provision of devices** required for the safety and comfort of disabled people (including visual signal devices);
- **Promote acceptance, respect, and understanding** of the different needs, language, behaviour and values of disabled people;
- **Enforce equal opportunity** for employment of disabled people. Increase the number of persons with disabilities, including members who are Deaf, to the number of government appointment to boards and/or agencies;
- **Early childhood intervention** should include teaching the parents how to include their disabled child in the family politics, and how to recognize the politics involved in any situation touched by the fact of disability;
- **Compulsory courses in Canadian politics in all schools** (Deaf and non-Deaf alike), taught by teachers trained and qualified for political education, and employing innovative and challenging methodologies;
- **Government should enact strong, pro-active legislation** requiring fully accessible political broadcasting, employment equity practices in the media, and the integration of disabled/Deaf programming and issues; (i.e., mandatory accessible all-candidates debates in every ridings during federal, provincial and municipal election campaigns.
- **Financial and resource support should be provided to disabled** consumer organizations to enable them to carry out non-partisan political workshops for their membership at least biannually (every two years);
- **Full accessibility of political party organization** meetings and information must be provided;

- **Political parties should undertake the active recruitment** of disabled members and election candidates; a practice that could be ensured by mandating candidates with disabilities in the slate of candidates to be named during a proportional representation election.

- **Elections Canada and the provincial and municipal election authorities** should provide 100 percent reimbursement of extra expenses undertaken during an election campaign by candidates who are disabled, regardless of the number of votes they receive;
- **There must be greater representation** of disabled people in government, civil service, business and unions, regulatory agencies, and commissions;
- **Training programs for the disabled** must be provided in the fields of self-awareness, self-assertion, empowerment, independence, participation, leadership, networking, information analysis, and implementation.

Transportation and Disability Policy Recommendations

Current legislation

The Canada Transportation Act (1996) and the Canadian Human Rights Commission regulate the accessibility policies for the disabled people.

The Canadian Transportation Agency is a regulatory agency with the authority to require transportation service providers within federal transportation network such as air, rail, and marine to improve accessibility issues.

Positions Outlined in The Convention on The Rights Of Persons With Disabilities And in International Acts

Transportation accessibility for the persons with disabilities is reflected in **Article 9** and **Article 21** of the UNCRPD.

Article 9 says that people with disabilities must have equal access to physical environment such as schools and hospitals and workplaces, transportation, information, communications, technologies, and other places and services open to the public. Governments must set standards and good practices for accessibility. For example, buildings should have information posted in Braille, public buildings like museums should provide professional Sign language interpreters, and Internet websites should have an accessible design.

Article 21 explains that people with disabilities must receive information in accessible formats and technologies in a timely manner and without additional cost when using official services, such as transportation.

Strengths And Weaknesses of The Current Situation in Canada

In their various reports, the Council of Canadians with Disabilities and the Canadian Association of the Deaf - Association des Sourds du Canada identified several problems with transportation accessibility:

1) **Physical barriers**: air and rail companies still have too many barriers; such as the access into the train or plane, the access to a person's wheelchair during travel, the public address systems in planes and rail cars, and the ticketing, security and custom processes and protocols.

2) **Psychological barriers**: transportation companies' staff apply their own judgement and opinions to disabled customers. This may be disrespectful and inappropriate;

3) **Airport barriers**: Domestic air carriers are now charging travelers to check their luggage. This is a barrier for passengers with disabilities who may need to travel with various aids, devices and supplies. Not all terminals (airports, train and bus stations, marine facilities) use adequate signage (e.g., electronic display boards) to announce boarding times;

4) **Service barriers**: travelers now find that a variety of services in terminals are offered through inaccessible touch screen devices. These devices are a barrier to travelers with physical and sensory disabilities;

5) **Technological barriers**: software does not always support adaptive technologies. Instead of updating systems, companies rely on outdated accommodations, such as TTYs;

6) **Systemic barriers**: without a proper legislation, companies are not motivated to make all the necessary changes. CTA has an Advisory Council on Accessible Transportation. However, their recommendations for improving accessibility have no enforcement or legislative power: they are voluntarily.

Possible Policy Recommendations

- **Policy development**: Canada could adopt the US regulatory accessibility model and utilize US Access Board guidelines and expertise – they already work. In the meantime, the government should work with the disability community to develop a deeper understanding of the barriers faced by people with disabilities and Deaf people.
- **International consultations**: in the United States, as well as in many other nations, there are best practices on inclusive and universal design. If these solutions work in other countries and meet the demands of the disabled communities there, such experience should be applied in Canada.
- **Internal consultations**: the Minister of Transport should appoint as full-time members to the Canadian Transportation Agency (CTA) disability community-based persons with expertise, including experiential knowledge in accessible transportation and lived experience of several disabilities.
- **Advisory Council On Accessible Transportation**: a public appeal process should be

made available if the Council's recommendations are ignored or fail to remove the barriers.

- **Knowledge sharing**: the government should monitor best practices in other jurisdictions, such as Ontario that improved the accessibility of their public transportation systems by creating accessibility criteria to the provincial gas tax program. Constant consultation with the disability communities should be maintained, as per the Accessible Canada Act.
- **Practical research**: the Minister should improve the capacity of the Transport Development Centre to make a research related to finding new means of advancing accessibility and universal design. It should apply to all federally regulated modes of transportation and service delivery. For example, all transportation terminals should provide and use good visual displays of information and announcements. The security personnel must be better trained to deal with disabled travelers.
- **Rights-based approach**: the solutions offered by the government should place human rights and dignity of an individual first. Accessible transportation design, including subway design in major metropolitan centers, should be based on inclusiveness, and not on a medical model.
- **The national gas tax program:** The Gas Tax Program in Ontario allocates provincial gas tax revenues to support local transit services, promoting accessible infrastructure and services for citizens with disabilities. This exemplary initiative fosters the creation of more sustainable, inclusive, and efficient public transportation networks. By adopting a similar approach, jurisdictions, the government can empower individuals with disabilities and enhance their quality of life.

Summary of Policy Literacy Review and Recommendations

The following recommendations went beyond the scope of consultations with persons with disabilities that were conducted throughout this project. They represent some of the collective insights and feedback gathered from previous consultations with individuals from the disability community in Canada throughout different projects, reflecting the community's concerns, aspirations, and needs.

Financial and Disability Policy Recommendations:

1. Increase investments in education, healthcare, and child care to prevent poverty provide a strong foundation for individuals.
2. Implement labor market reform by raising the minimum wage, offering flexible work hours, and providing better paid parental and maternity leave support.
3. Provide universal and affordable childhood education and childcare to benefit women's equality and help those in poverty.
4. Create a separate national program to meet the needs of disabled persons, including new financial resources from the federal government to assist provinces in providing better services. *Bill C-22* should be passed to implement this recommendation.
5. Establish a system for sharing and coordinating efforts among provinces and territories regarding policies and delivery methods for disability services.

6. Develop a national data collection system to improve Statistic Canada measurements when it comes to collecting any disability-related data.
7. Introduce new initiatives to alleviate poverty, including removing barriers for those with intellectual disabilities wishing to use financial and benefit services.
8. Create new employment incentives such as setting specific targets or mandated quotas for the employment of persons with disabilities in Labor Market Agreements with provinces, expanding EI (Employment Insurance).
9. Ensure the provision of devices required for the safety and comfort of disabled individuals, including visual signal devices.

Healthcare and Disability Policy Recommendations:

1. Review intake procedures at hospitals and healthcare facilities to ensure that disability is identified and properly attended to among registered patients.
2. Review all medical practices and procedures to make sure that all medical practices are accessible to disabled patients.
3. Consider systemic change to assist with placing disabled patients with family physicians in their regions and provide the necessary resources for sole-practitioner physicians to take on more disabled patients.
4. Raise awareness through public education and media campaigns about issues in health care such as the availability of doctors, including doctors with specialized knowledge to serve people with disabilities living in Canada.
5. Provide direct accommodations, such as transportation services, custom prosthesis, wheelchairs, hearing aids, support persons, or interpreters for disabled patients or cover the cost of accommodations to help ease the access for disabled patients.

Education and Disability Policy Recommendations:

1. Increase financial support for students with permanent disabilities to help cover the added costs for students with permanent disabilities who need exceptional education-related services or equipment (such as tutors, note-takers, interpreters, Braille interpreters, or technical aids).
2. Maintain a benefit under the Canada Student Loans Program to assist people with disabilities in repaying their student loans.
3. Provide more funding for national, regional and local projects to assist people with disabilities to find a job, become self-employed, or acquire necessary working skills via the Opportunities Fund for Persons with Disabilities.
4. Maintain the Vocational Rehabilitation Program under the Canada Pension Plan Disability Benefits to offer vocational counselling, financial support for training, and job search services to help recipients return to work.
5. Continue Lifelong Learning Plans (LLP) which allow individuals to withdraw funds from their registered retirement savings plans to finance training or education, including for family members with disabilities to increase employability.
6. Promote public understanding and awareness of the needs of persons with disabilities with the *Nothing About Us Without Us* campaign.

7. Ensure oversight of the needs of disabled elementary and secondary students, such as creating Special Education School Consortiums (such as Consortium Centre Jules-Léger) or Boards in provinces and territories that would provide guidance and oversee school administrators in delivering resources across the province for students identified with special learning needs and/or disabilities.
8. Provide education in an enabling environment that is tailored to the individual needs, skills, and preferences of disabled students, with a focus on providing education in American Sign Language within a Canadian post-secondary setting or campus that recognizes, promotes and celebrates that language. More campuses are needed in Canada to ensure the study, learning, and development of Canadian ASL and LSQ.

Technology and Communications Policy Recommendations:

1. Implement federal regulation to achieve access and equality for disabled citizens in telecommunications.
2. Prioritize inclusiveness and accessibility in the design of telecommunications architecture.
3. Encourage corporations to include and support accessibility accommodations in their services.
4. Ensure that any new policies do not create new difficulties for disabled persons.
5. Adopt a consistent approach that meets the needs of disabled people at a national level.
6. Each ministry and federally regulated entities must establish a compensated accessibility advisory committee led by a majority of self-identified people with disabilities to review all policy implementations for barriers.
7. Adopt captioning and interpretation of information and entertainment for accessibility.
8. Provide technical assistance, with a live person option, for accessing telecommunications services and systems to the public.
9. Recommend that the government to adopt and implement progressive accessibility standards, such as the *WCAG 2.1 Level AA*.[11]

Human Rights, Civil Rights, Civic Participation Policy Recommendations:

1. Enact strong legislation requiring fully accessible election practices in the local ridings, registered political parties and the media, specifically including the integration of disabled/Deaf programming and issues. For example, the provision on the election clerks to provide at a minimum one mandatory accessible all-candidates debates in every riding during federal, provincial, and municipal election campaigns.
2. Encourage political parties to actively recruit disabled members and election candidates. Recognize the inherent barriers to people with disabilities in the current election system to get elected and explore the potential of ensuring mandatory representation of people

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[11] Web Content Accessibility Guidelines (WCAG) 2.1 covers a wide range of recommendations for making Web content more accessible. Following these guidelines will make content more accessible to a wider range of people with disabilities.

with disabilities by mandating the number of candidates with disabilities in the slate of candidates required during “proportional representation” elections vis-à-vis “first-past-the-post”.

3. Increase representation of disabled people in government, civil service, businesses, unions, regulatory agencies, and commissions by mandating quotas for diversity appointments on boards, committees and staff of all federally regulated entities.
4. Explore and adopt some of the best practices of the International regulatory accessibility model and utilize their guidelines and expertise with the disability community to understand and address barriers faced by people with disabilities and Deaf people.

Transportation and Disability Policy Recommendations:

1. Utilize best practices and solutions from other countries through international consultations and apply them in Canada.
2. Appoint disability community-based experts, including those with experiential knowledge in accessible transportation and lived experience of disabilities, as ombudspersons within the Canadian Transportation Agency (CTA).
3. Establish an Advisory Council on Accessible Transportation and make a public appeal process available if the Council’s recommendations are ignored or fail to remove barriers.
4. Adopt a rights-based approach in solutions offered by the government, placing human rights and dignity of individuals first. Ensure that accessible transportation design, including subway design in major metropolitan centers, is based on inclusiveness.

Pillar 4: Modernizing Approaches to Defining ‘Disability’

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Créer ensemble des
changements durables.

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Sharing Guidelines

It is the hope of Eviance that the findings outlined in this report are used to inform policy and practice and improve inclusivity of persons with disabilities in society both in Canada and abroad.
Please acknowledge Eviance in the following ways:

- When referring to the report in published articles, PowerPoint presentations, websites, signage or other presentations use the proper citation above; and,
- This product and its content may not be used for commercial purposes.

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Introduction

This is the Final Report for Eviance's "Pillar 4" community engagement project, conducted for the Government of Canada's Disability Inclusion and Action Plan (DIAP). The present document aims to assist with the development of a modern approach to disability, which aligns with Pillar 4 of the DIAP. The Government of Canada committed to creating the DIAP in the September 2020 Speech from the Throne. The five objectives of the DIAP are to:

- Improve the social and economic inclusion of Canadians with disabilities.
- Reduce poverty among Canadians with disabilities.
- Contribute to the realization of a barrier-free Canada by 2040.
- Improve access to federal programs and services for persons with disabilities and ensure that disability inclusion is considered in all Government programs, policies, and services and
- Foster a culture of inclusion and a shift away from attitudes of ableism and discrimination (Employment and Social Development Canada, 2021).

Organizations responsible for the other three pillars of the DIAP are

- Inclusion Canada (Pillar1 – Financial Security).
- The Canadian Council on Rehabilitation and Work (Pillar 2 − Employment) and,
- The Canadian Association of the Deaf (Pillar 3 – Disability-Inclusive Spaces).

Related aims of the Pillar 4 engagement of the diverse disability communities include:

- Consulting with diverse disability communities to place a particular focus on "hard-to-reach and marginalized populations" (Muscular Dystrophy Canada, 2022).
- Sharing the information garnered through iterative consultations with diverse disability networks, for further input and then sharing with others in agreed-upon and accessible ways.
- Informing the DIAP by leveraging existing networks across disciplines and pillars when broadly disseminating information received from the consultations, meetings, and knowledge translation products.

In August of 2021, the Government of Canada called for proposals to solicit community perspectives and insights into the design and implementation of key initiatives under the DIAP. Independent Living Canada was designated the lead organization in partnership with Muscular Dystrophy Canada in this work. These partners contracted Eviance to engage diverse disability communities to collectively examine Pillar 4, specifically, the features of a modern definition of disability and on processes for applying that definition in program and service delivery under the DIAP.

Methodological Approach

Our work at Eviance is guided by and furthers the social justice intent of the Universal Declaration of Human Rights, the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and other international social justice frameworks. We are dedicated to the use of high-quality evidence in disability, inclusive of broader sectors', policies, programs, and practices. Our research activities include persons with disabilities in constructive and meaningful ways by using methods that include intersectionality, reflexivity, and innovation. Reflexivity means that we attend systematically to the context and process of knowledge construction by facilitating the time and space to listen, share and co-create (Buettgen et al, 2018). We believe that high quality evidence does not speak for itself; it must be socialized, which involves engaging in ongoing conversations related to content, context, culture, and capacity on disability issues. Our reflexive approach also means that we attend to the effects we have, as researchers, at every step of the research process. Thus, we have attempted to be clear about our values and thoughts as these are represented in our work. We value all individuals for their knowledge and unique contributions and embrace and facilitate inclusion and intersectionality. Intersectionality is a research, policy and practice paradigm which seeks to reveal the complex interactions among multiple social categories (Hankivsky & Cormier, 2009).

Accordingly, our methodology for this project highlights the experiences of people with disabilities from marginalized communities who are diversly located. By undertaking this work, we anticipate that there will be more representation in public discourse from communities that have been historically underrepresented. While our task is complex, we hope that defining disability in an inclusive and intersectional way will represent diverse persons with disabilities and will lead to a more inclusive and equitable Canada. The cross-disability sector as a whole will also benefit from this project (including, but not exclusively Eviance and our project partners), because exploring the various ways that disability is understood may provide stakeholders in the field with tools for greater equity in their advocacy, education, research, and direct support work.

Background on the Interviews for this Document

The individuals and organizations approached. This document captures the key messages Eviance has heard through 36 one to two-hour interviews conducted. Almost all respondents interviewed have disabilities and considered themselves somewhat "on the margins" of the disability community. Our aim was to listen to people's experiences, perspectives, and voices that have not garnered major attention in policy and program development. In addition to their experiences of living with disability, several of these respondents also have extensive knowledge about related policy and program issues. Seven of the interviews were conducted with people who presently focus on issues of disability, policy, and programming in their professional work or have done so in the recent past. We consider these individuals to be subject matter experts.

Selected characteristics of the interviewees. Appendix 1 provides a statistical snapshot of the diverse characteristics of the people who made up our interview sample. As with the gender mix among people with disabilities in the broader population, more women than men comprised the interview respondents (66.7% and 30.6%, respectively). One respondent (2.8%) self-identified as gender non-binary (Appendix Table 1.1). Half of the interview respondents (50%) were 35 to 54 years of age. Some 5.6% were younger than 25 years, 8.3% were 25 to 34 years, and 22.2% were 55 to 64, and 5.6% were at least 65 years (Appendix Table 1.2). The median was between 35 and 54 years of age.

Nearly half of the respondents lived in Ontario (44.4%), with another 13.9% in British Columbia, 8.3% in Alberta, 2.8% in Saskatchewan, 19.4% in Manitoba, 2.8% in Quebec, 5.6% in Nova Scotia, and 2.8% in Prince Edward Island (Appendix Table 1.3). Most (66.7%) lived in large cities with 100,000 or more residents. However, 5.6% lived in remote or hard-to-reach communities, 5.6% lived in rural communities, 8.3% lived in small towns with fewer than 10,000 people, and another 13.9% lived in mid-sized cities of 10,000 to 100,0000 people (Appendix Table 1.4).

Most respondents were white/Caucasian (72.2%). One in nine were Indigenous persons (11.1%), 2.8% were Black, 2.8% were East Asian, and 5.6% were South Asian (Appendix Table 1.5). Another 5.6% were from other ethno-racial backgrounds. The main language of most was English (80.6%), with fluency in English and French being the main languages of 16.7% and American Sign Language for 2.8% (Appendix Table 1.6). Aside from English and French, other languages spoken by the respondents included Hebrew, German, Spanish, Ojibway, Kapampangan, Tamil, and Sinhala.

Regarding the highest levels of education, nearly half had a university degree, consisting of 8.3% who had a Bachelors' degree, 22.2% with a Masters' degree, and 16.7% with a PhD. Other respondents included 13.9% with a college/CEGEP diploma or trade certificate, 16.7% who had completed some postsecondary education, 11.1% with a high school diploma, and 11.1% with less than high school graduation (Appendix Table 1.7).

Half of the interview respondents (50%) were working for pay at a job or business (Appendix Table 1.8). Among those individuals, over half (57.9%) worked full-time (30 hours or more per week) and the remainder (42.1%) worked part-time (Appendix Table 1.9). Only about a quarter (23.5%) of those who were working were 55 years or older, compared with 44.4% of those who were not working. However, only four respondents said they considered themselves formally "retired."

The total household income of more than a quarter of respondents (27.3%) was less than $20,000 annually. Some 18.2% had incomes from $20,000 to $34,999 and 12.1% had incomes in the $35,000 to $49,000 range. Another 15.2% had incomes between $50,000 and $74,999 and 27.3% had incomes of $75,000 or more (Appendix Table 1.10). The median income was in the $35,000 to $49,999 range. However, the average income was in the $20,000 to $34,999 range, suggesting that the typical income was around $35,000 per year.

Appendix Table 1.11 shows that most respondents were comfortable self-describing as having a disability (77.8%), although slightly more than half who reported a disability when asked, said they would prefer it if others would use some other way of referring to them. Appendix Table 1.12 shows that people with most major forms of disability were represented in the interviews. People with physical disabilities (e.g., mobility, bending, reaching, grasping) made up the largest group (50%), but about one third of respondents were, respectively, people with seeing disabilities (30.6%), psychosocial disabilities (33.3%), and various "other" disabilities not shown on the table (33.3%). More than one in five (22.2%) had a disability that involved spoken communication, as did another 22.2% who had difficulties with learning (22.2%). Some 16.7% experienced a hearing disability, 11.1% had an or intellectual/developmental disability, and 13.9% preferred to self-describe their situation in other ways because the options provided in our question did not adequately capture their understanding or experiences of disability.

On more detailed analysis, it was found that 63.9% of all respondents had 2 or more disabilities. Of the four respondents who did not report having a disability, two were immediate providers of support for a child or sibling with a disability and two had first-hand experiences of living with shorter-term disabilities themselves, as well as responding to disability-related issues among family, friends, colleagues, and acquaintances.

We were directed by our funders not to reach out to Indigenous groups as they were doing their own consultation on the DIAP. In that context we reached out to diverse organizations and individuals in every province and territory for our interview sample; interviewees were recruited from across most regions of the country. In the short timeframe available to this project, it was not possible to arrange and conduct interviews with people in New Brunswick, Newfoundland and Labrador, or the northern territories. That said, our sampling strategy did enable us to follow through on our commitment to intersectional engagement of people with diverse social identities. Accordingly, we interviewed people with diverse disabilities, of both genders, gender non-binary persons, younger and older people, Indigenous persons, people from a variety of ethno-racial backgrounds, people who were working and those who were not, people with lower, midrange, and higher incomes, people with no educational certification, high school graduates, people with some postsecondary education, and people who were college and university graduates.

Interview instruments, consent form, and Community Ethics Review. Appendix 2 includes the three interview guides that were used for this community engagement project. The Short Interview Guide was used with most interviewees, whose sessions lasted about an hour; the English and French versions of this Guide are included in that Appendix. The Short Interview Guide for People First of Canada is a slightly amended version of the other Short Interview Guide and covers all the same content but uses more straightforward (plain) language for a few of the questions. These interviews also took about an hour to complete. The Detailed Interview Guide covers the same ground as the Short Interview Guide but has some additional technical questions. This guide was used in the interviews with the subject matter experts, which each lasted from about an hour and a half to two hours.

Appendix 2 also includes the consent form, that contains explanatory information, and which was sent to all participants along with the relevant interview guide. The consent form, interview guides, and other explanatory documents are components of the Community Ethics Review that Eviance completes for its projects. All respondents provided informed consent before being interviewed. Eviance provided support to individuals who needed assistance to understand the consent form or the interview questions.

Structure of the interviews. The general approach to the interviews was straightforward. After several preliminary demographic questions and a question about how respondents arrived at their present understanding of disability, we explored what the respondents considered the most important things for people to understand about disability and its definition. This discussion covered the key ideas that respondents felt should be included in a definition and the features they felt should not be included. We also explored how people might have felt pressure to “go along” with a definition of disability, even though the definition may not have adequately described their actual situation and needs. We then explored the most important things to include in and exclude from the process for determining whether people whose disability has been validated are eligible for programs and services. We explored who should be involved in the disability validation process, who should pay for the validation of disability where fees are charged, and who should be involved in review and appeal procedures where individuals disagree with the decisions government officials have reached.

For the in-depth interviews with the Detailed Interview Guide, we also explored several key terms that are used in definitions of disability at the federal level. The aim was to explore the strengths and limitations of such terms, whether respondents considered them appropriate, and modifications or alternatives that respondents believe should be considered.

All the interviews ended with a few more demographic questions and several open-ended questions on what else the respondents wanted us to know about a new approach to defining disability, about applying the definition in eligibility for programs and services, and about the interview itself.

Overall impressions of the interview data. Upon review of the interview transcripts and the interviewers' reflexive notes, the astonishing depth and breadth of the respondents' insights became clear. It has been a privilege to ask about and listen to people's experiences, opinions, and recommendations. We are most grateful to respondents for generously making available their time, insight, and candor.

The Scope and Content of this Document

It would be impossible in a brief document to relay all the insights provided by all interview respondents. What follows are key messages that we gleaned from the interviews. The in-text quotes and text boxes amplify key points in the respondents' own words.

We begin the main content of this report by providing a couple of high-level messages that recurred throughout the interviews. We then explore respondents' understandings and experiences of disability and the top ideas that respondents believe should be included in and excluded from any new definition of disability. We explore some of the language that is often used to describe disability. We also explore what respondents told us about some of the experiences, attitudes, and values they have encountered which have historically informed how the disability "system" defines disability and establishes eligibility for programs and services. While such experiences, attitudes, and values have often been difficult and troubling for people with disabilities to deal with, respondents pointed to how the underlying values and system processes could be reconfigured to foster more positive experiences in the future. We turn next to people's impressions of the definition of disability in the Accessible Canada Act (ACA), and then the features that respondents believe should and should not be present in the procedures for validating the presence of disability and for determining eligibility for programs and services. We also explore what respondents had to say about "proving" disability consistent with the definition of disability in the ACA, how a new approach to the definition of disability could be administered, and respondents' thoughts on reviews and appeals. The conclusion summarizes the main messages that we heard.

Key Messages

Overall

Inherent human dignity. A strong message that came through in all the interviews we conducted was about the inherent dignity of people with disabilities and the desire and expectation that they would be treated with respect and as equals in any processes to determine the nature of their "disability" and eligibility for programs and services.

Equality. The principle of equality was an underlying concern in what interview respondents told us about defining disability and the scope of the definition. A general message was that it would not be fair for a definition to privilege people with some selected conditions, impairments, or functional limitation as having disabilities, and to deny recognition of disability to others whose difficulties take other forms.

Capabilities. Another key message was that, despite whatever limitations people may experience because of disability, people with disabilities are capable of doing many things. Accordingly, the process of assessing people for the presence of disability should be designed to take account of the things people can do, or that they could do, with suitable supports. The system should be designed to foster that kind of approach instead of present approaches which tend to “pathologize” individuals based on the things they must prove they cannot do at all, or that they can only do with great difficulty.

Gather only the essential information. Further, while some degree of medical information may be necessary for assessing the presence of disability, respondents generally agreed that the information gathered for assessing disability should be kept to what is essential and that the disability determination process should not be highly medicalized, as it often is at present.

Said one respondent in putting together these overriding messages, “There probably is a role for some kind of …medical or biomedical or psychosocial assessment… I don't want to ignore that. But they need to be wrapped around other values so that we make sure we do not emphasize incapacities and construct, as Goffman[12] would say…. a ‘spoiled identity .’ You know, we don't want to stigmatize people. We also don't want to create a power relationship … where people get constructed as, if not powerless, as ‘less than’ so that they become the object for other people to take care of, or to treat, or to cure, or to fix.”

> *“… The three things I think are core to a definition of disability are, number one, historical disadvantage. So, it has to do with group membership and with the history of how members of that group have been treated. The second characteristic would be stigma – the way one is seen in the world and how that affects every interaction. The third would be context, because clearly what is a disability in one context may not be a disability in a very different context…. These [pivotal concepts] do shape what justice looks like. They shape a concept of justice that I think would be appropriate and helpful for people with disabilities…*
>
> *But when I think of things like whether you’re qualified to have someone come and remove the snow from your sidewalk or not, it probably doesn’t matter whether or not you’re historically disadvantaged. Rather, it’s very much about context and about functional capacity. So, I see the problems with that bigger definition and I’m quite intrigued by … how you’re going to bridge those realms and come up with a definition that can be made more*
>
> *“I have to … say certain things so I can get a benefit. It’s definitely complex. It’s not like they want it [the disability validation or needs assessment process] to be all encompassing. It’s hard to fit in with what they want you to be in that box. You have to make sure somebody believes you − that it’s not all ‘in your head’... No one tells you where to start. It’s hard to navigate the systems.”*

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[12] The respondent was referring to Erving Goffman, whose book “Stigma” (1963) and other works have had major influences in scholarship on disability.

Types, Durations, and Stability of Conditions for Signifying "Disability"

Clear preference was present across the interviews for a broad and inclusive approach to defining disability in terms of its forms, durations, and stability. Specific considerations are as follows:

Many types of disability.

- As there are many types of disability, any new definition should encompass them all.

Many causes.

- There are many causes of disability. The definition should either not depend on how disability was caused or include all causes.

Onset at any point in the lifespan.

- Disability can occur at many points in the lifespan. The definition of disability should either not depend on when it occurs or is first experienced or the definition should acknowledge that disability can occur or be first experienced at any point in the lifespan.

"I would say it's [disability is] a form of difference rather than deficit. It is an inherently neutral form of difference. The problems arise from what we make of that difference or how we … accommodate that difference – how we structure our world. I take it as a starting point that it is a neutral characteristic. But it is invariably associated with negative outcomes in society because of a range of extraneous factors that assign value to certain human characteristics and, in particular, negative value to many disability characteristics…"

Many disabilities are not evident to others.

- Some disabilities are evident to others, and some are not. The definition should incorporate both "visible" and "invisible" types of disability.

Continuous, progressive, and episodic.

- A disability can be stable and fairly predictable (continuous), progressive (increasing or "getting worse"), or may flare or "come and go" (episodic). Research from Statistics Canada (Morris, 2019) has found that nearly six out of ten people with disabilities have one or more conditions that are "dynamic," that is, which are progressive (i.e., get worse − 22.6%), or recur (24.9%), or which fluctuate (13.3%). The definition should incorporate all such expressions of disability as well as continuous disability (39.1%). It will be observed that there are nearly as many people with the recurrent and fluctuating conditions that comprise "episodic" disabilities (38.2%) as there are people with conditions that are continuous (39.1%).

"One of the things that's very troubling to me… is that there's been a sort of like infantilization that happens with disability… what I want people to know is that disability is just simply different. It's not good or bad, it just is. And I think that it would be helpful to have a little bit more of a nuanced understanding of disability beyond … a biomedical model…"

"Do I count as having a disability?... Episodic disability is tricky because it comes and goes so that I don't often fit. I can't always predict when and how long I'm going to be either immobilized or disabled…I'm thinking in particular … of the inability to work. I don't really fit with the definition of disability."

Variability of episodic disability.

- A person may have a long-term condition that flares or is episodic and which affects how they interact with their world. On some days, the condition may be more impactful on a person's activities than on other days. Even on the same day the condition may be more impactful at one time than another, such as in the evening versus the morning. A few of the more common such conditions are, for example, multiple sclerosis, some forms of arthritis, and fibromyalgia. Here, there is an ongoing *and* an episodic dimension of the same condition that affects a person's interactions with their environments. The definition of disability should be designed to acknowledge the ongoing *and* episodic nature of some conditions which many people experience.

Some disabilities are unpredictable.

- For some people, the unpredictability of their disability – especially episodic disabilities − is itself a major issue that plays havoc with making plans and following through on commitments. As one respondent pointed out, "That would be crucial in the area of employment." Several respondents urged that the unpredictability associated with disability should itself be factored into the definition.

Multiple disabilities are quite common.

- One person may have – and often does have − several types of disability. The definition should be designed to acknowledge this fact. Researchers for Statistics Canada recently found that over two thirds of people with disabilities have two or more types of disability and that the likelihood of having two or more types increases with age (Morris, Fawcett, Brisebois, & Hughes, 2018).

Layered experiences of continuous *and* episodic disability.

- Disability can be layered and interactive in the sense that a person may have one or more conditions that are stable and continuous, such as a mobility *and* a hearing impairment, and others that flare, such as lupus *and* depression. The definition of disability should be designed to capture multiple forms and the varied durations, fluctuations, and impacts of a person's situation.

A person's different levels familiarity with two or more disabilities.

- Some people have had a disability for many years, such as since birth, childhood, or early adulthood. They may have sustained another disability more recently, such as from an auto accident, occupational injury, or disease. The disability assessment process should be designed not only to recognize what may be several different

"I've been finding a lot of interest in the term 'dynamic disability,' which is essentially a disability that can look different, depending on the day, or minute, [or] week. Symptoms can look different. Mobility needs can look different. Access needs can look different. A lot of the time they have to do with chronic illnesses and that … are just pretty unpredictable… Sometimes I use a wheelchair... Sometimes I use a cane. And sometimes I can just walk… I think that's something that … is often harder for able-bodied people to understand or … that tends to be questioned. [It] kind of puts me in the awkward position of, 'Oh, you're not in the wheelchair anymore. You're feeling better.' And it puts me in the awkward position of being like, 'This is might only be until tomorrow.'"

"If I have an impairment you can't see, it doesn't mean I don't have it. It means that it's inside."

"I was diagnosed with cancer last year. But that's not considered a disability … not generally on its own…I am profoundly disabled: I have Spina Bifida. I also have C-PTSD [complex post-traumatic stress disorder], and I have some other mobility issues going on, and profound asthma compromise – immune system. So, it affects me day to day. However, the definition of disability and the Disability Tax Credit: I don't qualify. So, all of the supports and medications and things that I have to use, to live with my full and awesome life, I don't get deductions because I don't fit that definition."

points in time for the origin of several coexisting disabilities that a person experiences, but also the person’s different levels of familiarity with each of those disabilities.

Minimum duration for “disability”?

- Disability may be long-term (e.g., lasting for years) or short-term (e.g., lasting for a few weeks or months). Interview respondents did not provide a hard-and-fast rule for the minimum duration for a condition or limitation to be considered a disability. However, one respondent suggested that six months was probably “long enough” and hazarded that even three months might be considered. Several respondents indicated that they appreciated some limits will be necessary to forestall a flood of applications that could overwhelm processes for validating disability and for adjudicating eligibility for financial or other benefits.

“So often governments try to fit people into boxes. In my case the box was if you can’t make enough money to live, you’re disabled. But if you can do something, and live well and earn good money, you’re not disabled… for ever and ever and ever, Amen. So, I think this is one of the most important things to get away from.”

Definitions tend to be deficit-focused.

- Several interview respondents pointed out that many of the present approaches to assessing the presence of disabilities focus on people’s deficits, incapacity, and the things they cannot do at all or only with great difficulty. They urged that instead the disability determination process should be designed to explore how a person might be able to participate in society in ways that would make sense and be suitable to them. The process should explore the difficulties that prevent a person from participating (impairments/functional limitations in the context of opposing barriers), and the measures needed to address those difficulties. Such a process would not be focused on incapacity but instead on capacity activation and on the supports needed for that to occur. Several interview respondents indicated, however, that present approaches to identifying disability pay little attention to barriers that interact with impairments/functional limitations, or on the supports needed to address the resulting difficulties people experience in participating as equals in society.

“Well, certainly ... I would say it's [disability is] a form of difference rather than deficit.”

“I always find it a bit artificial that when people talk about disability …. they don't make any mention of the body. …We're talking about people who've got real things going on in their lives. Not to fall into the trap of a deficit model, or that we just stress the limitations, but [we do need] to acknowledge realistically and pragmatically that ... there are extra out of pocket expenses. There are other things people experience because of their impairments or their conditions. And a lot of that to do with the lack of support, lack of services, etc. [But] some of it is… the embodiment, the embodied experience of our lives.”

The need to acknowledge d/Deafness as a category.

- For a variety of reasons, it is fairly common for people who are d/Deaf to resist being categorized as “disabled.” Yet, many of the difficulties d/Deaf people experience are the same as or similar to the difficulties people labelled as “disabled” encounter. It should be possible for a person to indicate they are d/Deaf and for the

“Some people think of ‘impairment’ as a bad word.”

federal system to acknowledge them as facing essentially similar difficulties as people with disabilities. However, the federal system should take into account their unique challenges and needs.

A simple way of thinking about disability: Focus on *how* a person interacts with their environments, not *whether.*

- One plain language definition of disability that a respondent provided was as follows: "Disability should be defined as anything physical, emotional, sensory, or intellectual that impacts the way a person interacts with their environment... Disability can impact several parts [aspects] of a person's functioning.… Disability can impact *how* you interact with your environment and *how* you do things. But it doesn't necessarily impact *whether* you can do things... just *how."* This respondent was knowledgeable about various approaches to defining disability. Given their responses to our interview questions, the respondent's understanding of the "environment" included the natural, built, social, economic, technological, attitudinal, procedural, policy, legal, and other dimensions.

"They're having a deficit model of disability in … definitions… You're meant to be providing supports and lifelines for people. It immediately sets a tone of disability as a negative, whereas it's not something people can control about themselves. And they're navigating worlds and systems that are not built with disability… in mind. So having definitions that can start in a more positive way might help with a general understanding of disability."

"To be Deaf means that I watch with my eyes, and I talk with my hands.... We require a phone that flashes a light. We require a TV that has closed captioning. We require a VRI [Video Remote Interpreting], where, if we have an emergency we can call, or if we need a hospital or a doctor... There is also VRS system [Video Relay System] that you would call through on the phone... to go shopping... to place an order at a restaurant... It's very important to have that accommodation... Also what we need are interpreters for presentations... [and] to have interpreters available [more generally] ..."

Language for Describing Disability

Most of the interview respondents did not seem to have major difficulties acknowledging they have a disability. Many were comfortable with a variety of approaches to “naming” disability.

No clear preference was stated across all interviews for one word or combination of words that can best be used to capture the meaning of disability. However, there was generally a clear preference for terms that are non-technical, non-medical, in plain language, and free of jargon.

Medical terms: Okay, but only up to a point.

- Several respondents acknowledged there may be a place for medical and other technical terms in some aspects of determining and validating whether disability is present. However, respondents also urged that the disability assessment process should not be heavily medicalized as at present in many federal, provincial/territorial, and municipal programs.

> *“It would be great if pharmacy documentation... could also be used as proof of disability/ diagnoses. For example, the disease-modifying therapy I am taking is only prescribed to patients with MS [multiple sclerosis]. I wouldn't be on it if I didn't have a diagnosis of MS. There would have to be guidelines as there are many meds that treat a variety of conditions. But if a pharmacist or pharmacy receipt for a disease-specific medication could be used as proof of having a condition – that would be helpful!”*

Adopt language that reflects cultural understandings and preferences.

- One respondent pointed out that in some ethno-racially diverse communities, “health condition” is a more acceptable term than “disability.” Approaches to assessing the presence of disability should be attentive to such nuances and should be able to take cultural differences and preferences into account.

> *“The notion of impairment is a valid concept in many cases. Where I worry it might be a barrier is if a person has an emotional or mental difference that is not recognized as an impairment or that they themselves don’t feel is an impairment. I’m thinking of autistic people, for example.”*

Terms should be clearly defined in plain language.

- Terms such as “impairment” and “functional limitation” are closely related and can be difficult to distinguish from one another. If used at all, such terms should be clearly defined in plain language.

> *“If you use ‘impairment’, some people may not know what you’re talking about. You’ll need a definition.”*

Negative connotations should be avoided.

- Several respondents relayed how the term “impairment” has negative connotations that many people are not comfortable with. For example, “impairment” has many negative connotations associated with driving an automobile. Not all respondents shared that concern, however. The different views on this issue point to the need for several approaches to “naming” disability in ways that make sense to and are respectful of the people whose situations are being talked about.

> *“These definitions and the words matter… They construct identities and shape cultural stories and narratives.”*

> *“I guess [I don’t like] terms like ‘mild’, ‘moderate’, ‘severe’ because I feel those are demeaning, like ‘functional’ or ‘high functioning.’ Words hurt, and I think that’s why people don’t want to be called ‘disabled.’ You don’t want people to look at you differently, or you don’t want people to feel bad for you. You just want to live your life.”*

Words like ‘impairment’ and ‘functional limitations’ are not value neutral and should only be used in respectful processes, if at all

- While some respondents did not seem to mind the use of terms such as “impairments” and “functional limitations” to describe disability, others were quite uneasy about such terms as perpetuating biomedical and often derogatory approaches to disability. Echoing the views of several others, one respondent said the term “impairment” is, for her, “loaded” with negative connotations. A general impression left by respondents is that the respectfulness of the process in which such terms are used to describe disability requires as much attention as the words themselves.

“I don't love the word ‘impairment.’ I really don't. I don't know why. I think impairment is just loaded. It's just ***loaded*** *for me… It’s like ‘abnormality’… You know? … Impairment suggests like some sort of radical difference. To be impaired means to… be incapable or not able to make … sound judgment.”*

Some terms are inappropriate and should not be used.

- A few respondents pointed out how the word “impairment” may not be very suitable for describing the situation of someone with an emotional difficulty or someone on the autism spectrum. Such individuals may prefer terms such as “psychosocial disability” or “neurodiverse” or “functional difference” rather than “impairment” to reflect their situation and experiences. In addition, many people find the “R word”13 highly offensive; it should not be used at all.

“The most important thing I’d like people to think about when thinking about disability is that ‘able-bodied-ness’ is a temporary state… TABS: temporarily able-bodied people. Anybody who gets old enough is likely to be disabled in some way, so nobody should feel like the idea of disability doesn’t apply to them, and never will.”

Use language that is respectful, clear, and to the point.

- Reflecting on efforts to devise alternative language for terms such as “impairments,” “functional limitations” and similar words that historically have been used to capture the meaning of disability, one respondent expressed their opinion and the caution that “political correctness has gone over the top.” The language should be respectful, yet clear and to the point.

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13 We hesitate to provide an explanation of the “R word” because of the offense and hurt the word causes. For an explanation, consult a brief video by Lukoff (2019) at https://www.therwordfilm.com/

Taken together, the above ideas can be used as precautions against loading too much emphasis or value into any one word or combination of words to define disability. Indeed, perhaps more than one approach to concepts and terms could be given status in validating the presence of disability. Regardless of the exact methods chosen, one respondent cautioned, "It's very individual…. Use simple language so everybody understands it, but also so it is as positive as possible." Whatever approach is adopted should be respectful and attentive to the individual's unique situation and needs.

"Well, I think it's useful, whether it's impairments or functional loss or limitations. It helps us understand what the real needs of a person are. It helps us to focus in on how's those impairments can be compensated for. Maybe it's technology. Maybe it's staff. Maybe it's … the wide range of things that can be done. But they have to be in relation to the functional limitations of the person. So, I think it's useful in that way. I've never been offended by any description of my limitations. Some people would be… I find that I'm in a much stronger position... It just makes the solutions easier… I don't feel it makes me any less valuable as a person. It's just a simple fact. It's like, you're wearing glasses, I'm wearing a wheelchair. Yup, we both need them. And they're not interchangeable. They're unique to our individuality."

Assumptions, Values, and Historical Experiences

Interview respondents discussed several assumptions and values they have encountered in processes to identify whether they have a disability. The following are antidotes to the kinds of negative assumptions and values they have encountered:

> *“It's the meaning attached to the word. …We could redefine it and redefine it. But it if the stigma’s still there, it doesn't really matter… In terms of an addition in a definition, I don't want the chosen definition to reflect that the person who's living with a disability is ‘less than’… or that they're second-class citizens … with nothing to contribute... I would avoid anything that …would assign someone to a lesser station in life or a lesser category of being, and then limit them at the same time. Like, ‘You’re* ***here****. And you can’t come out of* ***that****.’”*

There is nothing “unusual” about disability or people with disabilities.

- Disability is part of the human condition. Programs and program officers should not treat people with disabilities as if there is something “weird” about them or as if they have something to be ashamed about.

Avoid making assumptions.

- People are diverse. Programs and program officers should not make assumptions about people based on their “label,” including assumptions about what they can and cannot do.

Focus (also) on capabilities.

- People have capabilities. Programs and program officers should place significant attention on finding out what those capacities may be and how to support them.

> *“There's a lot of shame around disability [especially in some communities] …. There's a lot of stigma … Even in my neighbourhood, I've known people who've committed suicide when they became [prevented from working because of disability] … Being able to work … is so important. When you're not being accommodated at work, the judgment from colleagues or the union is you should just stop working. But… if you're able to work and you're not, then you're just headed towards, like, depression… You need something to do sometimes, especially when you're dealing with serious health challenges. You just need to keep going.”*

Set people up for inclusion, not exclusion.

- People want to be included. The process for identifying the presence of disability should not set up a path towards social exclusion. As one interview respondent said, “Some people need 24-hour care. But they also want to live in society and be known as anyone else.”

Treat people with respect.

- People want to be treated with respect. The disability determination process should treat them accordingly.

Build trust.

- Some individuals are uncomfortable talking about their disability with people they don’t know very well. Programs and program officers should provide the time needed for trust to build and for people to feel comfortable speaking about their situation and needs.

> *“I have a huge problem.... It [disability], you know, comes from the Victorian era... ‘hand’ and ‘cap’ ... This is like a really negative connotation.... the association with ... begging. I have a huge problem with this.”*

Get to know individuals.

- Several respondents reported that they would appreciate it if the person identifying the presence of disability would take the time to get to know them as individuals. This would involve exploring the things with which they do and do not have difficulties in the context of their life and of what they would like to be doing. Several respondents pointed out that medical and other professionals seldom invest much time in exploring the forms and impacts of disability on what they could do and would like to be doing with their life.

Provide positive experiences that help undo the many negative experiences people have had.

- People have a long history of not being treated very well by disability “systems.” People often feel that systems are designed to keep them out and to deny benefits rather than to provide the support needed to participate fully as equals. Instead, a more collaborative dynamic needs to be established between the person seeking validation of disability and those whose responsibility is to validate disability. In the words of one respondent, “Programs and services need to be about how people can succeed and reach their potential, not about keeping people out.” In the words of another respondent, “Try to make the power dynamic as collaborative as possible.”

> *“Another thing they can do is list organizations or charities… because they can assist with filling out these forms. And if you have any questions, they can clearly say, ‘Oh, that means this and that means that’… So helping people get through all these loops so they understand…”*

Create more welcoming and supportive points of access and processes.

- Similarly, the social and emotional “climate” at the gates of the disability system is not always welcoming or supportive, an issue that should be addressed. As one respondent explained, “I'm still stunned at how many programs in Canada really don't comply with the *Charter of Rights* for they make people almost sign away their rights − which is illegal in itself. And the fear of reprisals people [with disabilities], parents, and others are worried about … If they were to question what the social worker said, or the psychologist, or the nurse, or the administrator − that they would get punished for it. … So, there's this fear factor… It's not all to do with the procedures. But if we can start by simplifying and publicizing the procedures in plain language, making sure they follow just basic notions of administrative fairness… Whatever the definition [of disability] is, there's process features of the procedures that need to be addressed.”

> *“It feels like you have to go along with [the language] to get the services. But also, you have to quantify the disability, like ‘Am I bad enough off to fit in?’”*

> *“I guess …I would want definitions to … be a little less rigid or not so located in deficit or… create that image that, if you're disabled and needing to access services, you’re a failure of some kind.”*

> *“And the question that I raise is, as an LGBTQ+ person: ‘Who would that definition eliminate, or how? How will that definition of disability once they have the definition, impact me?’ ‘Cause you know, whether it’s in touch with this disability or development plus another layer – the LGBTQ+ and a disability aspect – How would **that** [work]?”*

Shifting from providing ‘handouts’ to providing public service.

- Unlike healthcare services, disability-related support is not usually an entitlement – whether in the form of income or services. Essentially, people must ask various tax, income-support, education, social service, other public programs, and private-sector employers to do them a favour by recognizing and responding to their needs. But first individuals must prove that they deserve the favour. One respondent stated their alternative preference as follows: “If there was a [key idea that should be included in the definition of disability], it would be the idea about either entitlements or rights. Whatever programs or services we're talking about, and the definitions that will be designed to be the eligibility screens, these [should] not be seen as handouts or favours, or at the discretion of [officials]. For reasons of justice, or equity, or fairness, they should be seen as just public services − part of the infrastructure of a decent society, a society committed to fair chances and equal participation and those sorts of values.”

Gathering Enough of the Right Information, Not Too Much or Too Often

Don’t set up systems that require people to overstate incapacity.

- The disability “system” often requires that people show how incapable they are so they can get *any* of the support they need. As a result, people can sometimes feel under pressure to overemphasize their *in*-abilities in the disability determination process. As one respondent put it, “Sometimes you have to make yourself seem dumber than you actually feel so you can tick the box, fit in the circle.” Several respondents related similar experiences of themselves and others they know. Alternatives need to be found to the design of the disability determination process so it does not skew in favour of acknowledging and rewarding incapacity and so it does not generate a culture that emphasizes people’s lack of capacity rather than their capacity and potential.

Cut down on the required “paperwork,” digital and otherwise.

- Many interview respondents complained about the amount of “paperwork” they have had to complete themselves and that others have had to complete on their behalf, such as medical doctors. All this evidence is required so the disability “system” will recognize them as having a disability. Frequently, people whose condition is stable and long-term must have it reassessed, which evokes the need for more paperwork and the associated inconveniences and costs. Some feel that, regardless of whether it is actually required, far too much detail is gathered and provided to government officials in the assessments. As one respondent said, “We are beyond the days of all the paperwork! Think about the environment! What a waste… Some information is no one’s business…. If you’re not a doctor, there are things you don’t need to know.”

Cut down on reassessments.

- Several interview respondents pointed to the disability “system’s” needs for regular reassessments as a significant problem. There seemed to be a general understanding among respondents that, in situations where a person’s disability has not yet stabilized, such as after an accident, or is routinely in flux, such as an episodic disability, some reassessments may be reasonable and necessary. However, many individuals indicated that the need for repeated reassessments of a condition that is essentially the same as it has been for

”It's a question of the balance, and the way we frame it and the way we talk about it…. I would want to avoid a heavily medicalized or an approach that would either intentionally or unintentionally lead to creating an identity of people that emphasizes the ‘cans’ and the ‘won't's’ or the ‘un-ables’ and the ‘unemployables.’”

“So, I understand the need for a form. But I think it should just be something like a checkbox…. like muscular, skeletal, cognitive... but not where they are providing details about someone’s medical information and [a lot of details about] the specific limitations that are impacting them. This should not even be a space [on the form]. I don’t think the federal government or CRA [Canada Revenue Agency] or anyone else should have that much information about a person.”

many years, such as cerebral palsy or paraplegia or developmental/intellectual disability, is irksome and inconvenient, and a costly waste of personal and system time and resources.

“We’ve had our disabilities since we were born, or little. They've been part of our lives all our lives. And trust me, if they were going to improve, they would have improved by now!... There needs to be balances and checks. But I find sometimes there are too many balances, you know, especially for me, ‘cause my disability is something I've had all my life. The balances outweigh the checks…. It's not equal, but a bit of overkill….especially [for] developmental and intellectual [disability]. Those never go away. It's just the way the dice got rolled. So, I guess what I'm trying to say is, I just get tired of telling my story – repeating myself … So, I've got my story down to like a two-minute synopsis of what people need to know [about] what's important… And if they don't believe me, well then, I guess that's the way the dice roll for me.”

Impairment, Functional Limitations, and Barriers: What People Think About the ACA's Definition of Disability

We asked interview respondents their impressions of the definition of disability in the *Accessible Canada Act* and their level of comfort with it. As it is a complex definition, we broke it down into a few components. A central component in plain language is that disability is any impairment or functional limitation that interacts with a barrier. Together, a person's functional limitation (or impairment) in interaction with the barrier create disability. Disability is the hard time people have in participating fully and equally in society. A disability can be permanent, temporary, or episodic. That means it can a) be ongoing, or b) last a few days, weeks or months, c) may "come and go" or "flare up." A person's disability can be something that others may or may not be able to notice. We provided further information on the terms, "impairment," "functional limitations," and "barriers" for respondents who needed clarification.

Disability is experienced in a variety of contexts, as are the barriers associated with disability. Barriers can be experienced at home, school, work, in recreation, etc. Indeed, contexts and the barriers present, there, shape a person's experiences of disability. A person may not feel particularly "disabled" at home, but school or work may be entirely different because of the many barriers encountered, there.

Overall, respondents were either very comfortable (29.4%) or somewhat comfortable (52.9%) with the definition of disability in the *ACA*. Only 11.1% were in between comfortable and uncomfortable and 5.6% were somewhat uncomfortable. No one was very uncomfortable with the definition.

A few of the comments provided by respondents on the barriers dimension of the definition of disability are as follows:

Don't privilege some contexts over others where barriers are experienced.

- The definition of disability should be designed so as not to privilege some contexts over others in which disability and associated barriers are experienced. *Programs* may impose limits on the kinds of situations the programs are designed to address. But privileging some of those contexts' restrictions as more important than others should not be integral to the basic *definition* of disability.

[On the influence of contextual factors]
"There is also an element where the definition has to be sufficiently fluid to adapt… Let's take heat for example… conditions of temperature. Heat can have profound effects on human beings, and particularly with the climate changing. There are some people with certain conditions who are more severely affected by heat than the average person. And that isn't all people with disabilities… It [the severity of impacts] will vary with temperature: it may vary from day to day; it will certainly vary in Canada from season to season… If you're not eligible for door-to-door transportation for your condition because 80% of the time you don't need it, but when it's really hot you do need it, then the policy has to be sufficiently fluid to adapt. It's the same impairment – but [the policy should be fluid enough] to adapt to a different contextual element, like outdoor temperature."

[On the *UN Convention on the Rights of persons with Disabilities'* and the *ACA's* definition]
"Frankly, I personally think they're trying to make it s so broad that it truly loses any real meaning. Again, I think it comes from a reluctance to acknowledge that there are some aspects of disabilities that can't be erased by environmental modifications – there's a risk of overemphasizing environmental factors and not dealing with issues that are separate and apart from environments."

Recognize that the lack of support may be a barrier.

- The lack of support needed in a given context is itself barrier to inclusion, access, participation, and equality.

Recognize that the lack of support can aggravate a person’s condition.

- Without suitable support for inclusion and participation, a person’s underlying condition may become aggravated.

Recognize the variability of barriers.

- The definition of disability should be fluid enough to recognize that some external barriers or other contextual factors (such as outdoor heat) may not be present all the time, but when they are present, they can have more severe impacts on some people than others.

Figure out how to assess the presence and impacts of barriers.

- A general difficulty with the definition that several interviewees flagged was how to define and measure barriers. For instance, a few respondents questioned the validity and value of barriers that are only self-assessed. A person may perceive the presence or absence of a feature, such as a procedure at work or school, as having adverse impacts upon themselves. The respondent mused that this approach to defining disability, if taken at face value, “has lawsuit written all over it” and may work against people obtaining greater inclusion, access, and participation. For example, an employer may be skittish about being held liable for whatever barriers a prospective employee may perceive if hired. As a result, the employer may shy away from hiring individuals who may have and voice such perceptions in the first place.

> *“I've been applying for work … I've had no income since I have been on my own since last September, since I moved here. It's been like shockingly difficult. No one will have me because of my health condition. But getting on disability has been exceedingly hard… They basically told me to apply for welfare…. It's hard because… if you're applying for work, then you're not disabled. I'm like: ‘What do you mean? …If someone would hire me, I'd be working – that would be my preference. I don't wanna be on disability, but my injury rate is like back spectacularly high.’ I fell in the spring, about a month after I had COVID… and it was really bad… My recovery is really much slower than regular folks…”*

Figure out how to distinguish between disability-specific and other barriers.

> *“People are still going to have impairments. The impairments won’t be different. The new definition of disability [in the ACA] recognizes how barriers disable. When a person is in an environment that considers who they are and what they need, they will have an impairment but won’t be ‘disabled.’”*

- As well, as was pointed out by several respondents, many groups experience barriers, such as racialized and indigenous people, women, people living on low incomes, senior citizens, people who live in remote communities, people living in urban communities without accessible infrastructure, etc. People’s identity is “intersectional” in the sense that a person may have several disabilities *and* be a woman of colour *and* be older *and* live on a low income *and* live in a rural community with no accessible infrastructure. Where to draw the line between the barriers that are particular to disability and the barriers that are often experienced in relation to other social and demographic characteristics is an issue that requires attention and nuanced solutions.

Don’t conflate removing barriers and removing disability.

- A further conundrum is the relationship between barriers and disability. If disability is the result of the interaction between a person’s impairments or functional limitations and barriers, and if all barriers were to be removed, would a person’s disability entirely disappear? Few interview respondents would be comfortable with such a conclusion. Indeed, many consider the underlying, individually based, material fact of some level of impairment, functional limitation, or functional difference to be a dimension of their personal identity. This dimension of disability brings both difficulties and rewards and, in many cases, cannot be altogether eliminated or ameliorated by services, technology, built environments, procedures, medication, or other supports. And not all individuals would look upon the elimination of impairment, functional limitation, or functional difference as something necessarily good or to be sought.

> *“Technically, I can still work. Even though my accommodations weren't met, I'm still technically capable of working. So then, that creates a barrier for me when trying to access...the CPP-D [Canada Pension Plan – Disability benefit], because technically I can still work.”*

> *“It depends if my medication is working. If it’s working and the seizures aren't doing anything and not interrupting my life – the same with the chronic pain… However, if they're [the medications] not working … then, yes, it does have an effect. I’ve got to put my life on hold, my school, or even my job – I’ve had to take time off of work and all that. Then, yeah, I guess it is a disability. However, when the medication is working, it's not really affecting my life in any way.”*

Figure out the impacts of barriers in aggravating the experience of disability.

- These things said, there was widespread appreciation among interview respondents that disability-specific barriers do indeed exist, can have powerfully adverse impacts, and need to be addressed. Accordingly, ways need to be found to identify the presence of disability-related barriers and estimate their impacts.

Improving the Application Rules and Process for Federal Programs and Services

The interviewers asked respondents about the features that should and should not be included in the rules and procedures for applying for federal programs and services. Several respondents were involved with or had been involved with more than one level of government at the same time. Accordingly, respondents spoke based on their experiences with a variety of federal, provincial/ territorial, and municipal systems. We assumed that what people had learned from their involvements in non-federal systems were valid lessons and applicable to the federal domain.

“I’ve heard people who are senior bureaucrats say: ‘My wife and I have a son with autism, and we can't figure out the form’, and ‘I'm a senior bureaucrat. I know forms. I write s - -t like this. ...And I can't figure this out.’ Well, you know, God help everybody else!”

The ideas that follow would ideally inform the procedures a person would use for having their disability confirmed (validated) as well for applying for programs and services.

“I wonder if there's a way to acknowledge the history of disability – being stigmatized – and provide supports and services that acknowledge the stigma and [that] also reframe on empowerment. An understanding of disability as just another way of being in the world and that accessing these supports and providing these supports are a way to combat ableism.”

Things to Include

Provide diverse ways of accessing disability validation and other programs.

- Programs should provide people opportunities to apply in a variety of ways, such as by phone, fax, email, online, in person, and with or without an interpreter or other support person.

Be clear and transparent about what is required.

- Program information should be clear, transparent, and unambiguous about the criteria that need to be satisfied.

“... as long as the criteria is transparent and clear. I mean, there is a clear difference between someone who breaks a leg – that's a temporary disability – versus someone who has fibromyalgia, or a learning disability, or hearing loss. I mean, there's clear differences.”

Use plain language.

- Plain language should be used in all spoken, text-based, and audiovisual explanations of programs. Plain language should also be used in information about where to go and how to proceed if a person’s application is denied and they want to challenge the decision.

Provide other options for people who do not have access to the Internet.

- Application procedures should be made available in ways that do not depend exclusively on access to the Internet. Many people with disabilities cannot afford Internet access.

“I have lots of friends who don't have family members or whatever who have the ability to help them fill out the paperwork. I guess the best way to put it is we're trying to navigate a system that is setting us up for failure.”

Ensure the presence of an in-person component.

- There should be an in-person component for applications because some people have difficulties using the phone or computer to access services. Low literacy, lack of proficiency in English or French, and other cultural issues present difficulties for many.

Provide enough time.

- The person receiving an individual's application should take the time needed to get to know the individual and come to an understanding of their situation and the challenges they experience. They should provide the applicant sufficient time to process questions and think about their answers. One respondent said simply, "Try talking slower."

Facilitate dialogue and build trust.

- The person receiving an individual's application should also know how to facilitate dialogue and build trust. A respondent who seems quite outgoing, confident, and cheerful said, "I'm also shy. If people don't know me, they're going to wonder about me. I don't want to intrude."

Make provision for sign language interpretation where required.

- People who are d/Deaf should have the option of communicating with program officers through a sign language interpreter if this is what they need.

Run inclusive group information sessions.

- One respondent suggested that group sessions or classes should be run for people to learn about disability validation and direct service programs. This respondent suggested putting on more than one session and allowing people to come more than once. The sessions would be inclusive and open to people with and without disabilities − including people who provide support to individuals with disabilities.

Ensure people have the support they may need to complete forms and go through the process.

- The system for validating the presence of disability and other programs for determining eligibility for services should ensure the provision of support to help people to fill out forms and undergo the administrative processes. This will involve ensuring that sufficient trained staff are available (e.g., "Navigators") to provide the direct help needed. It may also involve establishing other arrangements to facilitate the individual's access to third party (e.g., disability-related) organizations that are adequately trained and possess enough resources to carry out this supportive role.

Serve people well from diverse cultural backgrounds.

- Application, review, and appeal processes should be designed to include and serve people well who come

"… always having to define your 'worst self' by your worst day … it's like you have to constantly prove that you're disabled. You know? It's not enough for a doctor or a specialist to say like: 'Wendy has a disability. This is what she can do this is what she can't do.' …Essentially, they're all insurance bodies…. PWD or Work Safe or Canada Pension Plan. They're like: 'Okay, well, your doctor said this. But we don't believe her [the doctor]. So, prove it.'"

"If I see ... laws or something like that, we have to get an interpreter in to interpret those things for us. It's very, ***very*** *important because the writing of the English is really tough. It's a tough way to communicate... It elongates the time that we're trying to communicate together. So, if we get an interpreter, everything just goes smoothly and quickly and I can answer quickly... That is a wonderful substitute − a much better choice for being in any situation and also helps to avoid misunderstandings... VR [Video Remote Interpretation] is one of the options to do that, and then it's [the communication is] much clearer and much nicer."*

"… It's complicated when ... there's all kinds of cultural understandings of disability and … ways that people have grown up with that stigma."

"So, there's a portion [of the application form that your doctor fills out... But they have the option to fax it off directly [to the government]. And so, I never saw what my psychiatrist wrote. I think that's just problematic in making sure that your application is cohesive, right?"

from diverse cultures and ethno-racial backgrounds. This will involve staff persons who understand different cultures' ways of thinking about "disability," including the stigmas and other difficulties that may be associated with disability in some communities and which the *ACA* is attempting to address.

Find alternatives to "sign offs" on disability by doctors and other professionals.

- The issue of requiring a doctor or other professional to verify disability needs workarounds for application processes. Many people do not have a regular doctor or live in a community where other professionals are scarce, such as those who are authorized to "sign off" on the presence of disability for the Disability Tax Credit. Accordingly, a person may not be able to turn to a local professional who personally knows them and has expertise to assist with disability validation. Similarly, a person may have a regular doctor, but that professional may understand little about disability or how it impacts the individual's life. Either way, some alternative needs to be found to system reliance on professionals who may not be available, or who may lack the necessary knowledge and skills, or who may not be prepared to dedicate an appropriate amount of time and attention, to assist with the validation of disability.

Find ways of dealing with backlogs for assessments and diagnoses.

- Application processes should recognize that some associated services may be backlogged for years, such as educational assessments – especially for people in moderate and low-income households. An interim solution should be found that will enable people to qualify provisionally until the proof the system requires can be obtained.

Provide good education and awareness-raising for staff persons and healthcare professionals.

- Many people do not "look disabled." Program officers should be educated about what various disabilities can involve, how disability may or may not be expressed, and were to turn for timely, reliable information for questions that may arise. Several respondents indicated that people with disabilities and their organization could play important roles in such staff development. It was also urged that healthcare providers be provided with good education and resources (e.g., posters) on any

"I know with some [newcomers to Canada], if they're coming from a poor echelon or a lower echelon, they don't even look at people who are perceived or labelled as 'higher' than that…. They've been told what their place is… So if I were to say, 'You know, you're entitled to this or that'… they're just so fearful of the government and the process that they won't access it. Or they won't even believe it [the program or benefit] is there …. like they believe there's some kind of a 'hook' or something. Yeah, I think it's really important to have that cultural interpretation and for someone just to help them along, assure them."

"But a lot of people don't have doctors, now, so they don't have your history. Like, a lot of people have to use walk-ins and they don't have the history… I took my elderly friend to see his doctor, who works in a walk-in clinic… And the guy started giving my friend, who's in his eighties and … he's blind and deaf in one ear – totally and pretty much blind and deaf in the other ear, too – and he's [the doctor was] giving him heck [and asked], 'Well, why don't you bring your medicines in? And so I just said, 'Well, couldn't you look on your computer? Like, you prescribe them to him.' 'Well [the doctor said], I don't have time to do that.' It's like 'Well, excuse me. He's not here as a walk. And it's not his fault that these are the hours he has to come in. You're his doctor'…You know, those are the kinds of challenges that people face, too."

new definition of disability consistent with the *ACA* that is adopted and for which the providers will have a role in validating disability.

Include people with disabilities and d/Deaf people as program officers who interact directly with individuals who approach the federal system.

- Several respondents indicated that it would be helpful and could help build trust if some of the people who serve individuals with disabilities themselves have disabilities. People who are d/Deaf should be able to interact with program officers who are also d/Deaf.

Relieve people from bearing the costs of obtaining the “proof” the system requires.

- The application process and “proof” of disability can involve costs that people have difficulty meeting, especially people living in moderate and low-income households. People who have more than one disability may be required to obtain multiple assessments and pay for these. Such individuals are at a particular disadvantage in the disability determination process. The application process and “proof” of disability should not involve costs for people, especially for people in moderate and low-income households. The basic principle should be that, as the federal government wants the proof of disability, the federal government should be the first payer for the proof. People with higher incomes could be required to pay a portion of the cost of disability validation, but at a rate geared to their ability to pay (e.g., geared to their total personal income).

Strive for short, easy-to-complete application processes.

- Application processes should be short and easy to complete. That is, they should not involve long delays and reams of “paperwork,” digital or otherwise.

Distinguish between a) continuous or progressive and b) recurrent or fluctuating disabilities.

- Any program for validating the presence of disability should be required to figure out which disabilities typically have high probabilities of being continuous or progressive, and those that have high probabilities of being episodic (recurrent or fluctuating). The program should reduce the frequency of required reassessments accordingly. Occasional spot checks could be used to

> *“If the person doesn't have the ability or access to work, [or] if the process of applying …. requires some kind of financial output, then … some kind of financial assistance could be given… Obviously, if they have a disability and they aren't able to access everything that's offered to them, it's our job … in society to even that or reconcile that difference.”*

> *“We are beyond the days of all the paperwork! Think about the environment! What a waste… Some information is no one’s business…. If you’re not a doctor, there are things you don’t need to know.”*

> *“There’s lots of staff turnover because of the amount of paperwork. Streamline to two or three pages of what you really need to know.”*

> *“Avoid reviews every year – every two or three years. If something changes, then [the individual can] approach their worker and explain, or if there are changes in their life. Less than annual reviews would be very helpful for staff and the people applying.”*

confirm that conditions, which have found to be stable and continuous, remain stable and continuous over time.

Judiciously note the probable need for future reassessment.

- In disability validation processes, space could be provided for assessors to indicate the probability of a person’s situation changing, e.g., their health is progressively deteriorating. Periodic reassessments could be used to establish whether such individuals are perhaps being under-served for a condition that has become more complex or whose impacts are more aggravated than when it was last assessed.

“I think the process of accessing a program or service needs to account for that labor and that exhaustion [of filling in forms] that comes with it when you're already … barely keeping your head above water. So just making the process very seamless, very clear and transparent, and easy…. Like on the website itself, it's ridiculous… It's [the solution is] just more of an intuitive thing – like, if I were a person opening this website, and I needed to access something, where would I look?”

Figure out how to assess the variable impacts of disability, including its unpredictability.

- A way needs to be found to assess episodic conditions that will capture a) the adverse impacts of the condition on a person’s activities and interactions with their environments, and b) the impacts of the environments on the individual and their condition, especially when the condition is prone to flaring. Some attention is also required in the assessment to determine the level of practical difficulty the condition imposes that presents problems for the individual in planning their life and undertaking commitments, e.g., for personal self-care, family, work, school, etc. Respondents did not provide solutions for this issue but flagged it as one that requires significant attention and practical solutions.

Recognize individual capacities.

- The process for assessing disability is presently “deficit focused.” Instead, without minimizing disability and its impacts, the process should also give due attention to people’s capacities and the supports they people to optimize their capabilities, but without imposing hardships for not adhering to performance and other behavioural expectations.

“How would you like it if you never really could plan your time because you never really know whether you're gonna have the energy to deal with what you think you're gonna be doing at that time? Most people say: ‘Are you, are you nuts? Hmm. That would be really difficult.’ That's exactly part of the problem here… The condition comes and goes, and … may be more or less painful – or whatever – when you're experiencing it. But the other wrench that gets thrown into the works, is … you can't predict … the havoc that is gonna play in your life, as you're always living with this uncertainty, which is itself is a real issue. ‘Will you be able to make this meeting next week?’ Well, I don't know about being able to get out of the bed that day.”

Recognize potentials for inclusion and participation that are limited by the barriers dimension of “disability.”

- Disability assessment processes usually pay little attention to the barriers that prevent people from gaining access and participating as equals in society. Yet barriers are integral to the definition and understanding of disability reflected in the *ACA*. Assessments of disability should be designed that will place sufficient attention on detailing the barriers that hinder people’s full inclusion and participation in society.

“With some ‘slack’ bureaucrats could do positive things. There is so much risk aversion and accountability these days. Parents or advocates should know about the extent to which officials actually have discretion on eligibility.”

Recognize that some people may be still learning about their disability.

- Some people are “new” to disability due to a recent injury; they may still be learning and finding their way with this new fact of life. The process for determining eligibility should acknowledge that some people may be struggling to understand and come to terms with their new situation.

> *“The more we can be honest and clear about what person-centred means and operationalize this, the better. At least, ensure the person is in the room or online if the discussions are about their future. Try to make the power dynamic as collaborative as possible.”*

Provide program officials with a degree of discretion.

- Programs for validating disability and providing services should allow a measure of “structured discretion” to program officials so they can ensure humane interactions and decisions and pursue creative solutions that will benefit people with disabilities.

Construct collaborative processes.

- Instead of processes in which officials wield power *over* people in disability determination and eligibility determination, there is a need for more collaborative processes that are person-centred and more client-driven.

> *“Let the sunshine of publicity shine on the dark corners of administrative procedures.”*

Publicize the procedures.

- Speaking about the often concealed and “shadowy” rules for determining who has disabilities and who will be deemed eligible for programs, one respondent recommended: “Publicize the procedures. Let the sunshine of publicity shine on the dark corners of administrative procedures.”

> *“…It would be nice if the people putting the questions to you or giving you this opportunity for services… were also disabled and maybe shared a disability with you, so that you didn’t feel [the process was] so ‘top-down’.”*

Employ people with disabilities as staff in validating disability and determining eligibility.

- It was suggested that the processes for validating disability and determining eligibility would seem more approachable for applicants if more people with disabilities were hired as staff persons who serve people with disabilities, and if people with disabilities were to be treated as valued “customers.”

> *“I don't understand why hearing people get to decide everything that's gonna happen – especially when they're deciding for deaf people.”*

Things to Avoid

Features to avoid embedding in procedures and programs for validating disability and providing services would be the opposites of the positive features described above. These features are not all examined in detail, here. However, interview respondents provided a few additional points that drove home a few key features to avoid.

"I was severely disabled by psychiatric treatment and all that attends it, and there are still things 'wrong' with me emotionally as a result of all that psychiatry did to me… It makes me really angry that the disabling occurs because of some medications and treatments. And I would add, not just medications and treatments, but all the entire thing of… being hauled to a hospital by police. The senselessness of the humiliation and the incarceration and torture masquerading as help. So, you know, it isn't just the treatments that disable… So, there's a way in which I can't fully love or trust because of what psychiatry did to me when I was young."

Avoid creating lengthy delays.

- One respondent summed up their advice based on personal experiences: "A person should not be put on hold for hours."

Avoid asking for "proof" that takes no account of when the impacts of disability are most pronounced.

- The system should provide individuals with scope to provide information that the system will take seriously about how their episodic disability affects them on days when the impacts are most difficult to deal with.
    - People whose disability flares in intensity may not have the energy to go for an assessment or to meet with a program officer on the days when they are most exhausted or otherwise impacted by their condition. But it is when their condition's impacts are most acute that the individual is in greatest need of recognition and support for disability.
    - If a person were to go for an assessment on a day when they are feeling stronger and more energetic, they may have difficulty "proving" that their disability is "serious" enough to warrant recognition and support.
    - A system workaround needs to be found for this conundrum.

Avoid reinforcing experiences of stigma, shame, and fear.

"Look at all our provincial government [processes]… 'Do I put this deficit based?'... They just look at the disability. They don't see the broader picture… like all the things, because of my disability, I can contribute but [that] I just contribute differently. Does that make sense? It makes sense to me in my head."

- The system needs to take account of the fact that a) disability is not a widely valued attribute in society and is in fact stigmatized, b) many people routinely experience exclusion because of disability, and c) many disincentives and penalties are built into systems against people candidly reporting their disability and their associated needs for support. As a result, people internalize negative socialization and may need encouragement and support to speak openly about their situation.
    - For instance, a person may avoid attracting attention to themselves by not disclosing their disability and their needs for support. That person may in turn be at

risk of having difficulties at work or in other situations because they have not disclosed their condition and requested the support they need. But the workplace or school may not welcome such disclosures and requests. When difficulties arise because disability has not been disclosed and supports have not been requested and therefore have not been made available, the individual may have to temporarily withdraw from their duties/activities until the disability-related issue has been resolved. For instance, it may take several days for an intense arthritic flare to subside, for pervasive anxiety or depression to pass, or for a person to figure out in their own personal time how to resolve a learning difficulty that has been problematic at work or school. The individual's withdrawal from duties raises the risk of their employer or instructor considering them unreliable, irresponsible, or erratic. The individual is also at risk of being considered dishonest for not being more candid about their condition and needs for support. However, the tradeoff in disclosing these facts upfront is that the individual may not get hired or admitted to a program in the first place.

> *"Disability is an experience of oppression or a place of discrimination that people will experience at some point in life if they are lucky enough to experience impairment or aging. The incidence of disability is low at birth; people acquire most disabilities through accident and illness. It's part of the human experience. Especially in the Western context, disability has been framed as something negative. People are phobic around disability. It's an experience that people would like to do all they possibly can to avoid. This comes out in the media, in how people talk about it, in stereotypes about disability."*

> *"In addition to being an immigrant, in addition to being poor… it feels like an adjudication, where someone's in a courtroom, and you're standing there, and you're being judged whether or not you're good enough or worthy enough to receive these – or official enough to receive these – services…."*

Avoid penalizing people for demonstrating their capacities.

- The disability assessment process should be designed to encourage inclusion and participation in society, and not to then discourage and penalize people for demonstrating their capacity for inclusion and participation.

    - If the aim of programming is to facilitate full participation as an equal in society, tying eligibility to verified severity of impairment/functional limitation and barriers that prevent a person from doing many things, creates a conundrum that must be addressed. On the one hand, eligibility may release the financial or other support that a person needs to participate as an equal in society. On the other hand, their participation can be used as evidence against eligibility because people with a severe level of disability are often presumed incapable of participating – the very designation which renders them eligible for the program or support in the first place.

> *"One of the things I want people to know is that disability doesn't mean lack of confidence, competence, or lack of ability to make one's own decisions, or that disability should be equated with lack of a risk taking… We're not … encouraged to take risks or to be independent… There's a lot of paternalism. "*

Don't penalize people where barriers to participation have been removed.

- If the *ACA's* definition of disability is applied simplistically, it may be assumed that a person must not be too disabled or must not be experiencing barriers if they participate – or so the logic can go. Accordingly, there is potential for the system to be skewed-by-design in favor of deeming the applicant non-disabled and ineligible if there is evidence of their inclusion and participation in society. This kind of system logic needs to be undone.

"Talk to us. Get to know us. Don't judge the book by its cover… The story is beautiful."

Avoid age as a criterion for inclusion into and exclusion from the definition of disability.

- Disability becomes more commonplace as people get older. For a *program* to impose an age restriction that targets only some persons with disabilities may not be ideal, but it is understandable. For example, some middle-aged adults may find resources useful that are only available to older people (e.g., a program's supports for independent living). Similarly, the resources that are only available to some young people younger than 18 or 21 years of age may continue to be needed throughout adulthood. However, this not the same thing as building an age restriction into the basic *definition* of disability, thereby eliminating all but those in an age category from qualifying as having a *bona fide* disability. Age should not be used as a criterion for inclusion into and exclusion from the basic definition of disability.

[Things to avoid in a definition of disability]
"The assumption of incapacity or assumption of lack of legal capacity…Because, as per the CRPD, every person has legal capacity by virtue of being a person. And when you deny that capacity, you deny personhood."

Avoid condescending attitudes and behaviour.

- Program officers should not "talk down" to individuals with disabilities. That is, there should be no condescension or judgementalism.

Do not make assumptions based on labels.

- Program officers should hold no assumptions about people's value, or about what they can and cannot do, based on their "label."

Do not use the "R" word.

- There should be no use of the "R" word, which many people regard as a highly insulting slur.

[About the 'R' word]
"It means slow and stupid and we're not slow and we're not stupid. …It's a definition of very slow, stupid and 'You don't know anything'. So don't call us that, or anybody else that. You know? It's just not a right word. It's unacceptable. We don't want it anywhere in the English language. But then we have to educate … just to make sure people know that – why, we don't want it, and what it is about, you know? Not a good word, for sure."

Avoid avoiding the individual with a disability.

- Program officers should avoid speaking with the support worker or family member who is supporting the individual with a disability. The program officer should speak directly with the individual instead, even if that person's communication is mediated by a sign language interpreter or some other form of interpretation.

Proving Disability Consistent With the ACA and the Kinds of Acceptable Proof

Using the *ACA's* definition of disability.

- We asked respondents whether they think people seeking federal programs or services for people with disabilities should have to "prove" they have a disability that is consistent with the *ACA's* definition. Overall, respondents approved using the *ACA* definition in this way (74.3%). A few were not sure (14.3%) and fewer were opposed to the idea (11.4%). Although our interview sample is not statistically representative of all people with disabilities, the finding suggests a high level of support for using the *ACA's* definition broadly in federal programs, a detail that perhaps warrants further consultation and research.

Validating disability.

- We also asked how people's disabilities should be validated. Respondents were invited to choose from several options that could all be considered valid and to add their own ideas to the list. Most people (80.6%) were in favour of the "system" recognizing disability that has already been recognized by any federal department or program, or by provincial/territorial governments (77.8%). Several respondents spoke about the extensive testing and paperwork involved for approval of provincial benefits. However, it was pointed out that the failure or refusal by one federal department or another level of government to confirm the presence of disability in the past should not be taken at face value to mean that a person does not have a disability. After all, programs and levels of government use definitions are not consistent with one another, and which capture only a "piece" of the picture. Instead, if rejected in the past, the individual should have access to a disability determination and validation process that is consistent with the *ACA's* definition.

> *"The circumstances of the people that we call 'disabled' are generally not enviable. There are very few people who would choose to have those circumstances. The suspicion, 'Oh, people [are just] wanting the benefits of programs intended for the people called disabled', are simply acting out a civil hostility resident in the population towards people with disabilities. There are people that are expected to beg and have been for a long time. And there are ways of encouraging the fact."*

> [On the definition of disability in the *ACA*]
> *"It's a good approach [the ACA's definition]. But if you try to go too broad, people who don't have a disability may try to apply."*

> *"Natural or [Indigenous] community healers should be seen as more appropriate than a health professional who flies in and probably doesn't know the person. How about ECEs (early childhood educators) in that community?"*

> [On using the ACA definition of disability for access to federal programs and services]
> *"There are many people out there that will … access the newest programs. And that's just kinda the world we live in… There's good people and there's bad people that will use surveys to get certain services which they're actually not eligible for. That'd be good [using the ACA definition]. Yes, you gotta confirm that you have one [a disability]…hat's bad of me saying, 'Yes, I have one' when, actually, I don't have one. Right?"*

Most respondents were also in favour of continuing to authorize professionals who specialize in impairments (e.g., eye and ear specialists, speech specialists, physiotherapists, psychologists), medical doctors, and nurse practitioners being involved in the disability validation process (all at 77.8%, respectively), in much the same way as a roster of these professionals can presently "sign of" on disability for the federal Disability Tax Credit. Overwhelmingly, however, respondents would prefer a much less "medicalized" approach than the procedures that are commonly used − "humongously medicalized" was how one respondent described them. Several respondents also spoke about the need for general practitioners to be better informed about disability.

One respondent suggested that other people who are respected in Indigenous communities could also be involved in the disability validation process. It was further suggested that leaders in other, typically small, communities could play an important role in validating the presence of a person's disability. For example, the mayor or council member of a small town could attest to the lack of accessible infrastructure in their community that presents barriers and makes life difficult for a community member who is seeking to have their disability validated.

"I think that every doctor should have a poster with your new [ACA] definition in their office… I think that there needs to be broad education. I think that every single person that is a healthcare provider has to have that definition hammered into their brain. I think that there is a lack of education with well-meaning healthcare providers that are now under extreme pressure because of the pandemic. They were already running on empty, and now … they're barely functioning. And, so, I think education is a really, ***really*** *important part of it for healthcare providers."*

There was some support (55.6%) for the validation of disability by peers with disabilities who work or volunteer for disability organizations and by professionals who specialize in addressing the barriers people encounter (63.9%). Respondents provided a few suggestions for enhancing and safeguarding the credibility of such validation, mainly through training, certification, and standardized procedures and tools for the people who would be conducting the analyses.

Paying for the validation of disabilities.

"The federal government wants the proof, so the federal government should pay for the proof."

"It just feels too dehumanizing … I think the proof of disability and the proof of diagnosis is just upsetting and it's dehumanizing. I do know that there's reasons for it... But I wish there was other ways because it's just the same way as when I'm out with the cane and someone's like: 'Oh, you're so young, why are you using that?' I'm like: 'I don't want to tell you I have a genetic disease…'"

- Several respondents commented on the cost of obtaining assessments, particularly where assessments for more than one condition or repeated assessments of the same condition are required. We asked respondents who should pay for assessments/validation of disability if fees were involved. There is almost no support (5.6%) for requiring individuals to pay who may lack the means to pay. There was some support (41.7%) for the idea of co-payment by the individual with a disability and other payer(s). However, that support was hedged around by the proviso that people on low and even modest incomes should not be required to pay and that even individuals with higher incomes should have the fees geared to their ability to pay.

- There was fairly widespread support − 77.8% of respondents − for the idea that the federal government (and other levels of government) should have major responsibilities for covering the costs of the assessments; several respondents said payments should be covered as part of Canada's public health care system. There was some support (58.3%) for insurers paying, but several respondents said that getting insurers to do so would likely prove difficult. About four in ten respondents (38.9%) said others could pay. Examples given were families, charities (including disability organizations), and those responsible for creating barriers. Several respondents said that the payers should be whomever is looking for the proof of disability, which would include government but could also include employers and unions.

- How fees for the assessments are determined was not a matter that most respondents were familiar with, but it was suggested that greater standardization of fees across regions and professions would be a good idea.

Recognize the need for and or use of disability-related supports as an indicator of disability.

- Several respondents spoke about how the need for or use of various supports for disability should be taken as evidence of the presence of disability. Such supports typically require some type of formal assessment from medical or other professionals and include mobility devices (e.g., wheelchair, walker), other disability-specific technologies, medications, procedural adaptations (e.g., processes at school or work), and human supports (e.g., attendant, sign language interpreter, personal support worker, tutor) a person may need in various contexts.

Harmonize Approach to Validating Disability

Harmonize disability determination within one major program that has status and is at arm’s length from determining eligibility for programs.

- Several respondents said it would be helpful to have something like a “one stop shop” at the federal level for confirming the presence of disability. It would have authoritative status and would be recognized across federal programs. It is unlikely that respondents meant that everyone should cue up at one and only one office. However, there would be a harmonized process that people could conveniently access. Although with some significant differences, it would function somewhat like the Disability Tax Credit’s (DTC) disability validation process, which serves as a ‘gateway’ to some other federal and even some provincial/territorial programs.

  It is difficult to imagine how the *ACA’s* definition of disability could be evenly administered without some single department or program being designated for this purpose. Ideally, it would have a culture of strong support for principles of equality, inclusion, access, and participation. To minimize conflicts of interest, this authority would also operate at arm’s length from programs that deliver direct services to people with disabilities. That is, confirming the presence of disability would not be conflated with determining eligibility for a program. In that sense, the new authority would be different than the DTC disability determination process, which is directly linked to eligibility for a tax credit and other benefits.[14] As well, the DTC definition of disability requires a major level of disablement. Episodic and many “mental” disabilities do not qualify. The application process is complex and involves costs to applicants. And many applications are rejected each year (Standing Senate Committee on Social Affairs, Science and Technology, 2018).

  Several respondents indicated that the federal disability designation would ideally be recognized by provincial/ territorial and municipal governments as well, although it was appreciated that this would probably take considerable time to bring about.

“I thought it would be easier to apply for disability in [name of province], and it's next to impossible. You can't even get an application form unless you prequalify. It says it's available online, but it's not. You just go round in circles on the web until you figure out how to find someone to talk to. And then, if you qualify financially, which I barely did, then they'll send you an application form… They are extremely discouraging of anyone who wants to apply. It's really hard.”

“I think that, if there was some kind of standardization across the [Canadian] federation, that would reduce the barriers. If the Federal Government pushed harder on provinces to modernize their systems... It really it comes back to ... not just making some blank kind of promise that, you know, things will get better, but actually doing something. We don't need promises, we need results and solutions.”

“… Sometimes you have to go through – it's almost like a maze through – a website to find out what these different forms are... And it's like: ‘Hey! I got this one, but I can't find this form.’ It would be more user-friendly if all the forms that I need for that specific program [were] to be on that same web page… instead of ‘You gotta go here, you gotta go here, you gotta go here.’ I feel sometimes like a rat in a maze. It could be a lot more straightforward and user-friendly...”

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[14] These include the Registered Disability Savings Plan, Canada Workers Benefit, and the Child Disability Benefit.

- The things to include and avoid that are discussed in the previous sections would apply to this new authority and its processes for validating disability.

Ensure the disability designation has status across departments and programs.

- “Disability” that has been duly confirmed by this authority should be transferrable/portable and have status across all federal programs. That is, people should not have to undergo a review or appeal concerning their disability if a department wants to challenge the determination reached by the authority that has validated disability. However, a department or program that provides direct service may request further information about a person’s disability to determine whether the program or service is intended or has the capacity to serve that person’s needs. Here the information sought would be supplementary and related to the program, not foundational for validating or challenging the presence of the applicant’s disability.

Reviews and Appeals: Who Should be Involved?

Given the central importance of validating disability consistent with the definition in the *Accessible Canada Act,* there was general recognition that review and appeal processes would be vitally important safeguards for administrative fairness. Here we define a review process as one in which a person can obtain a second opinion if their application for disability validation has been rejected. The second opinion would be provided by knowledgeable people whose views would have status in the validation process. It was suggested that the people who conduct the review should be different than those who participated in the initial decision not to accept a person's application. In contrast, we define a formal appeal process as one in which a review has probably been conducted and where the applicant still seeks to challenge the "system's" decision not to acknowledge the presence of disability in their case. Typically, this is a more formal process that may involve lawyers and significant costs.

"I'm thinking of all these things from the perspective of a visible minority. I think that, for a lot of people now navigating government systems, especially from poor countries – countries that had a dictator… there should be some kind of … social support [for reviews and appeals], like a cultural person who's both of the Western [culture] as well as familiar with the applicant's culture. And they should go along with them because again it is an intimidating process. I'm just trying to imagine this kind of appeal process in a big oval office. And of course [the support] person would speak that language if necessary. There should always be someone there who can do a cultural language – like a social interpretation – to help the person feel safe…"

We asked about who should be involved in addressing disagreements through review procedures and appeals where an individual wants to contest a decision that the government has been made about their disability or their eligibility for a program. As with the people who validate claims of disability, there was lukewarm support for the idea that government officials should be involved (50%). There was considerably more support for the involvement of medical doctors (77.8%), and nurse practitioners (63.9%), specialists in impairments (69.4%), specialists in barriers (75%), and knowledgeable people with disabilities appointed by disability organizations (77.8%). Several interview respondents said, however, that it would be preferable if the health-related professionals were to have personal knowledge of the applicant whenever possible, and that the "say" of government officials and health professionals should be balanced by other equally weighted perspectives, including those of people with disabilities.

Two respondents suggested that the review and appeal committees could consist of an equal number of, on the one hand, government representatives and other professionals and, on the other hand, people with disabilities from the community. The latter would play a key role in the decision-making. The panel would be chaired by a person with disabilities from the community, who would have the tie-breaking vote.

*"There **has to be** an independent body for appeals. There **must** be."*

"People should always be able to have an advocate of their choice accompanying them on these journeys."

Regardless of how the dispute-resolution process is structured, interview respondents pointed to the need for some provisos.

First, the people involved in hearing an applicant’s case should not base their decisions primarily on financial considerations or on what “the system” needs. Second, the process should not be overwhelming or intimidating for the applicant in terms of the number of people whom they must address, the unfamiliarity of the process’s cultural norms and expectations, and the formality of the process. Third, the dispute resolution should be available on a no-cost or highly affordable basis.

As an antidote to the applicant feeling overwhelmed and/or not being taken seriously in reviews and appeals, there was widespread support in the interviews for applicants being accompanied and supported by people they trust. These could include one or more people such as family member(s) or friend(s); personal advocate(s) or advisor(s) who understands government, legal and related procedures; lawyer(s); support person(s) from an organization that specializes in disability law; union representative(s); person(s) with lived experience of disability; and so on.

Conclusion

An important understanding of disability that emerged from the interviews and that was widely held among respondents is that the experience disability involves a personal and a social dimension. The personal dimension may or may not be constant and may or may not last a lifetime. In any single individual, disability may have elements of both constancy and fluidity. Some aspects may be quite predictable from day to day, while others can be quite unpredictable. But even the unpredictability may be more or less constant. A variety of social contexts and the barriers encountered in those contexts aggravate the experience of disability and the difficulties involved in gaining access to, being included within, and participating fully as an equal in society. Both the personal and societal dimensions should be recognized in identifying the nature, scope, and impacts of disability that any given individual experiences.

*"Disability should be defined as anything physical, emotional, sensory, or intellectual that impacts the way a person interacts with their environment... Disability can impact several parts [aspects] of a person's functioning… Disability can impact **how** you interact with your environment and **how** you do things. But it doesn't necessarily impact **whether** you can do things... just how."*

Another theme that emerged is that people do not lead their lives in the federal or the provincial, territorial, or the municipal domain in isolation from one another. Many individuals' lives cut cross all three domains because they must interact with more than one jurisdiction.

As well, a person does not experience disability in isolation from other dimensions of their life, such as being a man or woman, male or female, non-binary or LGBTQ2+, or being black, or having roots in South or East Asia, or being older or younger, or living in a rural community or a big city, or being relatively affluent or quite poor, and so on.

On layered experiences of different types of disability]
"All of those [ongoing and episodic experiences of disability] should be "and/or"… because his [overall] situation is ongoing. He has to take medication not only twice a day, but every 2 weeks. He also has to get an injection for antibiotics. So that is definitely ongoing. And he also … has flare ups… I'm sure other people experience the same thing… It should be "and/or" in each of those" [when recognizing and validating disability].

Regardless of all these experiences of difference, people want to be treated fairly, with respect, as equals. They like other citizens want to be able to take their place and participate fully in all that society offers to its citizens. They want to enjoy the quality of life that is within reach and that they know they are capable of living with suitable recognition and support.

"I cannot sit here and rehash you every symptom and experience that I have and how it affects me and how I need help, and then be made to feel very uncomfortable … because it is something I'm actively going through. …That is just not considered … when I'm sitting there getting upset and I'm thinking … 'I'm losing my health right now as a young person' and then to realize: 'I'm doing this because I want to be able to get [a support for disability]'."

A picture also emerged from the interviews of a single process or coherently harmonized set of processes for acknowledging and validating the presence of disability. The basic presence of disability would be the main thing to be established by this system or set of processes. Whether disability happened early or late enough in life, has lasted long enough, is "severe" enough, limits the capacity to earn a living, affects some selected functional activities instead of others – such details are about program eligibility criteria. That kind of information could perhaps be gathered in the disability recognition and validation process but are not essential to having a disability *per se* and should not be confused and conflated with the definition of disability. Ideally, program criteria would be written with people's lived experiences of disabilities clearly in view rather than requiring that people conform with narrow program criteria to be deemed as having a legitimate "disability."

The information gathered for describing a person's disabilities should be simple, clear, free from jargon, and respectful. Perhaps just as important, the process in which the terms are used should be respectful and non-adversarial.

Given the high stakes importance that would be associated with having disability acknowledged and validated, there should be multiple ways of obtaining this recognition. For instance, the processes should be fully accessible, in plain language, should not rely exclusively on the Internet, should have a fully accessible in-person component for those who need it. Disability validation should provide applicants and program officers enough time to get to know one another and should be designed to build trust instead of being adversarial. The process should be well equipped to serve people from diverse cultural backgrounds and should provide not only language and sign language translation but should also reflect an understanding of the assumptions, attitudes, and stigmas associated with disability in diverse cultures. Diverse people with disabilities would ideally serve as some of the program officers that meet with individual applicants. All program personnel, whether with or without disabilities, should undergo extensive training and awareness raising on types and expressions of disability, and experiences associated with disability.

The organizational culture of the process for acknowledging and validating disability should be grounded in principles of equality, inclusion, access, and participation, not primarily in "keeping people out" or saving the taxpayer's money. As interview respondents generally recognized and supported, the process must be responsible and accountable to the taxpayer. However, individuals should be well supported to have their disabilities recognized and validated and should have quick access to review processes where they wish to challenge the system's rejection of the disabilities they experience. If the dimensions of disability that inhere in the individual are unlikely to change, the individual should not be required to have those aspects of disability continually reassessed and reconfirmed. If the impacts of that condition are becoming more pronounced, the individual should be able to bring this to "the system's" attention without having to undergo a complete reassessment.

[To qualify for the DTC, a person must be unable to do an activity or take an "inordinate amount of time" (e.g., 90% or more of the time), even with appropriate therapy, devices, and medication:]
"As soon as they [doctors] look at that [the 90% threshold, they say], 'Well, with medication he is not affected 90% of the time.' However, if he doesn't take that medication 100% of the time, then he will be 90% or more affected by his illness. So, yes, he is 90%... A lot of medical professionals don't think that they should follow the form."

"I think the complexity of disability is another thing I'd like people to know better and understand. Because, again, … this very biomedical reductionist model of disability… doesn't result in wraparound supports for those of us who need them… Even in … home care, it doesn't result in complexity of support for people. It's very much... like: 'Well, if you need care will give you like basic care for ADLs [activities of daily living]. But if you need support … to go and work or volunteer or go to school, that's not available.' And I think it's because we don't see people with disabilities as all of us, as complex individuals who live multifaceted lives. So, it's reduced to this very one-dimensional view. I think that's quite harmful to the well-being and mental health of individuals with disabilities."

Even where an underlying condition fluctuates or recurs, the system should make realistic attempts to confirm the probability of it continuing to fluctuate or recur over time, rather than requiring the individual to undergo repeated reassessments. The practical impacts of fluctuating or recurring conditions on the individual's ability to plan their life and to follow through on commitments should be included as a dimension of the disability experience that the system recognizes and validates. While there will probably continue to be a system need for occasional reassessments for some individuals, ideally the requirement would be invoked only when genuinely needed.

With some reservations, most interview respondents were generally supportive of individuals having to show disability consistent with the definition in the *Accessible Canada Act.* That definition places significant focus on societal barriers and on interactions between those barriers and the individual dimensions of a person's disability, such as impairments, functional limitations, or differences in how people experience, learn about, and make sense of their world.

There was also some support in the interviews for the idea of a single program or authority, with status in the federal system, to which individuals should be able to go to have disability validated. At the very least respondents generally supported the development of a more coherent and unified approach.

However, a single entity or process for confirming the presence of disability would raise the stakes of obtaining and not obtaining the validation; a single process raises the possibility of a person being completely shut out of all federal programs that require the presence of disability as an eligibility criterion. Accordingly, it will be vital that sufficient and fully accessible emotional, cultural, and practical support is made available during the application process. The support should be available at no cost, particularly for people with moderate or low incomes. The federal government could itself make the personal component of the support available for the application process and could engage with disability and cultural organizations to augment federal capacity.

The availability of such support from non-governmental sources that are funded to provide it will be vitally important for effective and independent review and appeal processes that should be established for individuals to dispute the system's rejections of their experiences and claims of "disability." Funding and support to assist with disputes that get taken to review and formal appeal will be vitally important as a check and balance against systemic bias in the government's favour. Such a check and

"The definition that I like is the United Nations' definition that puts the accent in the encounter... in the barriers, that a person encounters. ...The handicap is not yours. The handicap is in the environment... I also recognize that some people with disabilities like to revendicate [restore, reclaim] their identities. And so they call themself a disabled person... I like the definition of Tom Shakespeare that says that it's a complicated situation that involves the person... the society, the culture, the mentality, because we are not isolated... We are in interaction with the society and with everything in the society. Disability depends on the culture, on the barriers that we encounter... what is in the heads of the people – [their] presumptions – and also in our bodies..."

balance will be especially important for people with moderate and low incomes, complex disabilities, or who come from diverse ethno-cultural backgrounds.

For a person to have one or more disabilities confirmed and validated by a single authority or set of procedures with status, and then to be met by other program criteria across federal departments that layer on additional requirements, would raise questions about the practical usefulness of the disability designation in the first place. Such additional requirements include many that presently operate in federal programs.

To address that issue, perhaps selected details associated with a person's disabilities that are relevant to various programs could be laid out as information of secondary importance in the core disability validation process. In addition, federal program criteria could be rewritten based on parameters that the validating authority ascertains and recognizes. Such parameters could include, for instance, age at onset, duration of disability to date, cause of functional limitations associated with disability, the barriers the individual typically encounters given their life circumstances, and the ways in which the personal dimensions of a person's disabilities are continuous, "progressive," fluctuating, and/or recurrent. These pieces of secondary information would comprise an array of indicators and measures because

- Most people with any disability have two or more.
- Not all of a person's disabilities necessarily represent the same degree of difficulty in all activities and social contexts. Many people have fluctuating or recurrent experiences of disability that overlap with other experiences of disability as continuous or as increasingly impactful over time.

Issues among others that require attention include:

a) A way of measuring the impacts of disability that takes account of the difficulties a person experiences with and without the supports they require in various social contexts, such as at home, school, work, shopping, recreation, public events, while in transit/travel, in the health care system, etc.

b) New approaches for assessing the impacts of the socially imposed restrictions that result from the barriers individuals contend with in a variety of contexts.

"I think the major thing about disability to make people understand is that people with disabilities face many social barriers ... due to the attitudes in systems that people face. And often the barriers in the system often limit the choices that a person with a disability has, ... whether that be in terms of income, whether that be in terms of employment and even accessing things as ... recreational activities, the affordability of food... So, it's those systemic attitudes that are the barrier to me... I mean it also is physical barriers, but what I've been seeing is it's in more social and systemic barriers."

"Having a disability can be a positive part of a person's identity. This doesn't mean denying all the barriers or difficulties that come with it. It's just acknowledging that not all of it is bad. Just like with identifying that a person wears glasses. There's still this thing around 'disabilities'. I think that sometimes even documents like the ACA try to 'normalize' disability to the point that it gets erased.... I wouldn't have what I have right now or be who I am right now without my disability. Like with everybody else, there's good parts and bad parts to my life, to having a disability. But this doesn't make it any less integral to who I am."

c) A measure of disability that will take the episodic and continuous expressions into account for individuals who experience one, the other, or both.

In addressing the relationship between barriers and the individually based dimensions of disability, there is a risk of reading the *Accessible Canada Act* simplistically and of assuming that the removal of barriers means “curing,” “fixing,” or otherwise removing disability. However, there was little support among the people we interviewed for interpreting the *ACA* in this way. Perhaps a more helpful way to understand the *Act’s* definition is that it places disability in a social context. The *ACA* acknowledges that, whatever difficulties a person may experience “privately” because of disability, those difficulties are often *aggravated* by the barriers the person *also* encounters in society. Barriers beyond the individual play an important role in limiting the extent to which a person can move into society, participate as an equal, and enjoy the high quality of life that is potentially theirs. While acknowledging the types and impacts of the person-level aspects of the disabilities they experience, several respondents attested to their excellent quality of life and spoke about the supports that have made this possible.

It may be useful to recall the straightforward insight of one respondent with complex needs who considered their quality of life very good: “Disability can impact several parts [aspects] of a person’s functioning… Disability can impact *how* you interact with your environment and *how* you do things. But it doesn’t necessarily impact *whether* you can do things.”

Further, recognizing disability per the *Accessible Canada Act* is about fostering inclusion, access, and participation, and optimizing potential and capacity. It should not be about facilitating access to these ‘goods’ and then requiring they be relinquished in exchange for qualified recognition and limited support for disability, as happens at present through many program arrangements.

Given the complexity and high-stakes importance of how disability is defined and how eligibility is determined, one interview participant provided the all-important reminder: “Run any ideas for a new definition past community groups, parents, etcetera.”

Despite the complexities that need to be addressed, one respondent summed up how new approaches could look for defining disability and for using that definition in determining eligibility for programs and services:

“*If we aim for a very inclusive and evolving definition that has a thorough and fully independent review process and appeal process, then, I think we can move towards a much more harmonized system, where individual programs have their criteria but the threshold of having a disability is a given. I think that would be a great service to the community. I think it's important that this will only work if* ***all*** *of those conditions are met. In other words, having the kind of appeal procedure that we've never seen before – or rarely seen before in government programs − where it actually involves non-government agents rendering decisions. If that is left out, then I don’t think the system will work…*

…There [also] needs to be some way of evaluating this system over time, … evaluating the impacts it is having and any problems that are coming up. There needs to be, as part of the accountability, a formal evaluation process…

…So, all the elements – of being inclusive, being geared toward bringing people in rather than keeping people out, having well-trained people with very transparent procedures, very accessible process − all of them, the whole thing − are essential. If any one of them is missing, then all bets are off and we won’t have made any improvements and we may make things worse. So, the bottom line is do it right and it should really take us into the future in an exemplary fashion.”

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Appendix 1 – Statistical Snapshot of Interview Respondents

Appendix Table 1.1 Genders of Pillar 4 interview respondents

Genders	Percent
Male	30.6%
Female	66.7%
Non−binary	2.8%
All (%)	**100.0%**
Number	**36**

Appendix Table 1.2 Age groups of Pillar 4 interview respondents

Age groups	Percent
Younger than 25 yrs	5.6%
25 - 34	8.3%
35 - 54	50.0%
55 - 64	22.2%
67 - 74	8.3%
75+	2.8%
Prefer not to say	2.8%
All (%)	**100.0%**
Number	**36**

Appendix Table 1.3 Provinces of Pillar 4 interview respondents

Provinces/territories	Percent
British Columbia	13.9%
Alberta	8.3%
Saskatchewan	2.8%
Manitoba	19.4%
Ontario	44.4%
Quebec	2.8%
New Brunswick	0.0%
Nova Scotia	5.6%
Prince Edward Island	2.8%
Newfoundland & Labrador	0.0%
Northern territories	0.0%
All (%)	**100.0%**
Number	**36**

Appendix Table 1.4 Types of communities of Pillar 4 interview respondents

Community types	**Percent**
Remote or hard to reach	5.6%
Rural	5.6%
Small town, fewer than 10,000 people	8.3%
Mid-sized city, 10,000 - 100,000 people	13.9%
Large city, 100,000+ people	66.7%
All (%)	**100.0%**
Number	**36**

Appendix Table 1.5 Ethno-racial diversity of Pillar 4 interview respondents

Ethno-racial groups	**Percent**
White/Caucasian	72.2%
Indigenous	11.1%
Black	2.8%
East Asian	2.8%
South Asian	5.6%
Other	5.6%
All (%)	**100.0%**
Number	**36**

Appendix Table 1.6 Main language of Pillar 4 interview respondents

Main languages	**Percent**
English	80.6%
French	0.0%
English and French	16.7%
American/Quebec Sign Language	2.8%
Other	0.0%
All (%)	**100.0%**
Number	**36**

Appendix Table 1.7 Highest education of Pillar 4 interview respondents

Highest education	Percent
Less than high school diploma	11.1%
High school diploma	11.1%
Some post-secondary	16.7%
College/CEGEP Diploma or Trades certificate	13.9%
Bachelor's degree	8.3%
Master's degree	22.2%
PhD	16.7%
All (%)	**100.0%**
Number	**36**

Appendix Table 1.8 Employment status of Pillar 4 interview respondents

Employment status	Percent
Working for pay	50.0%
Not working for pay	50.0%
All (%)	**100.0%**
Number	**36**

Appendix Table 1.9 Full-time or part-time work of Pillar 4 interview respondents (working only)

Employment status	Percent
Working full-time	57.9%
Working part-time	42.1%
All (%)	**100.0%**
Number (missing were not working)	**19**

Appendix Table 1.10 Total annual household income of Pillar 4 interview respondents

Income groups	Percent
Less than $20,000	27.3%
$20,000 - $34,999	18.2%
$35,000 - $49,999	12.1%
$50,000 - $74,999	15.2%
$75,000+	27.3%
All (%)	**100.0%**
Number (three preferred not to say)	**33**

Appendix Table 1.11 Whether Pillar 4 interview respondents self-identify as having a disability

Self-report as with disability	**Percent**
Yes	77.8%
No	22.2%
All (%)	**100.0%**
Number	**36**

Appendix Table 1.12 Types of disabilities of Pillar 4 interview respondents +

Types of disabilities	**Percent+**
Physical (e.g., mobility, bending, reaching, grasping)	50.0%
Hearing	16.7%
Seeing	30.6%
Communicating	22.2%
Learning	22.2%
Intellectual/developmental	11.1%
Psychosocial (e.g., mental health)	33.3%
Other	33.3%
Prefer to self-describe	13.9%
All (% Variable, depending on type)	**–**
Number	**36**

+Some respondents reported more than one kind of disability. Some respondents who do not self-describe as having a disability reported at least one type of disability when asked that question.

63.9% of respondents had 2 or more disabilities.

Among those who reported at least one disability, the average number reported was 2.5 types.

Appendix 2 − Interview Guides and Consent Forms

NOTE: The interview guides for this Appendix are here presented as unformatted text documents. The content is identical but some of the bold text, italicization, indentations, and other formatting have been removed.

Short Interview Guide

Introduction and reminders

- Hi. I’m __ from Eviance.
- Thanks for taking time to speak with me today.
- As mentioned in the background material we sent you, Eviance is conducting these interviews to get a sense of people’s views about a new definition of disability.
- We are interviewing you to get your sense of what disability means to you and what you think any definition should and should not include.
- I’ll begin with a few questions about you, then will explore what you consider the most important things for people to understand about disability and a definition. I’ll wrap up with a few more questions about you.
- Just to remind you, the information you provide will be kept confidential. Your name will not appear in any report or publication based on the interviews, and we won’t provide any other clues that would make it possible for a reader to figure out what you told us.
- The interview will take about an hour to an hour and a half to complete, but if you need a break or would like the interview to end at any point, just let me know. If I ask a question that you don’t feel comfortable answering, just let me know and we’ll move on.
- To help with my own notetaking, I’d like to have Zoom record the interview and generate a transcript. Only me and other members of the Eviance research team will have access to this information. It will be kept confidential and will be destroyed within a year.
    - Are you comfortable with that?
- Do you have any questions before we begin?

About you

First, I’d like to ask a few questions about you.

1. In which province or territory, do you live?
a) British Columbia
b) Alberta
c) Saskatchewan
d) Manitoba
e) Ontario
f) Quebec
g) New Brunswick
h) Nova Scotia
i) Prince Edward Island
j) Newfoundland and Labrador
k) Yukon
l) Northwest Territories
m) Nunavut

2. What kind of community do you live in? Please answer to the best of your knowledge.
a) In a remote or difficult-to-get-to part of the province
b) In a rural community
c) In a village or town with less than 10,000 people
d) In a mid-sized city or town with from about 10,000 to 100,000 people
e) In a city with 100,000 people or more

3. In what age group are you?
a) Younger than 25
b) 25-34
c) 35-54
d) 55-64
e) 65-74
f) 75+
g) Prefer not to say

4. What is your gender?
a) Female
b) Male
c) Non-binary
d) Or, something else
e) Please specify __________

5. Please identify which of the following groups you belong to. Select any that apply.
a) Caucasian (white)
b) Indigenous
c) Black and/or of African Descent
d) Arab

e) East Asian (e.g., Chinese, Japanese, Vietnamese, Thai)
f) South Asian (e.g., East Indian, Pakistani, Sri Lankan)
g) Other racialized or visible minority
h) Please specify: ____________

6. Please select any of the following that apply to you. Select any that apply.
a) Main language is English
b) Main language is French
c) Fluent in French and English
d) Knows a language other than French or English i) Specify: __________
e) Uses American Sign Language (ASL) or Langue des signes du Québec (LSQ) to communicate

Your experiences and understandings of disability

There are many ways of thinking about “disability.” I’d like to explore your own understanding.

7. What is the most important thing you would like people to understand about disability (or the top two or three things)? Feel free to draw from your own personal experiences or the experiences of others you know.

Answer:

8. How did you come to those understandings of disability?

[Interviewer: If needed, probe for]:
- Direct personal experiences
- Experiences/understandings of friends/colleagues
- Understandings of those who provide support (e.g., attendant, personal support worker)
- Understandings of family members
- Personal reading and reflections
- What laws or UN conventions and treaties say, etc.]

Answer:

9. Do you think of yourself as having a disability?
a) Yes
b) No

[Interviewer: If yes, to Q9, go to Q10. Otherwise, go to Q11.]

10. Which type or types of disability do you have?

[Interviewer: Check applicable terms or write out the response if not matched by items in the list.]

Answers
a) Physical (e.g., mobility, bending, reaching, grasping)
b) Hearing
c) Seeing
d) Communicating
e) Learning
f) Intellectual/developmental
g) Psychosocial (e.g., mental health)
h) Other (please describe) ___________
i) Prefer to self-describe __________
j) Prefer not to say

11. Do you prefer to think of yourself in some other way INSTEAD of as having a disability?
a. Yes
b. No

12. [If yes…] Please explain.
Answer:

13. Do you ever feel forced to go along with systems, [programs], or people who may want to refer to you as having a disability? [Probes: For instance, have you had to “fit” within a definition of disability to receive a service or take part in a program? Have you ever felt excluded from a program or service because you didn’t “fit” within its definition of disability?]
a) Yes
b) No

14. [Interviewer: If yes to Q13 What are the pressures that make you feel that you have to go along with being referred to as having a disability?
Answer:

15. Would you like it better if people were to refer to you in a different way instead of using the term “disability”?
a) Yes
b) No

16. [Interviewer: If yes to Q15] What approach [or words] would you prefer? Please explain.

Answer:

[Interviewer: If respondent feels they already answered this in Q12, go to Q17.]

Your approach and the ACA’s approach to defining disability

Now I’d like to ask you a few questions about defining disability.

17. In your opinion, what is the most important idea (or the top two or three ideas) you think should be included in any new definition of disability?
Answer:

18. Why would you include that idea [those ideas]?
Answer:

19. What is one idea (or the top two or three things) that you believe really should NOT be included in a modern definition of disability?
Answer:

20. Why would you NOT include that idea [or those ideas]?
Answer:

The Accessible Canada Act (ACA) defines a disability as any impairment or functional limitation that, in interaction with a barrier, hinders a person's full and equal participation in society? A disability can be permanent, temporary, or episodic. That is, it can: a) be ongoing; or b) last a few days, weeks or month; or c) may "come and go" or "flare up." A disability may be evident or non-evident. That is, it can be something that others may or may not be able to notice.

21. How comfortable are you with this way of defining disability? [Interviewer: If the respondent doesn't seem to understand what is meant by "impairment," "functional limitation" or "barrier," read from the Definitions Cue Card.]

a) Very comfortable
b) Somewhat comfortable
c) So-so − in between comfortable and uncomfortable
d) Somewhat uncomfortable
e) Very uncomfortable
f) Not sure/no opinion

22. Would you like to make any comments about this way of defining disability?

Answer:

Applying for federal programs and services

Now I'd like to ask you a few questions about the procedures for applying for federal programs and services for people with disabilities.

23. What are one or two things you think the procedures should include to enable people to receive the programs and services they are looking for?

Answer:

24. Why would you include those things in the procedures? For instance, how would those things help ensure people receive the programs and services they are looking for?

Answer:

25. Still thinking about applying for federal programs and services for people with disabilities, what are one or two things you think the procedures should NOT include?

Answer:

26. Why would you exclude those things from the procedures? For instance, how would not including those things better help ensure people receive the programs and services they are looking for?

Answer:

27. For a person to obtain a program or service from the federal government, should they have to prove (or confirm in some way) that they have a disability that is in keeping with the definition in the Accessible Canada Act? We talked about that definition a few minutes ago. [Interviewer, if needed, re-read the lead-in to Q21.]

a) Yes

b) No [Go to Q30.]
c) Not sure/no opinion

28. [If yes…] What kind(s) of proof or confirmation of disability should the federal government recognize so a person can, simply and without burdens, obtain the programs or services they are looking for? I'll read you a list. Feel free to suggest your own ideas.

The federal government should recognize….
a) A person's history of disability that has already been recognized by the federal government
b) A person's history of disability that has already been recognized by a provincial or territorial government
c) Confirmation of "disability" by a professional who specializes in human impairments or functional limitations.
This could be a hearing specialist/audiologist, eye specialist/optometrist, learning specialist, psychologist, specialist in psycho-educational assessment, psychiatrist, speech-language pathologist, rehabilitation specialist, occupational therapist, physiotherapist, etc.
d) Confirmation of "disability" by a person with a similar disability who works for, or is a recognized volunteer with, a disability organization.
This would be a person with a similar disability who is a Board member, Committee member, other recognized volunteer, or staff person of the organization.
e) Confirmation of "disability" by a person who works or volunteers with an organization that addresses barriers.
This could be someone with knowledge and skills in addressing the accessibility of technology, buildings, instructional materials, communication systems, education programs, instructional methods, policies, and procedures (e.g., in businesses, schools, colleges, universities, community recreation programs), etc.
f) Confirmation of "disability" by a medical doctor
g) Confirmation of "disability" by another health professional, such as a nurse practitioner
h) Your own ideas i) _____________

29. If the above individuals would charge a fee to confirm "disability," who should pay the fee? I'll read you a list. Please feel free to name payers not included in the list.
a) The person seeking confirmation of their disability, regardless of their ability to pay
b) The person seeking confirmation of their disability, but with the amount to be paid geared to their ability to pay
c) The federal government
d) Insurers
e) Other payers [Please specify] i) _________________

30. Sometimes a person may disagree with a federal government decision about whether they should receive a program or service. Who should be involved in addressing such disagreements? I'll read you a list. Please feel free to provide your ideas about any others who should be involved as payers.
a) Government officials

b) Medical doctors
c) Nurse practitioners
d) People who specialize in addressing impairments or functional limitations
e) People who specialize in addressing barriers
f) People with disabilities from (or appointed by) diverse disability organizations
g) Others [Please specify] i) _____________

31. Please feel free to provide any suggestions about how the federal government can recognize and provide programs and services to persons with disabilities, in ways that would simplify access and reduce difficulties for the people who apply.
Answer:

A little more about you

32. I'd like to conclude with a little bit more information about you. Again, feel free not to answer these questions but they will help us understand the diversity of the people who are taking part in the interviews.

What is your highest level of education or schooling?
a) Attended elementary or high school, no diploma
b) High school graduate
c) Some postsecondary education, but without a diploma, degree, or certificate
d) Diploma or certificate from college/CEGEP, trade school, other postsecondary school or internship program
e) Bachelor's degree
f) Master's degree
g) Academic or professional doctorate degree
h) Other (Please specify)
  i. _________________

33. What is the best description of your present employment status?
a) Working for pay at a job or business (including if you are away from work because of vacation, illness, or temporary layoff)
b) Not working for pay at a job or business
c) Prefer not to say
[Interviewer: Note if the respondent says they are caring for one or more children or senior, are providing informal support to someone with a disability, or volunteer in their community.]

[Note to interviewer: Ask Q34 only if Q33 is "a. Working for pay at a job or business."]

34. Thinking about all your jobs together, do you work …
a) Full-Time, that is, usually for 30 hours or more per week?
b) Part-Time, that is, usually for less than 30 hours per week?

35. What is your average household income? Household income means the income from everyone living in the household, or just your income if you live alone.

a) Less than $20,000
b) $20,000 to $34,999
c) $35,000 to $49,999
d) $50,000 to $74,999
e) $75,000 or more
f) Prefer not to say

Concluding remarks and wrap up

I've come to the end of all the questions I wanted to ask you. Thank you for so generously providing your time to answer.

36. Is there anything else you would like to add about what a new definition of disability should and shouldn't include?

37. Do you have any comments or suggestions about this interview?

Thanks again!

Bref guide d’entrevue

Présentations et rappels

- Bonjour. Je m’appelle ______ et je travaille à Eviance.
- Merci de prendre le temps de vous entretenir avec moi aujourd’hui.
- Tel que mentionné dans les documents de référence que nous vous avons envoyés, Eviance effectue ces entretiens pour avoir une idée de l’opinion des gens en ce qui concerne une nouvelle définition du handicap.
- Nous vous rencontrons pour savoir ce que le handicap signifie pour vous et ce que vous pensez qu’une définition devrait ou ne devrait pas inclure.
- Je commencerai par vous poser quelques questions sur vous, puis j’examinerai ce que vous considérez comme les éléments les plus importants à comprendre sur le handicap et à inclure dans la définition du handicap. Je terminerai avec d’autres questions à votre sujet.
- Je tiens à vous rappeler que l’information que vous fournirez restera confidentielle. Votre nom n’apparaîtra dans aucun rapport ou publication qui traitera des entretiens, et nous ne fournirons aucun autre indice qui permettrait à un lecteur de savoir ce que vous nous avez dit.
- L’entretien durera environ une heure à une heure et demie, mais si vous avez besoin d’une pause ou si vous souhaitez mettre fin à l’entretien à n’importe quel moment, dites-le-moi. Si je vous pose une question à laquelle vous n’êtes pas à l’aise de répondre, veuillez me le dire et nous passerons à la suivante.
- Pour m’aider dans ma prise de notes, j’aimerais utiliser la fonction d’enregistrement de Zoom pour produire une transcription. Seulement moi et les autres membres de l’équipe de recherche d’Eviance aurons accès à cette information. Les renseignements resteront confidentiels, et seront détruits dans un délai d’un an.
    - Êtes-vous à l’aise avec cela?
- Avez-vous des questions avant de commencer?

À propos de vous

Tout d’abord, j’aimerais vous poser quelques questions à votre sujet.

1. Dans quelle province ou quel territoire habitez-vous?
a) Colombie-Britannique
b) Alberta

c) Saskatchewan
d) Manitoba
e) Ontario
f) Québec
g) Nouveau-Brunswick
h) Nouvelle-Écosse
i) Île-du-Prince-Édouard
j) Terre-Neuve-et-Labrador
k) Yukon
l) Territoires du Nord-Ouest
m) Nunavut

2. Dans quel type de collectivité vivez-vous? Veuillez répondre au meilleur de vos connaissances.
a) Dans une région éloignée ou difficile d'accès
b) Dans une collectivité rurale
c) Dans un village ou une ville de moins de 10 000 habitants
d) Dans une ville ou un village de taille moyenne comptant de 10 000 et 100 000 habitants
e) Dans une ville de 100 000 habitants ou plus

3. Dans quel groupe d'âge vous situez-vous?
a) Moins de 25 ans
b) 25 à 34 ans
c) 35 à 54 ans
d) 55 à 64 ans
e) 65 à 74 ans
f) 75 ans ou plus
g) Je préfère ne pas répondre

4. Quelle est votre identité de genre?
a) Femme
b) Homme
c) Non binaire
d) Autre
e) Veuillez préciser : _________

5. Veuillez indiquer à quels groupes vous appartenez parmi les suivants. Sélectionnez tous ceux qui s'appliquent.
a) Caucasiens (blancs)
b) Autochtones
c) Noirs ou d'ascendance africaine
d) Arabes
e) Asiatiques de l'Est (ex., Chinois, Japonais, Vietnamiens, Thaïlandais)
f) Asiatiques du Sud (ex., Indiens de l'Est, Pakistanais, Sri Lankais)
g) Autre minorité racisée ou visible
h) Veuillez préciser : _________

6. Veuillez sélectionner tous les éléments suivants qui s'appliquent à vous :

a) Ma langue principale est l'anglais
b) Ma langue principale est le français
c) Je parle couramment le français et l'anglais
d) Je connais une autre langue que le français ou l'anglais – veuillez préciser : ___________
e) J'utilise l'American Sign Language (ASL) ou la Langue des signes du Québec (LSQ) pour communiquer.

Vos expériences et votre compréhension du handicap

On peut concevoir le « handicap » de nombreuses façons. J'aimerais explorer votre propre compréhension de cette notion.

7. Selon vous, quelle est la chose la plus importante que les gens doivent comprendre à propos du handicap (ou les deux ou trois choses les plus importantes)? N'hésitez pas à vous inspirer de vos expériences personnelles ou de celles d'autres personnes que vous connaissez.

Réponse :

8. Comment êtes-vous parvenu(e) à cette compréhension du handicap?

[Personne dirigeant l'entrevue : si nécessaire, posez des questions sur :

- Des expériences personnelles directes
- Des expériences/compréhensions d'amis ou de collègues
- La compréhension de personnes qui fournissent du soutien (un accompagnateur, une préposée aux bénéficiaires, etc.)
- La compréhension de membres de la famille
- Des lectures et réflexions personnelles
- Ce que disent les lois ou les conventions et traités de l'ONU, etc.]

Réponse :

9. Vous considérez-vous comme une personne ayant un handicap?

a) Oui
b) Non

[Personne dirigeant l'entrevue : si la réponse est oui à la Q9, passez à la Q10. Sinon, passez à la Q11.]

10. Quel(s) type(s) de handicap avez-vous?

[Personne dirigeant l'entrevue : cochez les termes énoncés par la personne ou écrivez ses propres mots s'ils ne correspondent pas aux termes dans la liste].

La personne a répondu :

a) Handicap physique (se déplacer, se pencher, tendre les bras, saisir, etc.)

b) Handicap auditif
c) Handicap visuel
d) Handicap lié à la communication
e) Difficultés d’apprentissage
f) Handicap intellectuel/développemental
g) Handicap psychosocial (ex. : santé mentale)
h) Autre (veuillez préciser) ___________
i) La personne préfère s’autodécrire ________________
j) La personne préfère ne pas répondre

11. Préférez-vous vous considérer d’une autre manière PLUTÔT que comme une personne ayant un handicap?
a. Oui
b. Non

12. [Si oui] Veuillez expliquer.
Réponse :

13. Vous arrive-t-il de vous sentir obligé(e) d’accepter que des systèmes, des [programmes] ou des personnes vous désignent comme une personne ayant un handicap? [Sondez : par exemple, avez-vous déjà dû vous conformer à une définition du handicap pour recevoir un service ou participer à un programme? Vous êtes-vous déjà senti(e) exclu(e) d’un programme ou d’un service parce que vous ne correspondiez pas à la définition d’une personne ayant un handicap?]
a) Oui
b) Non

14. [Personne dirigeant l’entrevue : si la réponse est oui à la Q13] Qu’est-ce qui fait en sorte que vous avez parfois l’impression que vous devez accepter qu’on vous désigne comme une personne ayant un handicap?
Réponse :

15. Aimeriez-vous que les gens vous désignent d’une manière différente, sans utiliser le terme « handicap »?
a) Oui
b) Non

16. [Personne dirigeant l’entrevue : si la réponse est oui à la Q15] Quelle approche (ou quels mots) préféreriez-vous? Veuillez expliquer.

Réponse :

[Personne dirigeant l’entrevue : si la personne pense avoir déjà répondu à cette question à la Q12, passez à la Q17.]

Votre approche et celle de la Loi canadienne sur l’accessibilité (LCA) pour définir le handicap

J’aimerais maintenant vous poser quelques questions sur la définition du handicap.

17. Selon vous, quelle est l’idée la plus importante, ou les deux ou trois idées les plus importantes, qui devraient être incluses dans toute nouvelle définition du handicap?
Réponse :

18. Pourquoi incluriez-vous cette idée ou ces idées?
Réponse :

19. Quelle est l’idée la plus importante (ou les deux ou trois plus importantes) qui, selon vous, ne devrait vraiment PAS être incluse dans une définition moderne du handicap?
Réponse :

20. Pourquoi n’incluriez-vous PAS cette idée ou ces idées?
Réponse :

La Loi canadienne sur l’accessibilité (LCA) définit un handicap comme étant toute déficience ou limite fonctionnelle qui, en interaction avec un obstacle, nuit à la participation pleine et égale d’une personne dans la société. Un handicap peut être permanent, temporaire ou épisodique. En d’autres mots, un handicap peut : a) être permanent; b) durer quelques jours, semaines ou mois; ou c) apparaître et repartir ou s’exacerber. Un handicap peut être apparent ou non apparent. En d’autres mots, un handicap peut être perçu ou non par les autres.

21. Dans quelle mesure êtes-vous à l’aise ou d’accord avec cette façon de définir le handicap? [Personne dirigeant l’entrevue : si le répondant ne semble pas comprendre ce qu’on entend par « déficience », « limite fonctionnelle » ou « obstacle », lisez l’aide-mémoire.]
a) Très à l’aise
b) Assez à l’aise
c) Comme ci comme ça – entre à l’aise et mal à l’aise
d) Un peu mal à l’aise
e) Très mal à l’aise
f) Pas certain(e)/pas d’opinion

22. Avez-vous des commentaires sur cette façon de définir le handicap?

Réponse :

Demandes à des programmes et services fédéraux

J’aimerais maintenant vous poser quelques questions sur les procédures de demande à des programmes et services fédéraux pour les personnes handicapées.

23. Nommez un ou deux éléments qui amélioreraient les procédures de demande à des programmes et services fédéraux, afin de permettre aux gens de bénéficier des programmes et services qu’ils recherchent.

Réponse :

24. Pourquoi incluriez-vous ces éléments? Par exemple, comment ces éléments contribueraient-ils à assurer que les personnes reçoivent les programmes et services qu'elles recherchent?

Réponse :

25. Toujours en parlant de demandes à des programmes et services fédéraux pour les personnes handicapées, pourriez-vous nommer un ou deux éléments que les procédures de demande ne devraient PAS inclure?

Réponse :

26. Pourquoi excluriez-vous ces éléments? Par exemple, comment le fait d'exclure ces éléments permettrait-il de mieux assurer que les personnes reçoivent les programmes et services qu'elles recherchent?

Réponse :

27. Pour qu'une personne reçoive l'aide d'un programme ou d'un service du gouvernement fédéral, devrait-elle avoir à prouver (ou à confirmer d'une manière ou d'une autre) qu'elle a un handicap conforme à la définition de la Loi canadienne sur l'accessibilité? Nous avons parlé de cette définition il y a quelques minutes. [Personne dirigeant l'entrevue : si nécessaire, relisez l'introduction de la Q21.]

a) Oui
b) Non [Passez à la Q30.]
c) Pas certain(e)/pas d'opinion

28. [Si oui :] Quel(s) type(s) de preuve ou de confirmation de handicap le gouvernement fédéral devrait-il reconnaître pour qu'une personne puisse, simplement et sans contraintes, obtenir l'aide des programmes ou services qu'elle recherche? Je vais vous lire une liste. N'hésitez pas à suggérer vos propres idées.

Le gouvernement fédéral devrait reconnaître…
a) Le handicap d'une personne qui a déjà été reconnu par le gouvernement fédéral.
b) Le handicap d'une personne qui a déjà été reconnu par un gouvernement provincial ou fédéral.
c) La confirmation du « handicap » par un ou une professionnel(le) spécialisé(e) en déficiences ou en limites fonctionnelles.
Il pourrait s'agir de spécialistes de l'ouïe/audiologistes, de spécialistes de l'œil/optométristes, de spécialistes de l'apprentissage, de psychologues, de spécialistes de l'évaluation psychopédagogique, de psychiatres, d'orthophonistes, de spécialistes de la réadaptation, d'ergothérapeutes, de physiothérapeutes, etc.
d) La confirmation du « handicap » par une personne ayant un handicap similaire qui travaille pour un organisme du domaine du handicap ou qui fait officiellement du bénévolat pour un tel organisme.
Il pourrait s'agir d'une personne ayant un handicap similaire et qui est membre du conseil d'administration ou d'un comité, qui fait officiellement du bénévolat ou qui est membre du personnel de l'organisme.

e) La confirmation du « handicap » par une personne qui travaille ou fait du bénévolat pour un organisme du domaine des obstacles.
Il pourrait s'agir d'une personne ayant des connaissances et des compétences en matière d'accessibilité de la technologie, des bâtiments, du matériel pédagogique, des systèmes de communication, des programmes éducatifs, des méthodes pédagogiques, des politiques et des procédures (p. ex., en entreprise, dans les écoles, les collèges, les universités, les programmes de loisirs communautaires), etc.
f) La confirmation du « handicap » par un médecin.
g) La confirmation du « handicap » par d'autres professionnels de la santé, comme une infirmière praticienne.
h) Vos propres idées i) _____________

29. Si les intervenants mentionnés précédemment facturent des frais pour confirmer un « handicap », qui devrait payer ces frais? Je vais vous lire une liste. N'hésitez pas à nommer des payeurs qui ne figurent pas dans cette liste.
a) La personne qui demande que son handicap soit confirmé, quelle que soit sa capacité de payer.
b) La personne qui demande que son handicap soit confirmé, mais le montant à payer est déterminé en fonction de ses moyens financiers.
c) Le gouvernement fédéral.
d) Les assureurs.
e) Autres payeurs [veuillez préciser] : i) _________________

30. Il peut arriver qu'une personne ne soit pas d'accord avec la décision du gouvernement fédéral de lui accorder ou non un programme ou un service. Qui devrait participer au traitement de tels désaccords? Je vais vous lire une liste. N'hésitez pas à donner vos idées sur d'autres personnes qui devraient participer en tant que payeurs.
a) Des fonctionnaires du gouvernement
b) Des médecins
c) Des infirmières praticiennes
d) Des personnes spécialisées dans le traitement des déficiences ou des limites fonctionnelles
e) Des personnes spécialisées dans l'élimination des obstacles
f) Des personnes handicapées travaillant pour (ou désignées par) des organismes du domaine du handicap
g) Autres [veuillez préciser] : i) _________________

31. N'hésitez pas à faire des suggestions sur la façon dont le gouvernement fédéral pourrait reconnaître les personnes handicapées et fournir des programmes et des services à ces personnes, et sur la façon de simplifier l'accès et de réduire les difficultés pour les personnes qui présentent des demandes de services au gouvernement.
Réponse :

Pour en savoir un peu plus sur vous

32. J’aimerais conclure en vous demandant un peu plus d’information sur vous. Encore une fois, n’hésitez pas à ne pas répondre à ces questions, mais elles nous aideraient à comprendre la diversité des personnes qui participent aux entretiens.

Quel est votre plus haut niveau d’éducation ou de scolarité?
a) J’ai fréquenté l’école primaire ou secondaire, sans diplôme
b) Diplôme d’études secondaires
c) Études postsecondaires, sans diplôme, grade ou certificat
d) Diplôme ou certificat d’un collège, d’un cégep, d’une école de métiers, d’un autre établissement postsecondaire ou d’un programme de stage
e) Baccalauréat
f) Maîtrise
g) Doctorat universitaire ou professionnel
h) Autre (veuillez préciser)
i. _________________

33. Quelle est la meilleure description de votre situation professionnelle actuelle?
a) Travail rémunéré, emploi ou entreprise (y compris si vous êtes absent ou absente pour cause de vacances, de maladie ou de mise à pied temporaire)
b) Je ne travaille pas contre rémunération dans un emploi ou une entreprise
c) Je préfère ne pas répondre
[Personne dirigeant l’entrevue : notez si la personne dit qu’elle s’occupe d’un ou de plusieurs enfants ou d’une personne âgée, qu’elle apporte du soutien informel à une personne handicapée ou qu’elle fait du bénévolat dans la collectivité.]

[Personne dirigeant l’entrevue : posez la Q34 uniquement si la réponse à la Q33 est « a » (travail rémunéré).]

34. En considérant tous vos emplois, le cas échéant, travaillez-vous :
a) À temps plein, c’est-à-dire habituellement 30 heures ou plus par semaine?
b) À temps partiel, c’est-à-dire habituellement moins de 30 heures par semaine?

35. Quel est le revenu moyen de votre ménage? Par revenu du ménage, on entend le revenu de toutes les personnes vivant chez vous, ou seulement votre revenu si vous vivez seul(e).
a) Moins de 20 000 $
b) 20 000 $ à 34 999 $
c) 35 000 $ à 49 999 $
d) 50 000 $ à 74 999 $
e) 75 000 $ ou plus
f) Je préfère ne pas répondre

Mot de la fin et conclusion

Je vous ai posé toutes les questions que j’avais à aborder. Je vous remercie de m’avoir si généreusement accordé votre temps.

36. Souhaitez-vous ajouter autre chose sur ce qu’une nouvelle définition du handicap devrait et ne devrait pas inclure?

37. Avez-vous des commentaires ou des suggestions à propos de cette entrevue?

Merci encore!

Short Interview Guide – For People First of Canada

Introduction and reminders

- Hi. I'm __ from Eviance.
- Thanks for taking time to speak with me today.
- Eviance is doing these interviews to understand people's ideas about how to define disability.
- We are interviewing you to understand what disability means to you. We also want to know what you think any definition of disability should and should not include.
- I'll begin with a few questions about you. Then we'll talk about what you consider the most important things for people to understand about disability and a definition. I'll finish with a few more questions about you.
- Just to remind you, the information you provide will be kept confidential. Your name will not appear in any report or publication based on the interviews. We won't provide any other details that would make it possible for a reader to figure out what you told us.
- The interview will take about an hour to complete. If you need a break or would like the interview to end at any point, just let me know. If I ask a question that you don't feel comfortable answering, just let me know and we'll move on. If you have any questions, you can also ask Monica or Shelley.
- To help with my own notetaking, I'd like to have Zoom record the interview. Only me and other members of the research team will have access to this information. It will be kept confidential and will be destroyed within a year.
    - Are you comfortable with that?
- Do you have any questions before we begin?

About you

First, I’d like to ask a few questions about you.

1. In which province or territory do you live?
a) British Columbia
b) Alberta
c) Saskatchewan
d) Manitoba
e) Ontario
f) Quebec
g) New Brunswick
h) Nova Scotia
i) Prince Edward Island
j) Newfoundland and Labrador
k) Yukon
l) Northwest Territories
m) Nunavut

2. What kind of community do you live in? Please answer to the best of your knowledge.
a) In a remote or difficult-to-get-to part of the province
b) In a rural community (not in a city or town)
c) In a village or town with less than 10,000 people
d) In a mid-sized city or town with from about 10,000 to 100,000 people
e) In a city with 100,000 people or more

3. In what age group are you? I’ll read you a list.
a) Younger than 25
b) 25-34
c) 35-54
d) 55-64
e) 65-74
f) 75+
g) Prefer not to say

4. What is your gender? I’ll read you a list.
a) Female
b) Male
c) Non-binary
d) Or, something else
e) Please specify _________

5. Please identify which of the following groups you belong to. You can select all that apply to you. I’ll read you a list.
a) Caucasian (white)
b) Indigenous (e.g., First Nation, Innu, Métis)
c) Black and/or of African descent

d) Arab
e) East Asian (e.g., Chinese, Japanese, Vietnamese, Thai)
f) South Asian (e.g., East Indian, Pakistani, Sri Lankan)
g) Other racialized or visible minority
h) Please specify: ____________

6. Please select any of the following that apply to you and your main language. Select any that apply. I'll read you a list.
a) Main language is English
b) Main language is French
c) Fluent in French and English
d) Knows a language other than French or English i) Specify: __________
e) Uses American Sign Language (ASL) or Langue des signes du Québec (LSQ) to communicate

Your experiences and understandings of disability

There are many ways of thinking about "disability." I'm going to talk to you and ask questions about what you think "disability" means.

7. What is the most important thing you would like people to understand about having a disability (or the top two or three things)? Feel free to think about your own personal experiences or the experiences of others you know.
[Interviewer: Prompt if needed] What does having a disability mean to you? What do you think people need to understand about having an intellectual or developmental disability?
Answer:

8. What helped you or made you understand what disability means?'
[Interviewer: If needed, probe for]:
- Direct personal experiences
- Experiences/understandings of friends/colleagues
- Understandings of those who provide support (e.g., attendant, personal support worker)
- Understandings of family members
- Personal reading and reflections
- What laws or UN conventions and treaties say, etc.]

Answer:

9. Do you think of yourself as having a disability? Or do you identify as having a disability?
a) Yes
b) No

[Interviewer: If yes, to Q9, go to Q10. Otherwise, go to Q11.]

10. Would you be willing to share which type or types of disability you have?

[Interviewer: Check applicable terms or write out the response if not matched by items in the list.]

Answers
a) Physical (e.g., mobility, bending, reaching, grasping)
b) Hearing
c) Seeing
d) Communicating
e) Learning
f) Intellectual/developmental
g) Psychosocial (e.g., mental health)
h) Other (please describe) ___________
i) Prefer to self-describe __________
j) Prefer not to say

11. Do you think of it as having a disability or do you prefer to think of yourself in some other way INSTEAD of as being labeled as having a disability? How do you think of it inside?
a. Yes
b. No

12. [If yes…] Please explain.
Answer:

13. Do you ever feel forced to go along with systems, [programs], or people who may want to refer to you as having a disability? [Probes: For instance, have you had to “fit” within a definition of disability to receive a service or take part in a program? Have you ever felt excluded from a program or service because you didn’t “fit” within its definition of disability?]
a) Yes
b) No

14. [Interviewer: If yes to Q13 What are the pressures that make you feel that you have to go along with being referred to as having a disability?
Answer:

15. Would you like it better if people were to refer to you in a different way instead of using the term “disability”?
a) Yes
b) No

16. [Interviewer: If yes to Q15] What approach [or words] would you prefer? Please explain.

Answer:

[Interviewer: If respondent feels they already answered this in Q12, go to Q17.]

Your approach and the Accessible Canada Act's approach to defining disability

Now I'd like to ask you a few questions about defining disability.

17. In your opinion, what is the most important idea (or the top two or three ideas) you think should be included in any new definition of disability?

Answer:

18. Why would you include that idea [those ideas]?

Answer:

19. What is one idea (or the top two or three things) that you believe really should NOT be included in a new definition of disability?

Answer:

20. Why would you NOT include that idea [or those ideas]?

Answer:

21. Now I'm going to read you the definition of disability in the Accessible Canada Act (ACA). It says a disability is any impairment or functional limitation that interacts with a barrier. Together the functional limitation and the barrier create disability. Disability is the hard time people have in participating fully and equally in society. A disability can be permanent, temporary, or episodic.

    That means it can: a) be ongoing; or b) last a few days, weeks or months; or c) may "come and go" or "flare up." A person's disability can be something that others may or may not be able to notice.

a. What do you think about this definition? How easy to understand or hard to understand is this definition?

Answer:

b. How comfortable are you with this way of defining disability? [Interviewer: If the respondent doesn't seem to understand what is meant by "impairment," "functional limitation" or "barrier," read from the Definitions Cue Card.]

i. Very comfortable
ii. Somewhat comfortable
iii. So-so − in between comfortable and uncomfortable
iv. Somewhat uncomfortable
v. Very uncomfortable
vi. Not sure/no opinion

22. Would you like to make any comments about this way of defining disability? Is there anything you would change?

Answer:

Applying for federal programs and services

Now I'd like to ask you a few questions about applying for federal programs and services for people with disabilities. For example, the Disability Tax Credit.

23. What are one or two suggestions you have to improve the application rules and process for federal programs and services, so people can receive the services they are looking for?

Answer:

24. Why would you include those things in the rules and -process? For instance, how would those things help make sure people will receive the programs and services they are looking for?

Answer:

25. Still thinking about applying for federal programs and services for people with disabilities, what are one or two things you think the rules and process should NOT include? What kinds of things do you not want to see?

Answer:

26. Why would you exclude those things from the rules or process? For instance, how would not including those things better help make sure people receive the programs and services they are looking for?

Answer:

27. If someone wants to be part of a program or get a service from the federal government, should they have to prove (or confirm in some way) that they have a disability that is defined in the same way as in the Accessible Canada Act?
We talked about that definition a few minutes ago. [Interviewer, if needed, re-read the lead-in to Q20.]

a) Yes
b) No [Go to Q30.]
c) Not sure/no opinion

28. [If yes…] What kind(s) of proof of disability should the federal government accept so a person can obtain the programs or services they are looking for, simply and without burdens? I'll read you a list. Feel free to suggest your own ideas.

The federal government should recognize….

a) A person's history of disability that has already been accepted by the federal government
b) A person's history of disability that has already been accepted by a provincial or territorial government

c) Confirmation [proof] of “disability” by a professional who is an expert in human impairments or functional limitations.
This could be a hearing specialist/audiologist, eye specialist/optometrist, learning specialist, psychologist, specialist in psycho-educational assessment, psychiatrist, speech-language pathologist, rehabilitation specialist, occupational therapist, physiotherapist, etc.
d) Confirmation of “disability” by a person with a similar disability who works for a disability organization, or is a recognized volunteer with a disability organization.
This would be a person with a similar disability who is a Board member, Committee member, other recognized volunteer, or staff person of the organization.
e) Confirmation of “disability” by a person who works or volunteers with an organization that addresses barriers.
This could be someone with knowledge and skills in addressing the accessibility of technology, buildings, instructional materials, communication systems, education programs, instructional methods, policies, and procedures (e.g., in businesses, schools, colleges, universities, community recreation programs), etc.
f) Confirmation of “disability” by a medical doctor
g) Confirmation of “disability” by another health professional, such as a nurse practitioner
h) Your own ideas i) _____________

29. If the above individuals would charge a fee to confirm “disability,” who should pay the fee? I’ll read you a list. Please feel free to name payers not included in the list.
a) The person trying to get proof of their disability, even if they can’t afford it.
b) The person trying to get proof of their disability, but with the amount to be paid that fits how much they’re able to pay
c) The federal government
d) Insurers (for example, for an employer’s health plan, or private health insurance such as Blue Cross or Manulife)
e) Other payers [Please specify] i) _________________

30. Sometimes a person may disagree with a federal government decision about whether they should receive a program or service. Who should be involved in addressing or deciding such disagreements? I’ll read you a list. Please feel free to provide your ideas about any others who should be involved in addressing such disagreements.
a) Government officials
b) Medical doctors
c) Nurse practitioners
d) People who specialize in addressing impairments or functional limitations
e) People who specialize in addressing barriers
f) People with disabilities from (or appointed by) diverse disability organizations
g) Others [Please specify] i) _____________

31. Please feel free to provide any suggestions about how the federal government can recognize people’s disability and provide the programs and services they need. Ideally, this would be ways that simplify people’s access and make it easier to apply. Do you have any suggestions that we haven’t talked about yet?
Answer:

A little more about you

32. I'd like to end with a little bit more information about you. Again, feel free not to answer these questions if you don't want to. But they will help us understand the diversity of the people who are taking part in the interviews.

What is your own highest level of education or schooling that you have?

a) Attended elementary or high school, no diploma
b) High school graduate
c) Some postsecondary education, but without a diploma, degree, or certificate
d) Diploma or certificate from college/CEGEP, trade school, other postsecondary school or internship program
e) Bachelor's degree
f) Master's degree
g) Academic or professional doctorate degree
h) Other (Please specify)
   i. ___________________

33. What is the best description of your present employment status?
a) Working for pay at a job or business (including if you are away from work because of vacation, illness, or temporary layoff)
b) Not working for pay at a job or business
c) Prefer not to say
[Interviewer: Note if the respondent says they are caring for one or more children or senior, are providing informal support to someone with a disability, or volunteer in their community.]

[Note to interviewer: Ask Q34 only if Q33 is "a. Working for pay at a job or business."]

34. Thinking about all your jobs together, do you work …
a) Full-Time, that is, usually for 30 hours or more per week?
b) Part-Time, that is, usually for less than 30 hours per week?

35. What is your average household income? Household income means the income from everyone living in the household, or just your income if you live alone.
a) Less than $20,000
b) $20,000 to $34,999
c) $35,000 to $49,999
d) $50,000 to $74,999
e) $75,000 or more
f) Prefer not to say

Concluding remarks and wrap up

I’ve come to the end of all the questions I wanted to ask you. Thank you for so generously providing your time to answer.

36. Is there anything else you would like to add about what a new definition of disability should and shouldn’t include?

37. Do you have any comments or suggestions about this interview?

Thanks again!

Detailed Interview Guide

Introduction and reminders

- Hi __. Thanks for taking time to speak with me today.
- As mentioned in the background material we sent you, Eviance is conducting these interviews to get a sense of people's views about a new definition of disability.
- We are interviewing you to get your sense of what disability means and what you think any definition should and should not include.
- I'll begin with a few questions about you, then will explore what you consider the most important things for people to understand about disability and a definition. I'll wrap up with a few more questions about you.
- Just to remind you, the information you provide will be kept confidential. Your name will not appear in any report or publication based on the interviews, and we won't provide any other clues that would make it possible for a reader to figure out what you told us.
- The interview will take about an hour to an hour and a half to complete, but if you need a break or would like the interview to end at any point, just let me know. If I ask a question that you don't feel comfortable answering, just let me know and we'll move on.
- To help with my own notetaking, I'd like to have Zoom record the interview and generate a transcript. Only other members of the Eviance research team and I will have access to this information. It will be kept confidential and will be destroyed within a year.
  - Are you comfortable with that?
- Do you have any questions before we begin?

About you

First, I’d like to ask a few questions about you.

1. Which province or territory do you live in?
a) British Columbia
b) Alberta
c) Saskatchewan
d) Manitoba
e) Ontario
f) Quebec
g) New Brunswick
h) Nova Scotia
i) Prince Edward Island
j) Newfoundland and Labrador
k) Yukon
l) Northwest Territories
m) Nunavut

2. What kind of community do you live in? Please answer to the best of your knowledge.
a) In a remote or difficult-to-get-to part of the province/territory
b) In a rural community
c) In a village or town with less than 10,000 people
d) In a mid-sized city or town with from about 10,000 to 100,000 people
e) In a city with 100,000 people or more

3. In what age group are you? I’ll read you a list.
a) Younger than 25
b) 25-34
c) 35-54
d) 55-64
e) 65-74
f) 75+
g) Prefer not to say

4. What is your gender?
a) Female
b) Male
c) Non-binary
d) Or, something else
e) Please specify i) _________

5. Please identify which of the following groups you belong to. Select any that apply.
a) Caucasian (white)
b) Indigenous
c) Black and/or of African Descent
d) Arab
e) East Asian (e.g., Chinese, Japanese, Vietnamese, Thai)

f) South Asian (e.g., East Indian, Pakistani, Sri Lankan)
g) Other racialized or visible minority
h) Please specify: i) _____________

6. Please select any of the following that apply to you for the language or languages you speak. Select any that apply.
a) Main language is English
b) Main language is French
c) Fluent in French and English
d) Knows a language other than French or English i) Describe _________________
e) Uses American Sign Language (ASL) or Langue des signes du Québec (LSQ) to communicate

Your experiences and understandings of disability

There are many ways of thinking about "disability." Before we get into some of these approaches that are "out there" in society, I'd like to explore your own understanding.

7. What is the most important thing you would like people to understand about disability (or the top two or three things)? Feel free to draw from your own personal experiences or the experiences of others you know.

Answer:

8. How did you come to those understandings of disability?
[Interviewer: If needed, probe for:
- Direct personal experiences
- Experiences/understandings of friends/colleagues
- Understandings of those who provide support (e.g., attendant, personal support worker)
- Understandings of family members
- Personal reading and reflections
- What laws or UN conventions and treaties say, etc.]

Answer:

9. Do you think of yourself as having a disability?
a) Yes
b) No
[Interviewer: If yes, go to Q10. Otherwise, go to Q13.]

10. Which type or types of disability do you have?
[Interviewer: Check applicable terms or write out the response if not matched by items in the list.]
Answers
a) Physical (e.g., mobility, bending, reaching, grasping)
b) Hearing
c) Seeing

d) Communicating
e) Learning
f) Intellectual/developmental
g) Psychosocial (e.g., mental health)
h) Other (please describe) ___________
i) Prefer to self-describe __________
j) Prefer not to say

11. Do you prefer to think of yourself in some other way INSTEAD of as having a disability?
a. Yes
b. No

12. [If yes…] Please explain.

Your approach to defining disability

There are many ways of defining disability. We'll explore several of those in a few minutes. Before we do that, I'd like to explore your ideas about a definition.

13. In your opinion, what is the most important idea (or the top two or three ideas) you think should be included in any new definition of disability?
Answer:

14. Why would you include that idea [those ideas]?
Answer:

15. What is one idea (or the top two or three things) that you believe really should NOT be included in a modern definition of disability?
Answer:

16. Why would you NOT include that idea [or those ideas]?
Answer:

17. Have you been aware of situations where people feel forced to go along with systems, programs, or people who may want to refer to a person as having a disability? [Probes: For instance, has someone had to "fit" within a definition of disability to receive a service or take part in a program? Has someone felt excluded from a program or service because they didn't "fit" within its definition of disability?]
a) Yes
b) No

18. [Interviewer: If yes to Q17 What are the pressures that make people feel that they have to go along with being referred to as having a disability?
Answer:

Applying for programs and services

Now I’d like to ask you a few questions about the procedures for applying for programs and services for people with disabilities.

19. What are one or two things you think the procedures should include to enable people to receive the programs and services they are looking for?

Answer:

20. Why would you include those things in the procedures? For instance, how would those things help ensure people receive the programs and services they are looking for?

Answer:

21. Still thinking about applying for programs and services for people with disabilities, what are one or two things you think the procedures should NOT include?

Answer:

22. Why would you exclude those things from the procedures? For instance, how would not including those things better help ensure people receive the programs and services they are looking for?

Answer:

Elements of familiar approaches to defining disability

Now I’d like to ask your opinions about some of the definitions of disability that are “out there” in the *UN Convention on the Rights of Persons with Disabilities* and in laws and programs in Canada. These include the *Accessible Canada Act*, the *Canadian Human Rights Act*, the Disability Tax Credit, the Canada Pension Plan Disability benefit, the *Employment Equity Act*, and a few other major laws and programs in Canada.
I’m going to read you a few ways of these ways of defining disability and will ask your impressions. I’m also going to ask whether you find anything disrespectful about these approaches and, if it were up to you, whether you would change, add to, or remove anything from those approaches.

Impairment

Some definitions use the idea of an “impairment” to explain disability. An “impairment” makes it difficult for a person’s body, mind, emotions, or senses to do what those of most people can do without major problems. The World Health Organization defines an impairment as any loss or unusualness of mental or bodily function. An impairment can be physical, mental, intellectual, cognitive, can affect learning or communication, or can be sensory (that is, can affect seeing or hearing). Some definitions use impairment in the context of barriers. That is, a disability occurs when a person with an impairment encounters a barrier that hinders their full and equal participation in society. We’ll explore this idea in a few minutes. Until then…

23. What are your impressions of using “impairment” to explain the meaning of disability? For example, how would you feel about requiring a person who says they have a disability to show they have an impairment?

[Note to interviewer: Please probe for...

- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

24. [Note to interviewer: Summarize the general gist of the respondent’s comments by selecting whether they:

a) Agree with using “impairment.”
b) Disagree with using “impairment.”
c) Are somewhere in between agreeing and disagreeing.
d) They simply don’t seem to know.]

25. Do you find anything disrespectful about using “impairment” to explain the meaning of disability?

a) Yes
b) No
c) Don’t know, not sure, no opinion
d) Prefer not to answer

26. [Note to interviewer: If “yes,” please explore briefly.]

27. If it were up to you, would you change, add to, or remove anything from this approach?
[Note to interviewer: If “yes,” please explore briefly.]

Functional limitation

Some definitions use the idea of a “functional limitation” to explain disability. The definitions say a person must have at least one functional limitation to have a disability. Functional limitations are the difficulties a person experiences in performing tasks and activities affected by impairments. These include seeing, hearing, speaking, walking, using hands or fingers, doing other physical activities, learning, remembering, concentrating, problem solving, following instructions, perceiving, understanding, remembering, maintaining emotional well-being, etc. Some definitions do, while others do not, connect functional limitations to barriers in their definitions of disability.

28. What are your impressions of using “functional limitation” to explain the meaning of disability? For example, how would you feel about requiring a person who says they have a disability to show they have a functional limitation?

[Note to interviewer: Please probe for...
- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

29. [Note to interviewer: Summarize the general gist of the respondent’s comments by selecting whether they:

a) Agree with requiring that a person must experience a “functional limitation.”
b) Disagree with requiring that a person must experience a “functional limitation.”
c) Are somewhere in between agreeing and disagreeing.
d) They simply don’t seem to know.]

30. Do you find anything disrespectful about requiring that a person experience a “functional limitation” to have a disability?

a) Yes
b) No
c) Don’t know, not sure, no opinion
d) Prefer not to answer

31. [Note to interviewer: If “yes,” please explore briefly.]

32. If it were up to you, would you change, add to, or remove anything from this approach?
[Note to interviewer: If "yes," please explore briefly.]

Barriers

Some definitions say that a disability occurs when a person's impairment or functional limitation interacts with "barriers." Barriers include anything beyond the individual that hinders their full and equal participation in society. A barrier can be anything, including anything physical, architectural, technological, or attitudinal, anything that is based on information or communications, or anything that is the result of a policy or a practice. In the definition in the *Accessible Canada Act* and the *UN Convention on the Rights of Persons with Disability*, a disability occurs when a person's full and equal participation in society is limited because of interactions between barriers on the one hand, and impairments or functional limitations on the other hand.

33. What are your impressions of using "interactions between impairments or functional limitations and barriers" help to explain the meaning of disability?
[Note to interviewer: Please probe for...
- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

34. [Note to interviewer: Summarize the general gist of the respondent's comments by selecting whether they:
a) Agree with using "interactions between impairments and barriers."
b) Disagree with using "interactions between impairments and barriers."
c) Are somewhere in between agreeing and disagreeing.
d) They simply don't seem to know.]

35. Do you find anything disrespectful about using "interactions between impairments or functional limitations and barriers" to explain the meaning of disability?
a) Yes
b) No
c) Don't know, not sure, no opinion
d) Prefer not to answer

36. [Note to interviewer: If "yes," please explore briefly.]

37. If it were up to you, would you change, add to, or remove anything from this approach?
[Note to interviewer: If "yes," please explore briefly.]

A "condition"

Some definitions of disability say it is "a condition" or is caused by a condition. Examples are emotional, psychological, or mental health conditions such as anxiety, depression, bipolar disorder, addictive substance use, anorexia, etc.

38. What are your impressions of using the idea of a "condition" to explain the meaning of disability?
[Note to interviewer: Please probe for...

- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

39. [Note to interviewer: Summarize the general gist of the respondent's comments by selecting whether they:
a) Agree with using a "condition."
b) Disagree with using a "condition."
c) Are somewhere in between agreeing and disagreeing.
d) They simply don't seem to know.]

40. Do you find anything disrespectful about using a "condition" to explain the meaning of disability?
a) Yes
b) No
c) Don't know, not sure, no opinion
d) Prefer not to answer

41. [Note to interviewer: If "yes," please explore briefly.]

42. If it were up to you, would you change, add to, or remove anything from this approach? [Note to interviewer: If "yes," please explore briefly.]

Ongoing versus temporary or episodic

Some definitions say that an impairment, functional limitation, or condition must be ongoing, continuous, or permanent to be considered a disability. An impairment, functional limitation, or condition that is temporary, recurring or fluctuating (episodic) is not the same as a "disability."

43. To define the meaning of disability, what are your impressions of requiring that it must be ongoing and not temporary or episodic?
[Note to interviewer: Please probe for...
- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

44. [Note to interviewer: Summarize the general gist of the respondent's comments by selecting whether they:
a) Agree with requiring that disability be something that is "ongoing" or "continuous."
b) Disagree with that disability be something that is "ongoing" or "continuous."
c) Are somewhere in between agreeing and disagreeing.
d) They simply don't seem to know.]

45. Do you find anything disrespectful about defining disability as something that must be ongoing?
a) Yes
b) No
c) Don't know, not sure, no opinion
d) Prefer not to answer

46. [Note to interviewer: If “yes,” please explore briefly.]

47. If it were up to you, would you change, add to, or remove anything from this approach?
[Note to interviewer: If “yes,” please explore briefly.]

Temporary and episodic

Some definitions of disability acknowledge that an impairment, functional limitation, or condition may be temporary, or that it may be recurring or episodic, e.g., it may “come and go” or vary in intensity.

48. To define the meaning of disability, what are your impressions of using the idea that an impairment, functional limitation, or condition may be temporary or that it may be “recurring” (episodic) or may vary in intensity?
[Note to interviewer: Please probe for...

- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

49. [Note to interviewer: Summarize the general gist of the respondent’s comments by selecting whether they:
a) Agree with using the idea of “recurring” (episodic).
b) Disagree with using the idea of “recurring” (episodic).
c) Are somewhere in between agreeing and disagreeing.
d) They simply don’t seem to know.]

50. Do you find anything disrespectful about defining disability as something that may be “recurring”?
a) Yes
b) No
c) Don’t know, not sure, no opinion
d) Prefer not to answer

51. [Note to interviewer: If “yes,” please explore briefly.]

52. If it were up to you, would you change, add to, or remove anything from this approach?
[Note to interviewer: If “yes,” please explore briefly.]

Minimum length of time

Some definitions of disability require that an impairment, functional limitation, or condition must last for at least a certain amount of time to be considered a disability. Such amounts of time vary across definitions and include for at least six months, at least one year, at least fifteen months, and so on.

53. To define the meaning of disability, what are your impressions of requiring that it must last for at least a certain amount of time?
[Note to interviewer: Please probe for...

- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

54. [Note to interviewer: Summarize the general gist of the respondent's comments by selecting whether they:
a) Agree with requiring that disability must last for at least a certain amount of time.
b) Disagree with requiring that disability must last for at least a certain amount of time.
c) Are somewhere in between agreeing and disagreeing.
d) They simply don't seem to know.]

55. Do you find anything disrespectful about requiring that a disability is something that must last a certain amount of time?
a) Yes
b) No
c) Don't know, not sure, no opinion
d) Prefer not to answer

56. [Note to interviewer: If "yes," please explore briefly.]

57. If it were up to you, would you change, add to, or remove anything from this approach?
[Note to interviewer: If "yes," please explore briefly.]

Limitations in basic activities of daily living

Some definitions use the idea of "difficulties or limitations in basic activities of daily living" to explain disability. The definitions say a person must have difficulties in at least one of these activities to have a disability. Examples are performing mental functions necessary for everyday life, problem solving, goal setting and judgement (taken together), and adaptive functioning. Other examples are feeding or dressing oneself, speaking so as to be understood in a quiet setting by a familiar person, hearing so as to understand in a quiet setting with a familiar person, or eliminating bodily wastes through bowel or bladder functions.

58. What are your impressions of requiring that a person experience "difficulties or limitations in basic activities of daily living" to have a disability?
[Note to interviewer: Please probe for...
- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

59. [Note to interviewer: Summarize the general gist of the respondent's comments by selecting whether they:
a) Agree with requiring that a person experience "difficulties or limitations in basic activities of daily living."
b) Disagree with requiring that a person experience "difficulties or limitations in basic activities of daily living."
c) Are somewhere in between agreeing and disagreeing.
d) They simply don't seem to know.]

60. Do you find anything disrespectful about requiring that a person experience “difficulties or limitations in basic activities of daily living” to have a disability?
a) Yes
b) No
c) Don’t know, not sure, no opinion
d) Prefer not to answer

61. [Note to interviewer: If “yes,” please explore briefly.]

62. If it were up to you, would you change, add to, or remove anything from this approach? [Note to interviewer: If “yes,” please explore briefly.]

A person’s own opinion of disadvantage

One definition says that, for a person to have a disability, they must consider themselves at a disadvantage in employment because of an impairment or functional limitation. If they consider themselves at a disadvantage in employment because of an impairment or functional limitation, they have a disability. Even if they have received an accommodation, if they still consider themselves at a disadvantage in employment, they have a disability.

63. What are your impressions of using a person’s opinion about being disadvantaged in employment to explain the meaning of disability?
[Note to interviewer: Please probe for...
- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

64. [Note to interviewer: Summarize the general gist of the respondent’s comments by selecting whether they:
a) Agree with using a person’s opinion about whether they consider themselves disadvantaged.
b) Disagree with using a person’s opinion about whether they consider themselves disadvantaged.
c) Are somewhere in between agreeing and disagreeing.
d) They simply don’t seem to know.]

65. To explain the meaning of disability, do you find anything disrespectful about using a person’s opinion about whether they consider themselves disadvantaged?
a) Yes
b) No
c) Don’t know, not sure, no opinion
d) Prefer not to answer

66. [Note to interviewer: If “yes,” please explore briefly.]

67. If it were up to you, would you change, add to, or remove anything from this approach? [Note to interviewer: If “yes,” please explore briefly.]

An employer’s perception of a person’s disadvantage

One approach defines a person as having a disability if they think their employer considers them disadvantaged in employment because of their impairment or functional limitation. This approach also applies to a potential employer. For instance, a person may think an employer is likely to consider them disadvantaged because of an impairment or functional limitation.
[Note to interviewer: This definition is found in law but may seem a little convoluted. Try to capture the respondent's impressions without spending too much time trying to explain the definition.]

68. To explain the meaning of disability, what are your impressions of using a person's sense that their present employer considers them disadvantaged in employment, or that a potential employer probably would consider them disadvantaged?

[Note to interviewer: Please probe for...

- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

69. [Note to interviewer: Summarize the general gist of the respondent's comments by selecting whether they:

a) Agree with using a person's sense that an employer considers them disadvantaged.
b) Disagree with using a person's sense that an employer considers them disadvantaged.
c) Are somewhere in between agreeing and disagreeing.
d) They simply don't seem to know.]

70. To explain the meaning of disability, do you find anything disrespectful about using a person sense of whether an employer considers them disadvantaged?

a) Yes
b) No
c) Don't know, not sure, no opinion
d) Prefer not to answer

71. [Note to interviewer: If "yes," please explore briefly.]

72. If it were up to you, would you change, add to, or remove anything from this approach?
[Note to interviewer: If "yes," please explore briefly.]

Severity

Some definitions of disability require that a person's impairment, functional limitation, or condition must be "severe" to be a disability or must be responsible for a person experiencing "markedly restricted" ability to do various activities.

73. To define the meaning of disability, what are your impressions of requiring that it must be something "severe" or must result in "markedly restricted" activities?

[Note to interviewer: Please probe for...

- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

74. [Note to interviewer: Summarize the general gist of the respondent's comments by selecting whether they:

a) Agree with requiring that it must be something “severe” or must result in “markedly restricted” activities.
b) Disagree with requiring that it must be something “severe” or must result in “markedly restricted” activities.
c) Are somewhere in between agreeing and disagreeing.
d) They simply don’t seem to know.]

75. Do you find anything disrespectful about requiring that disability must be something “severe” or must result in “markedly restricted” activities?
a) Yes
b) No
c) Don’t know, not sure, no opinion
d) Prefer not to answer

76. [Note to interviewer: If “yes,” please explore briefly.]

77. If it were up to you, would you change, add to, or remove anything from this approach? [Note to interviewer: If “yes,” please explore briefly.]

Disfigurement

Some definitions of disability include “disfigurement.” Disfigurement means where a person’s appearance appears significantly different than what people usually expect. Disfigurement can be present at birth or caused by medical conditions, injuries, illnesses, violence, and other causes at any other point in life.

78. What are your impressions of using “disfigurement” to explain the meaning of disability? [Note to interviewer: Please probe for...
- Why the person feels this way.
- Reasons for any particularly strong support for or dislike of this approach.]

79. [Note to interviewer: Summarize the general gist of the respondent’s comments by selecting whether they:
a) Agree with using “disfigurement.”
b) Disagree with using “disfigurement.”
c) Are somewhere in between agreeing and disagreeing.
d) They simply don’t seem to know.]

80. Do you find anything disrespectful about including “disfigurement” in the meaning of disability?
a) Yes
b) No
c) Don’t know, not sure, no opinion
d) Prefer not to answer

81. [Note to interviewer: If “yes,” please explore briefly.]

82. If it were up to you, would you change, add to, or remove anything from this approach? [Note to interviewer: If “yes,” please explore briefly.]

The *Accessible Canada Act*’s way of defining disability

The *Accessible Canada Act* (ACA) defines a disability as any impairment or functional limitation that, in interaction with a barrier, hinders a person’s full and equal participation in society? In this definition, a disability can be permanent, temporary, or episodic. It may be evident or not evident, that is, it may be something that others are aware or unaware of.

83. How comfortable are you with this way of defining disability? [Interviewer: If the respondent doesn’t seem to understand what is meant by “impairment,” “functional limitation” or “barrier,” read from the Definitions Cue Card.]

a) Very comfortable
b) Somewhat comfortable
c) So-so − in between comfortable and uncomfortable
d) Somewhat uncomfortable
e) Very uncomfortable
f) Not sure/no opinion

84. Would you like to make any comments about this way of defining disability?
Answer:

Applying for federal programs and services

85. For a person to obtain a program or service from the federal government, should they have to prove (or confirm in some way) that they have a disability that is in keeping with the definition in the Accessible Canada Act? We talked about that definition a few minutes ago. [Interviewer, if needed, re-read the lead-in to Q83.]

a) Yes
b) No [Go to Q88.]
c) Not sure/no opinion

86. [If yes…] What kind(s) of proof or confirmation of disability should the federal government recognize so a person can, simply and without burdens, obtain the programs or services they are looking for? I’ll read you a list. Feel free to suggest your own ideas.

The federal government should recognize….

a) A person’s history of disability that has already been recognized by the federal government
b) A person’s history of disability that has already been recognized by a provincial or territorial government
c) Confirmation of “disability” by a professional who specializes in human impairments or functional limitations.
[Interviewer: If the respondent needs clarification, read this:]

This could be a hearing specialist/audiologist, eye specialist/optometrist, learning specialist, psychologist, specialist in psycho-educational assessment, psychiatrist, speech-language pathologist, rehabilitation specialist, occupational therapist, physiotherapist, etc.

d) Confirmation of “disability” by a person with a similar disability who works for, or is a recognized volunteer with, a disability organization.

[Interviewer: If the respondent needs clarification, read this:]

This would be a person with a similar disability who is a Board member, Committee member, other recognized volunteer, or staff person of the organization.

e) Confirmation of “disability” by a person who works or volunteers with an organization that addresses barriers.

[Interviewer: If the respondent needs clarification, read this:]

This could be someone with knowledge and skills in addressing the accessibility of technology, buildings, instructional materials, communication systems, education programs, instructional methods, policies, and procedures (e.g., in businesses, schools, colleges, universities, community recreation programs), etc.

f) Confirmation of “disability” by a medical doctor

g) Confirmation of “disability” by another health professional, such as a nurse practitioner

h) Your own ideas i) _____________

87. If the above individuals would charge a fee to confirm “disability,” who should pay the fee? I’ll read you a list. Please feel free to name payers not included in the list.

a) The person seeking confirmation of their disability, regardless of their ability to pay

b) The person seeking confirmation of their disability, but with the amount to be paid geared to their ability to pay

c) The federal government

d) Insurers

e) Other payers [Please specify] i) _________________

88. Sometimes a person may disagree with a federal government decision about whether they should receive a program or service. Who should be involved in addressing such disagreements? I’ll read you a list. Choose any that apply. Please feel free to provide your ideas about any others who should be involved as payers.

a) Government officials

b) Medical doctors

c) Nurse practitioners

d) People who specialize in addressing impairments or functional limitations

e) People who specialize in addressing barriers

f) People with disabilities from (or appointed by) diverse disability organizations

g) Others [Please specify] i) _____________

A common definition of disability?

Sometimes people think it might be a good idea to have one common approach to defining disability across all federal laws and programs, such as the definition provided by the ACA.

89. Can you foresee any advantages or disadvantages to having one common definition?

a) Advantages

b) Disadvantages

c) What’s your preference? Please explain.

A little more about you

I’d like to conclude with a little bit more information about you. Again, feel free not to answer these questions but they will help us understand the diversity of the people who are taking part in the interviews.

90. What is your highest level of education or school?
a) Attended elementary or high school, no diploma
b) High school graduate
c) Some postsecondary education, but without a diploma, degree, or certificate
d) Diploma or certificate from college/CEGEP, trade school, other postsecondary school or internship program
e) Bachelor’s degree
f) Master’s degree
g) Academic or professional doctorate degree
h) Other (Please specify)
  i. ________________

91. What is the best description of your present employment status?
a) Working for pay at a job or business (including if you are away from work because of vacation, illness, or temporary layoff)
b) Not working for pay at a job or business
c) Prefer not to say

[Interviewer: Note if the respondent says they are caring for one or more children or senior, are providing informal support to someone with a disability, or volunteer in their community.]

[Note to interviewer: Ask Q92 only if Q91 is “Working for pay at a job or business.”]

92. Thinking about all your jobs together, do you work …
a) Full-Time, that is, usually for 30 hours or more per week?
b) Part-Time, that is, usually for less than 30 hours per week?

93. What is your average household income? Household income means the income from everyone living in the household, or just your income if you live alone.
a) Less than $20,000
b) $20,000 to $34,999

c) $35,000 to $49,999
d) $50,000 to $74,999
e) $75,000 or more
f) Prefer not to say

Concluding remarks and wrap up

I’ve come to the end of all the questions I wanted to ask you. Thank you for so generously providing your time to answer.

94. Is there anything else you would like to add about what a new definition of disability should and shouldn’t include?

Answer:

95. Please feel free to provide any suggestions about how the federal government can recognize and provide programs and services to persons with disabilities, in ways that would simplify access and reduce difficulties for the people who apply.

Answer:

96. Do you have any comments or suggestions about this interview?

Thanks again!

Interview Consent Form [Plain Language]

Canadian Centre on Disability Studies Research Team

Principal Investigator: Dr. Susan L. Hardie (Executive Director)

Senior Research Officer: Cameron Crawford

Research Officer/Project Manager: Mah-E-Leqa Jadgal

Eviance is conducting interviews to get a sense of people's views about a new definition of disability. The reason we are doing this project is to gather information about what disability means to you. What we find out will be shared with others in the community and shared with the Employment and Social Development Canada, who is funding this project. We will be asking you what you feel the strengths and limitations of definitions of disability are, and how they might be improved. This project will support the ESDC with developing Canada's Disability Inclusion Action Plan (DIAP). We are working with two organizations on this project: Independent Living Canada and Muscular Dystrophy Canada. Other organizations are also doing research for the Action Plan. For more information about the project, please review the interview questions that we provided and/or contact the Project Manager at [enter email address].

About the Interview

The interview will ask you to reflect on your opinions and thoughts about various approaches to how disability is defined. The interview will include questions about you, and about what you consider the most important things for people to understand about disability are. We will also ask you what things should be included when a definition of disability is used.

If You Agree to Participate in the Study

If you agree to participate in the study, you will be asked to participate in **an interview by phone or by Zoom** that will last **about an hour to ninety minutes**. With your permission, the **interview** will be audio-recorded. The researcher(s) will also take hand-written notes. You will receive $100 for participating in an interview for your time and for sharing your knowledge.

Your Participation is Voluntary

You are free to choose to participate or not to participate in the study and you may choose to stop participating at any time. Your participation is completely voluntary. Your decision not to participate or withdraw from the study will not influence your relationship with your organization or any other group associated with this project, or the nature of your relationship with researchers or with staff at Eviance either now or in the future. If you choose to withdraw from the study, all associated data collected will be immediately destroyed wherever possible. If you choose to withdraw you will still be offered compensation of $100 for your participation**.**

Potential Risks

You may be concerned about the confidentiality and anonymity of your responses and the effect your responses may have on your personal and/or professional communities and/or partnerships. For example, you may share information that could be perceived as negative, you may also feel uncomfortable when you start thinking about some of the questions that you are asked. If this happens, you can take a break from the interview or, if you want, you can stop completely. You can also feel free not to answer any questions you are not comfortable answering and stop at any time. If you want to continue to talk about these things, that’s fine, too. We will make sure the data from the interview is confidential to help minimize any negative impacts of the interview for you. The research team will do our best to mitigate these risks by ensuring that interview data is kept securely and confidentially. Only the members of the research team will be aware of who participates in research activities. No identifying information will be shared in final reports. Final reports will use the generic descriptors to identify participants.

If you request accommodations for this interview, the project team will work closely with you to ensure that you feel accommodated, safe, and comfortable. For example, if you would like the support of a caregiver or if you require ASL interpretation, please let us know.

Benefits

You may or may not receive any direct benefit from participation. You might find that it makes you feel glad to talk about some of your experiences or to share your knowledge, thoughts and ideas about the definition of disability. Other good things that might happen may be that individuals and groups working to improve the lives of people with disabilities learn from reports that are made from this study and take steps to improve the lives of people with disabilities.

Confidentiality

The information you provide will be kept confidential to the fullest extent possible by law. Your name will not appear in any report or publication of the research. Original copies of the audio recordings will be destroyed after we have written out all the words, and transcripts or notes will be destroyed, by deletion from the computer and hard drive after 8 years.

Written and audio recordings of our conversation will be securely stored in a password protected computer on a secure Eviance server with identifying information removed. Consent forms will be stored separately from transcripts and notes on a password protected computer on a secure Eviance server. Members of the research team will be the only ones who have access to the notes, transcripts and consent forms.

We will not put your name in any reports. We may want to write something that you said, word for word, in a report because you have made an important point. This is called a "direct quote." We will only use your quote, words exactly like you said them, if you give us permission by participating in this interview, and then we will not use your name, or other identifying information about you so that other people can know what was said, but won't know who said it. So, if you give consent to participate in this interview, you will also be giving consent to use your quotes. The research team will share draft reports and other project deliverables with you for your review and feedback on confidentiality and anonymity.

Please note that telephone and email are not a secure means of communication; therefore, confidentiality cannot be guaranteed.

Study Results

The results of the study will be shared with the ESDC, who are funding the project. They will also be shared with our project co-leads, Independent Living Canada and Muscular Dystrophy Canada. They may appear in reports, conferences, and presentations. The results may also be published in electronic newsletters, blogs, promotional materials or in reports or journals.

You may choose to receive an electronic copy of the final report on the final page of this form by providing your email address. Upon completion of this project, summaries of the results of this research may be made available through the Eviance website.

Contact for Information About the Study and Contact for Complaints

If you have questions at any time about the study or the procedures, or you experience adverse effects as a result of participating in this study, you may contact the principal investigator, Dr. Susan L. Hardie, at susan.hardie@eviance.ca and at (204) 809-5954.

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, you may also contact Peter Dunn, Chair, Eviance Research Committee at pdunn@wlu.ca or 1-905-627-7557.

Consent Form

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institutions from their legal and professional responsibilities.

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to withdraw from the study at any time without giving a reason and without any negative consequences.

Your signature below indicates that you have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study.

I agree to the use of non-identifying quotations in any publication that comes of this research.

YES ☐ NO ☐

I would like to receive an electronic copy of the final report of this study.

YES ☐ NO ☐

Please provide your email address to receive an electronic copy of the final report

Participant Name (please print) Date (yyyy/mm/dd)

Participant Signature

Pillar 4: Modernizing Approaches to Defining ‘Disability’

PEOPLE
FIRST
OF CANADA

PERSONNES
D'ABORD
DU CANADA

Introduction

This is a report on a community consultation from People First of Canada (PFC). This work is part of the development of the Government of Canada's *Disability Inclusion Action Plan* (DIAP). This consultation was done to support the community engagement work of Eviance, as they take the lead to develop Pillar 4 of the DIAP: *A Modern Approach to Disability*.

The purpose of PFC's consultation was to hear directly from people labeled with an intellectual or developmental disability and to bring their feedback to the development of the DIAP.

The key messages and recommendations in this report come directly from people with an intellectual or developmental disability. They are also called 'self advocates' in this report. This work is an effort to make sure their voices are heard, and they have the opportunity to contribute to the DIAP in a meaningful way.

Background

People First of Canada is a national non-profit organization. It represents people who have been labeled with an intellectual or developmental disability. Members support each other to reclaim their right to be recognized as full citizens. This is done through peer support, sharing personal stories and developing leadership skills. Members support human rights, accommodation rights, and the right to make their own decisions.

The organization is unique and fully member led. PFC works to educate and influence communities and government to ensure that all people labeled with intellectual disabilities are fully included and supported to live as equal citizens in Canada.

PFC was approached by Eviance to be a part of the work on Pillar 4 of the DIAP. Eviance was looking for feedback and recommendations from People First members. This outreach was an extension of a consultation done in June of 2022. It was meant to give more opportunity for self advocates to contribute to the development of Pillar 4.

The consultation began in the fall of 2022. PFC members and others in the disability community were invited to be a part of the process.

Approach and Methods

The goals for this consultation were to listen to peoples' experiences and feedback, and give room for every self advocate attending to share their thoughts. The plan was to have six online focus groups and invite People First members from every region of Canada.

An online consultation invitation was created in both French and English. This was emailed to all People First members and also shared on social media.

In addition, the focus group invitation was shared with the following organizations.

- Canadian Down Syndrome Society
- L'Arche Canada
- Smile Canada

- Independent Living Canada
- Youth Alliance for Intersectional Justice

Originally, there were six online focus groups planned. But there were several people who could not attend. So there was an additional focus group held for anyone who could not attend the scheduled ones. In total, seven online focus groups were held during the period of November 10 to December 6, 2022. The focus groups had the following regional descriptions.

1. Western
2. Northern
3. Prairie
4. Central
5. Atlantic
6. French-speaking (Francophone)
7. Mixed regions

Each focus group was led by two co-facilitators. One was a self advocate and the other was a PFC staff member. All the focus groups were held in English. The Francophone focus group had French translation.

Make up of Focus Groups

In total, this consultation included 37 people. Each identified as having an intellectual or developmental disability.

The following provinces and territories were represented in the focus groups.

Province or Territory	**# of attendees**
Yukon	1
Northwest Territories	1
British Columbia	8
Alberta	6
Saskatchewan	1
Quebec	5
Ontario	8

New Brunswick	2
Nova Scotia	2
Prince Edward Island	1
Newfoundland and Labrador	2
Total	**37 attendees**

Focus Group Questions and Accessibility

Another goal of the consultation was to present everything in plain language. Questions for the focus groups were based on the initial consultation developed by Eviance. These questions were reviewed by the two self advocate co-facilitators before the focus group. Changes were made following their suggestions. The final questions are in Appendix 1.

The focus groups were also led in plain language to make them as accessible as possible. All the information was shared through PowerPoint slides, as well as being read out loud. Questions were also on the screen and in the chat function of the online meeting room. Everyone was given time to answer the questions or ask for clarification when needed.

What We Heard

After the focus groups, all of the transcripts were put together and separated into themes. These are the key messages that were heard during the consultation. Each message falls under one of the seven focus group questions that were asked. Those questions are supported here by direct quotes from self advocates.

1. What People Should Understand about Intellectual and Developmental Disabilities

The first question for the focus group was about intellectual and developmental disabilities. Self advocates were asked what they thought other people needed to understand about their disability. They clearly said they wanted to be treated as equals in society, but that this doesn’t always happen. Self advocates also said they often feel segregated and excluded.

- “People want to be treated just like everyone else. Like equals.”
- “Treat us like everyone else because we're all the same. It's okay to have an intellectual disability or special needs - treat us like equals and don't treat us like children.”
- “I think for me, I've learned people look down on me because of the syndrome that I have and just because of my disability, and I've learned to see everyone with disabilities equally.”
- “There is a lot of stigma around disability.”

- “We should be treated with the same respect as anyone else. A lot of people think you can’t do things.”
- “We are like normal people. We should be respected and treated fairly and not abused and called names. We shouldn't be pushed. We should have our rights to do things we want to do and go where we want to go. Shouldn’t put us down and say we can’t do this and that.”
- “Yeah, we have a disability, but people need to understand we are human. We have the same feelings and stuff. We want to be friends. We want to be around people. You know, from my experience, some people see us different … just because we have a disability.”
- “In a way, everyone has some kind of disability and sometimes you just don’t see it. It’s hidden. There are more challenges and different ways and they may need more time, but if you don’t give them a chance, you don’t know what they can do. Never give up.”
- “There are many cases I've seen, and I've also experienced it from people, you know. They tend to kind of segregate or something of that nature, but when doing that, it often does not feel good.”

People also shared that having an intellectual or developmental disability can be an invisible disability. Sometimes, it’s not noticed or taken as seriously as some physical disabilities that are visible. But that an invisible disability is just as ‘real’ as a visible disability.

They are also tired of having to explain their disabilities over and over and often have to do this in different situations.

- “That angers me when you do have a disability, but it's not visible to other people. And then somebody else could have a disability and it's visible. You got to keep on explaining yourself over and over.”
- “Sometimes it's hard for you to prove you have a disability, but you know you have one. There's a lot of invisible ones that the federal government needs to learn, that not all of them are visible.”

People also said that they had a lot to teach others about having a disability but weren’t given that opportunity. The consensus was that self advocates are the experts on having an intellectual or developmental disability because of their lived experience.

- “I mean, you’ve got to do a lot of teaching.”
- “With an intellectual disability it’s a given that I’m able to say what I think. I have a moderate intellectual disability, but … I’m always going to walk with my head up high and say what I have to say.”

- “I want people to get more educated on intellectual disabilities. And then I want to make more education so they don't fear us or expect us to do something that we don't want to do.”

The groups also spoke about how not every self advocate is the same. Everyone has different abilities and may require different types of support. Accommodation and accessibility needs can look different for everyone.

- “I think the most important thing for people to realize is that intellectual disabilities are so unique and different that you can't define it as one thing.”
- “Because I've actually heard a few people try and tell me that all people with FASD, like I have, are all the same. We all act the same. We all do the same thing and that's not true. You have to understand that we're all different.”
- “I try to educate people and let them know that ‘Yeah, I do have a disability but I'm different.’ I'm not the same as another person. I don't think like that. I don't act like them. I am me. And if you can't see past my disability and see me for me, then that's your problem. Because a lot of people can't see past my disability and I don't like that.”
- “Where we're all coming from is we’re just people with intellectual and developmental disabilities. We just want to belong like everybody else, and they're just like everybody else who might have different personalities or different perspectives on things. We're not all going to agree. And we're just human beings and we just want to be a part.”

2. Description of Disability

People were asked if they ever felt forced to fit into a description of disability. This could happen in order to take part in a service or a program. Some people agreed that they felt this way, while others did not. But many said that they often felt judged or discriminated against. Overall, they said that they felt like their opinions didn’t matter. They also said that they face many barriers just because of what other people expect from them.

Yes, people have felt like they had to try to fit in.

- “I feel like I'm the square trying to fit in the circle model and it doesn't really work very well.”
- “I am who I am. So, if I fit in, I fit in. I don't know - if I think I need something, I'm willing to fight for it.”
- “Yes. I have felt like I had to fit in and act a certain way just because the other people expected. It has happened in my past as a child and is still happening now.”
- “It's happened to me a lot. I have felt forced to take part of programs or go to places where I don't want to go because it feels like I have no choice.”

No, people have not felt like they had to try to fit in.

- “For me, I don't feel forced. Simply because I'm somebody that has always gone against the grain of what society expects of me. And if they want to label me as having a disability, that's fine because I do that already … So, you know what - I'm okay with not fitting in to get a service or program because I'm going to probably be that person that's going to challenge them and get things changed to help other people.”
- “I don’t really feel that way.”
- “Personally, in my personal experiences, I've never been forced to go with any ideas.”
- “No, I don't feel so - I tried to live the best life I can.”
- “I can't compromise on what I like and what I don't like. If I like something I will do it. If I don't, I can't do it for a long time. Because it's just not me. It's not me. You know, I already compromised enough in my life.”

Yes, people have felt judged or discriminated against.

- “I have been looked down… and it doesn't make me feel good at all.”
- “How people are looking at us. It's how we feel, it doesn't matter.”
- “And most people tend to have this kind of discriminating reaction or kind of looking down on me, because I have disability and it's quite annoying. And things like this actually do mess with my mental state. So, a couple of times, I might not actually have the boldness to stand up for myself, just because I feel intimidated. But it doesn't actually mean that I can't actually contribute personally to that particular group or setting.”
- “I think that sometimes I'm not forced to go along, but there's roadblocks that get put in place by people that think they know what I can and can't do.”

3. Definition of Disability

People were asked about a definition of disability. The definition was from the *Accessible Canada Act* (ASA). People were asked if it was easy or hard to understand. People were asked if it described disability in the right way.

Some people said that it was easy to understand and they wouldn’t change anything. But most people said that it was actually hard to understand. They also said that it is challenging to find just one definition for disability.

This definition is easy to understand.

- “I would say, agree totally with the definition. Obviously, I agree with the part that disability can be permanent. It could also be temporary. It could also come as an episode also.”
- “Yes, it does describe people.”
- “I would say keep it the way because it has explained it perfectly.”
- “I would agree that the definition is right.”
- “It is easy to understand because it includes all kinds of disabilities.”

This definition is hard to understand.

- “I think there's a lot of language being used that is really complicated.”
- “Sort of hard to understand because it says that your disability disappears. And then it reappears? I know I always have a disability, but I make it a part of me, and I don't want to get rid of it because then I wouldn't know how to be myself.”
- “It is hard to understand. I don't think it's plain language enough for some people.”
- “I cannot understand where they get their words. Use simpler words – this is difficult for me to complete and for other people to read and get the true meaning of it.”
- “No, it's not easy to understand. It's quite hard.”
- “Honestly, it's confusing to me. I understand that there's different types of disabilities and everything. It just seems like it's not written down in orders like all over the place. The part I don't understand is the temporary stuff they put in there… I understand that things can come and go and all that and they can flare up. But there's a lot of disabilities out there that are permanent and hidden. And that a lot of people don't know about…I think this explanation could be rewritten in a different way.”
- “There's no one way to define it. Because we're all different. I mean, there are different forms of autism. There are different forms of visual impairment. So, it's very individualized.”
- “It's too many words. It's not sharp enough. I'm sorry, but when things are really long, my eyes start to glaze over about halfway through when I'm reading.”
- “So, I like part of it, but it's got to be shorter.”
- “You shouldn’t be labeling them by what degree their handicap is, they should be treated as equals in society.”

4. New Definition of Disability

People were asked what should or should not be in a new definition of disability. There were two main ideas that were repeated. The first is that people with an intellectual or developmental disability want to be involved in writing the definition. The second is that it should be written in plain language.

What should not be included in a new definition of disability?

- “A definition of our disabilities should not limit us. It needs to be there, but it should never limit what we can and can't do.”
- “I wouldn't have the word ‘disabled.’ There should be a new word… because I think that creates a division.”
- “They don't need to … label us all [as one group].
- “Don't call us handicap.”
- “I would say definitely not an impairment but that we have different needs. We have different abilities.”
- “I think that if you use really childish words, I will just disregard you completely. Because I am way beyond being a child right now. I'm a fully grown adult and I should be treated like one.”
- “Something like impairment should not be included in that definition.”
- “With the word disability, you are putting a barrier and a division there. So, you're dividing people.”

What should be included in a new definition of disability?

- “I think we're differently abled in all aspects. To be honest. I don't like the word disability. I like the words diversely abled.”
- “One idea I would include would be that we're all unique. We all have our different opinions and our own ideas. And we shouldn't be labeled. Not the same as everybody else, but differently.”
- “I think one of the things I always say is we include people first. We are people first before we are anything and anybody. We are people with a disability. If we have to put disability in the definition … I don't want them to judge us because of our disability.”
- “I think that it's important for people to know that sometimes more than one disability goes together.”
- “A definition of our disabilities should not limit us. It needs to be there, but it should never limit what we can and can't do.”
- “It should be in plain language.”
- “They should explain what ‘barrier’ means and what ‘functional limitation’ means.”
- “What I would include is that we're just the same as everybody else.”
- “They should have people with disabilities sitting there when they're doing it. Because we know - we've been through this. We have the experience.”

5. Access to Federal Services and Programs

The groups were asked what suggestions they had to improve access to federal programs and services for people with an intellectual or developmental disability. Two examples of federal programs were used: the Disability Tax Credit (DTC) and passport applications. Attendees were asked to think about their experiences with these programs, and any others, and share their ideas on how to make them more accessible.

Self advocates gave feedback on where to keep information about federal programs, as well as what steps could be taken to make those programs more accessible.

One suggestion was that federal programs should be put together in a ‘one-stop shop’ so that they were easier to find and to use.

- “If you could just do the one form for everything ...”
- “My suggestion would be to make a one-stop shop. So, if you applied for one thing you can apply for everything all at once with one application.”
- “Filling out paperwork is tough – same questions and then you have to wait a long time for the answers. Runaround took almost a year to get a service approved.”
- “For those that are already under the provincial system and they want to apply for a tax credit, that information could be passed on to the federal government for their documentation. Then you wouldn't have to reapply through another agency again. There's got to be a way that you can do it and save a lot of red tape is what I'm trying to say.”
- “I just think it would save a lot of hassle or issues.”
- “Don’t want to repeat the same questions over and again because you're answering the same things to different organizations.”

The most frequent suggestion to make federal programs and services easier to understand was to use plain language. People also suggested using bigger fonts, clearer instructions, less questions, and more pictures and videos.

- “Can you put in more plain language?”
- “My suggestion to improve application rules would be to not make it so incredibly complicated.”
- “It needs to be simplified and put in plain language. Just because I get tired of retelling my story and filling out paperwork a zillion times for something else.”
- “I think that more plain language needs to be used. There needs to be a more simple, person-centered kind of way for people with disabilities to be able to access the disability tax credit on their own without going to your mom and dad.”
- “Explain it to us. Maybe not give us a form because not everyone is good at reading. Have someone sit down and explain it to me or somebody else. And then plain and simple English, or plain and simple French, or plain and simple whatever language they speak.”
- “Do not use big words.”
- “Plainer language, shorter forms, better doctors and less questions. Definitely less questions would help.”
- “Shorter sentences and simpler language. Pictures and pictograms would help a lot.”
- “Shorter application forms.”

- "Every time I go, they ask questions that I don't have the answer. What would help me is pictures to help explain. It's difficult for me to write – I shake a lot. Also, bigger font. Words I can understand better."
- "There needs to be like videos or there needs to be some kind of easier way to understand the forms."
- "I also think it's important that when they're giving out information or asking for things that they should make it shorter - within a page or two. I find every time I go on the government website to research some information, I ended up reading pages and pages and hours and hours of documents and then I get overwhelmed because I forget what I read on page one by the time I get to page 10. If they could take everything that they write simplified into a page or two, I think that would also be helpful."
- "Unfortunately, with any of these federal programs, I've had others do it for me because they find it overwhelming for me to be involved in it. So, for in my personal circumstance, it just seems to be easier for the people around me to just do it for me."
- "I think for me, I have the staff there with me when I go to doctor's appointments, in case they use big words that I don't understand. They [staff] put it in words that I do understand."

People said that they had challenges actually finding federal services. This became a barrier to accessing the services they might want to use. They gave suggestions on how to make federal services more visible, including better advertising and increased community outreach.

- "I think it should be an advertisement like what website to go and how to get that information."
- "I personally think it would be handy if it was well advertised and well known about it. So that the public knows about it so that it's more accessible to the public, you know, to get information about it."
- "On the internet, there should be websites that are easier to understand that are more adapted."
- "I believe if there's more publicity, more information about it online, and if maybe you could possibly get it, maybe through television. I think it will really go a long way."
- "They need to advertise it … throw it out there, put it on the radio, put it on the TV."

People reported that once they found the federal services, they still had barriers to accessing them. These barriers included high costs, lack of support, and complicated processes.

- "I think with the cost of the paperwork, if the government could cover the cost for the paperwork to be filled out, because a lot of it you need doctors to fill it out for you. And so, the cost can outweigh the benefits sometimes and people get frustrated and they're like, 'I don't want to fill this out if it's going to cost me $300 to fill out and I'm not even guaranteed to get it at that point'."

- “The worst of it is the doctor. Not all doctors understand disability or not all doctors know this very well … It just makes it difficult if you have to keep going to doctors appointments to find a doctor that understands your disability to fill out that part of a form and to make sure it's filled out correctly.”
- “Doctors do not want to spend a lot of time filling out papers. Maybe shorten the format up and plus put it in plain language so that the participants or the person with a disability can understand the information that's being presented to them.”
- “I think they should be providing the funding if we need to go see a doctor. We're jumping through hoops to potentially get something that we might not even get approved for.”
- “I did get the DTC and I am on provincial disability as well. And it was really challenging because I had to go back and forth with the doctor that gave me my autism diagnosis. And I also had to actually pay a private doctor to fill it out. So, I think they should make it easier.”
- “My mom has helped me like with the passport form and stuff. But I would want somebody else to help me. So, I can be more independent.”
- “It can be very difficult if you know you're trying to get something or get some information and sometimes they don't see you and they'll talk over they want to try to talk over your head.”
- “In my personal experience, I always had to have a support worker with me when applying for income support or something. Just to show that ‘Yeah, I do have a disability, and this is my support worker.’ It's the reason why I'm here, so that I understand what's going on in case they use big words. But we should be able to show up by ourselves and not have a support worker with us. If we feel comfortable going by ourselves.”

6. Proof of Disability

People were asked about proof of disability. This was in relation to accessing federal services meant for people with disabilities. The response was mixed. People understood that funding was limited. They said it should go to the people who really need it and qualify for it. They understood that proof would help in getting services. But they also spoke about the challenge of getting proof for an invisible or hidden disability.

Yes, people should have to prove they have a disability.

- “I think that they should because, I mean, it's for a specific subgroup of people. And why should it [funding] be going to people that don't need the service? Generally speaking, the financial resources are incredibly limited in the first place. So, you would just hope that they would go to the right people.”
- “There should be proof. I mean … otherwise, you're going to have people apply who may not be eligible for the program.”
- “Yes, I would say yes, like you’ve got to have proof right?”

- “I do agree that you do need to prove it because in some way when you go to you apply for certain things like tax credits or social assistance, whatever the case may be, they need some documentation and proof.”
- “If someone wants to be part of a program, I think yeah, they should have to prove in some way or form because there may be people out there that the may take advantage of certain things.”
- “I think it's very important for the government to require proof of disability of some sort. Because otherwise, anybody could just apply and there would be no money for anybody because everybody would be applying.”

No, people should not have to prove they have a disability.

- “My dad would say ‘yes’, but I like to say ‘no we shouldn’t.’”
- “No, you shouldn’t have to prove it. Even if you have a disability, it doesn’t mean you’re not better than someone else. Some people have a disability that doesn’t show at all.”
- “It becomes a little tricky.”

Not sure if people should have to prove they have a disability

- “I think it depends on the kind of disability you have. Like if it's an obvious disability that they can, like, obviously tell from the appearance that that person has a disability. I don't think they need to prove that they have a disability. They should be able to just see that they have a disability and take it from there. But for those who have the hidden disability, like me, I think it would be okay to ask the person if they have a disability or not.”
- “I’ve got nothing to hide. But if you can see you got a disability and even though we had a disability we couldn’t get the service because we were doing too much volunteering for the community. And to me that’s not fair.”

7. Frequency and Use of Proof of Disability

People agree that proof of disability should not have to be done over and over again. They agreed it should only have to be done once for the federal government.

- “I think you should be able to go through that process once and not again. Because I know … sometimes they will ask you again. You should only have to have that process done once.”
- “When you say you have a disability, it's like ‘no, you don't have that,’ and you had to go through doctors. I had to do that year after year after year.”
- “So, there should be a professional saying that ‘okay, you have this this,’ and then you can go, but only one time should be sufficient. One note.”

There were discussions in almost every focus group about sharing proof of disability. People felt that the federal government should be able to use information from the provinces and territories as proof of disability.

- “As long as we're getting something from a provincial government like Community Living BC, some type of a letter through the ministry … Now you're proving that you have a disability because you're receiving their services and they are only there for people with developmental and intellectual disabilities.”
- “If our provincial government is giving us the disability funds or disability services already, then we should be able to get the federal disability services that are available. And if we can't, it becomes this disconnect from federal versus provincial.”
- “They need to all line up with each other.”
- “Any kind of documentation from the government, such as social assistance or getting the disability tax credit, should be proof.”
- “There should be some internal processes where if you're already on provincial or federal disability, that it's already in the system. So that way you don't have to fill it any more paperwork. Like if the government knows you're disabled. Why do they need to know again?”
- “Provincial and federal governments should be talking to each other so that we have to do less paperwork.”
- “Some designation on our taxes, so we are not constantly filling out paperwork, because that is annoying and frustrating, because it's never simplified most of the time.”
- “If you're under the provincial government plan for any sort of disabilities, why can't the federal government go and get that information from them? And then that would save people reapplying if they're eligible … we don't have to go through the doctor and healthcare system to get all these papers filled out.”
- “Is there a way for those two systems of government to talk to each other so that they can share that information?”
- “I think when you apply for something provincially that you don't have to fill out extra paperwork to get like the disability tax credit. If you get the disability stuff in your province, it should just qualify you for the disability tax credit. Instead of having to fill out a whole new form.”

People said that proof could come from many different professionals. This includes doctors and other medical professionals as well as educators.

- “You shouldn't have to go to a doctor if you have proof in a filing cabinet, like in a school somewhere.”
- “I think in terms of giving proof or evidence, I think the government should accept certificates from schools and also from hospitals.”
- “I think a doctor's note would be helpful.”
- “To include medical practitioners, people who deal with mental health operations and neurodivergent artists, artistic people, because some of these traits or disabilities are not a physical challenge.”

- “If you get it from some type of professional to send a letter, then that's all you need. But if you want a friend or family, there should be multiple references, backup, what they feel your challenges are.”
- “Doctors and teachers is a good proof.”

People also said that more testing or assessments should not be needed to get federal services.

- “I don't think there should be a test. I think there could be a form that needs to be filled out. But with the eligibility of a professional so it can be your service provider in your agency that you get services from.”
- “I think I know personally that for me, I've already had a lot of testing and all that stuff ...”
- “It needs to be people in the field of your disability that are allowed to really be the ones to tell the federal government.”

Recommendations for Change

These are the recommendations from the focus groups. People First of Canada hopes these will be considered in the development of the Disability Inclusion Action Plan.

1. Create a new definition of disability. Make sure it is in plain language. It needs to be easy to understand. It needs to include invisible disabilities. People with intellectual and developmental disabilities should help lead the process. They should be involved in making a new definition.

2. Make all federal programs and services available in plain language. Forms should be changed so that they are shorter and easier to understand. People want to have independence. They don’t want to rely on a network of support to navigate programs. They want to do it on their own.

3. Make information about federal services and programs available in a variety of ways. This should include accessible websites and videos, and plain language information. Advertise services and programs in highly visible areas such as social media, television and also in person.

4. Automatically qualify people for federal supports and services. People who get disability supports from their province or territory should qualify for federal disability programs. They should not have to go through another application process. If someone is receiving provincial or territorial disability supports, they should automatically qualify for all federal disability services and support without having to fill out another application.

5. Make proof of disability required only once. If people want to access more than one federal service or program, that proof should not be required again.

6. Include more professionals that can give proof of disability. This should include more than just doctors. It should include other medical professionals. It should include teachers, counsellors, and service providers. a wide range of professionals including medical professionals, service providers, and educational professionals. It should not rely on finding a medical doctor to provide this proof.

Conclusion

The unique perspective of people with intellectual and developmental disabilities needs to be heard at every step of this process. This consultation was an opportunity for People First of Canada to engage self advocates from every region in Canada.

The recommendations developed in this report address the barriers raised by self advocates. It also includes their solutions. This information will be important to developing the Disability Inclusion Action Plan and making sure that it works for everyone.

Appendix 1 - Focus Group Questions

Question 1
There are many ways to think about “disability.” What is the most important thing people need to understand about having an intellectual or developmental disability?

> Prompt: Feel free to think about your own personal experiences or the experiences of people you know.

Question 2
Do you ever feel forced to go along with ideas or people who may want to label you as having a disability? For example, do you have to fit in to get a service or take part in a program?

> Prompt if needed: Do you feel like you have to fit to someone’s description of disability?

Question 3
This is a definition of disability and it’s part of the *Accessible Canada Act* (ACA). Right now, it says a “disability is any impairment or functional limitation that interacts with a barrier. Together the functional limitation and the barrier create disability.” This definition says that disability is the challenge people have in participating fully and equally in society. And a disability can be permanent, temporary, or episodic. That means it can: a) be ongoing; or b) last a few days, weeks or months; or c) may “come and go” or “flare up” and someone has an episode of it. Also, a person’s disability can be something that others may or may not be able to notice.

What do you think about this definition? Is this easy or hard to understand? Does this definition describe people in the right way?

> Prompt:
> What do you think about the idea that disability may come and go?
> What do you think about the idea that a person’s disability could be something that others may not be able to see?

Question 4
As we talked about, it’s hard to define disability. What’s the most important idea that should be included if you were going to write a new definition of disability?

> Prompt: Why are these things important to you?

Question 5
What is one idea that you believe really should NOT be included in a new definition of disability? What should they not talk about?

> Prompt: Why would you NOT include that idea [or those ideas]?

Question 6

What suggestions do you have to improve the application rules and process for federal programs and services? For example – maybe you have tried to access the Disability Tax Credit or some other program. What would make it easier for you to access programs?

Prompt: What kinds of things do you *not* want to see?

Question 7

If someone wants to be part of a program or get a service from the federal government, should they have to prove (or confirm in some way) that they have a disability.

What could people use to prove to the federal government that they have a disability? What kind(s) of proof of disability should the federal government accept so that people can get the services they need.

Prompt: How do they make it easier?

Contact Us

To learn more about this project, please visit: https://muscle.ca/services-support/advocacy/diap/

Please email research@muscle.ca for any questions or feedback.