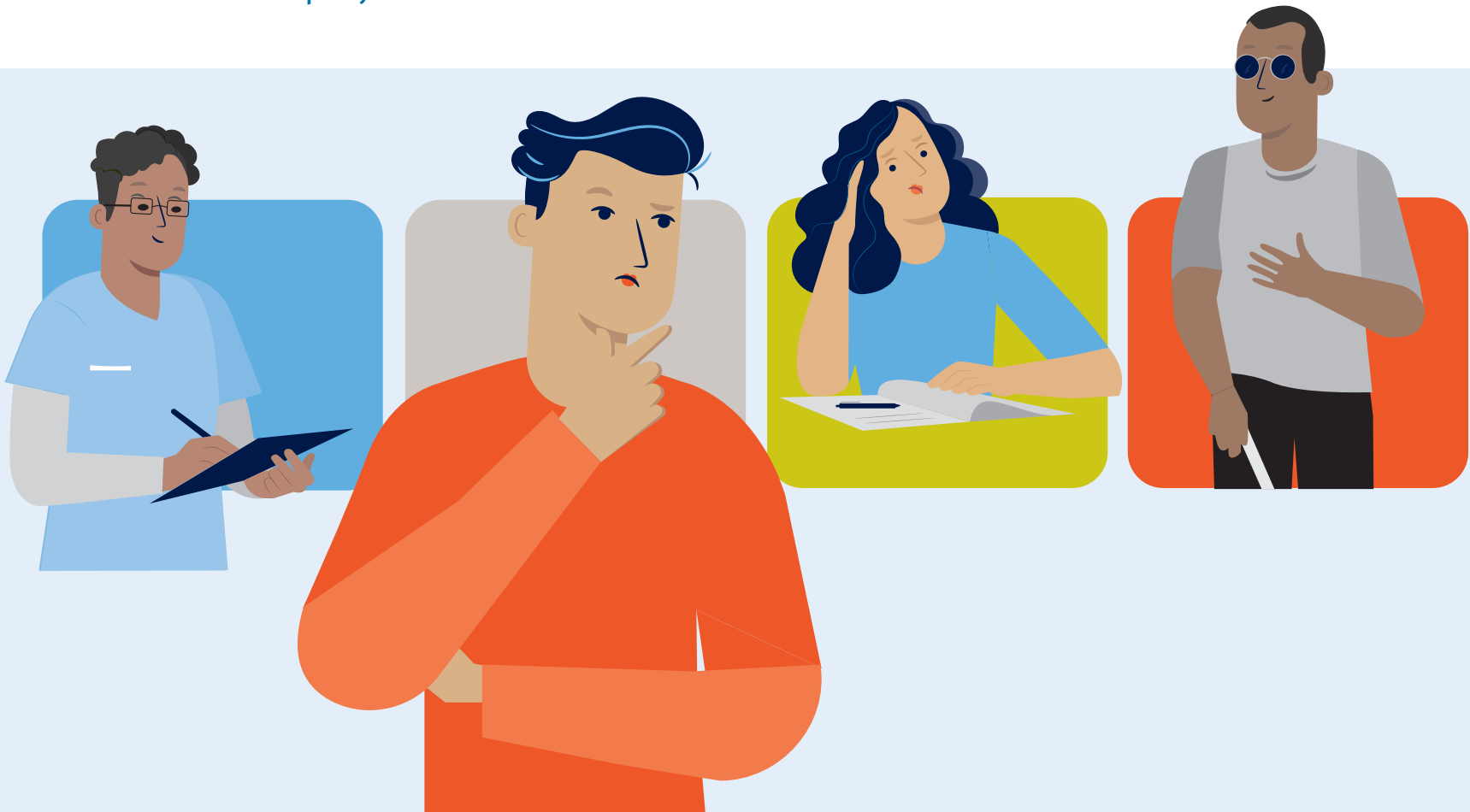


Roadblocks and Resilience

Insights from the Access to Benefits for Persons
with Disabilities project



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Executive summary

Canada has many income benefit programs that many Canadians find difficult to navigate, however benefit application processes for people with disabilities are the most challenging of all.



Prosper Canada, Disability Alliance B.C., the Social Research and Demonstration Corporation, and Plan Institute have undertaken a three-year **Access to Benefits for Persons with Disabilities** project to develop a potentially scalable service to effectively support people with disabilities to access government benefits they are eligible for, but not receiving.

This report provides insights on the barriers people with disabilities in British Columbia face in accessing key income benefits. These insights, and the accompanying service principles that participants identified, were obtained by reviewing existing research, directly engaging 16 B.C. residents with disabilities and interviewing 18 researchers and service providers across Canada. We will use these insights to inform development and testing of a pilot service to support people with disabilities to access disability benefits.

Our research focused on the federal Disability Tax Credit and the B.C. Disability Assistance program and found that disability benefits are the most challenging benefits of all to access. Applicants are required to obtain formal disability assessments from multiple healthcare professionals and to navigate many application steps and forms – more than are typical for other types of benefits.

In Phase 1 of the project, we found that four main barriers generally underlie disability benefit application processes and manifest in different ways along the applicant journey:

- 1 **Benefit application processes are complex and unclear**
- 2 **The burden placed on healthcare providers gets passed on to people with disabilities**
- 3 **Every step requires time, energy, connections, and access to resources that many applicants lack**
- 4 **Benefit application processes are dehumanizing.**

In Phase 2, we will design, develop and test an access to benefits service model for people with disabilities that meets the following key principles identified by project participants:

- Give me a consistent human relationship throughout this process
- Build a roadmap for me to follow
- Humanize my experience with straight talk
- Activate new advocates and navigators
- Get the word out to the most disconnected people
- Make it accessible to everyone

Too often, processes to access and retain supports discourage, thwart, and dehumanize people seeking help, rather than opening up a path to a better life. We can and must do better.

Introduction

Canada has many income benefit programs that many Canadians find difficult to navigate, however benefit application processes for people with disabilities are the most challenging of all.

Typically involving many more steps and costs, the experience is often onerous and expensive and can be profoundly discouraging and even dehumanizing for those who apply.

In 2020, Prosper Canada embarked on a three-year **Access to Benefits for Persons with Disabilities** project in partnership with Disability Alliance B.C., the Social Research and Demonstration Corporation, and Plan Institute, with funding from the Government of Canada's Social Development Partnerships Program. The aim of the project is to develop a potentially scalable service to effectively support people with disabilities – at no or low cost to them – to access government benefits they are eligible for, but not receiving.

Objective of this report

This report provides insights on the barriers people with disabilities in British Columbia face in attempting to access the federal Disability Tax Credit and the B.C. Income Assistance program for people with disabilities. These insights, and the accompanying service goals participants outlined to us, will help inform the next phase of our work – developing and piloting a service to support people with disabilities to access disability benefits.

The insights and information in this report are well-known to the disability community. This brief is intended to amplify, not replace, their voice.



Methods

Prosper Canada conducted one-hour semi-structured interviews with 18 researchers and service providers across Canada



Prosper Canada explored the following questions:

- What do government benefits (e.g., federal Disability Tax Credit and B.C. disability assistance) mean to the disability community?
- To what extent are these benefits being accessed by the disability community and why?
- What challenges do people with disabilities face in accessing these benefits?
- What ideas do you have to help people with disabilities to access these benefits?

We also invited 16 B.C. residents with disabilities to share their perspectives in any of the following ways:

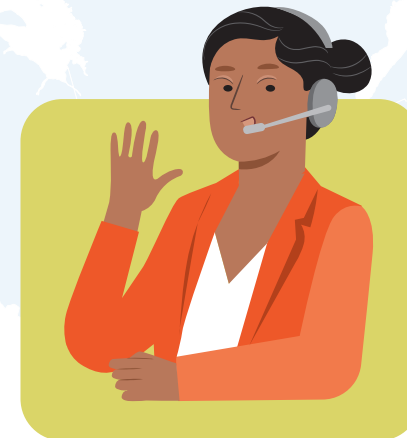
- Weekly written reflections over a one-month period
- One-hour video or telephone interview
- An art project of the participant's choosing
- A collage documenting the participant's journey to getting disability benefits
- Photo-journaling over a one-month period.

Our engagement with people with disabilities focused on the following questions:

- What steps did you need to take to get your disability benefits?
- What did you need to demonstrate to qualify for disability benefits?
- How did you find out about disability benefits?
- What would you change about the process you had to go through?

We recruited participants through social media, as well as the Disability Alliance B.C. and Plan Institute networks. We did not stratify participants by location, and as a result almost all of our participants live in major cities.

Lastly, we synthesized findings from existing research on barriers people with disabilities encounter in accessing income benefits (see list of references).



Meet Joseph

Joseph is a person with a disability who shared his perspective through weekly written reflections. He is a middle-aged man living in B.C., not a composite.

While everyone’s experiences are different, Joseph’s story tells us in his words about his journey to obtain the Person with Disabilities (PWD) designation required to access B.C. Disability Assistance.

Joseph’s story is one of resilience and persistence in the face of challenging benefits programs. It highlights where things are working and where they break down, helping to identify where improvements are needed. His words are reproduced verbatim, except where modified for clarity (shown in square brackets). We have included quotes from other participants in the journey map.

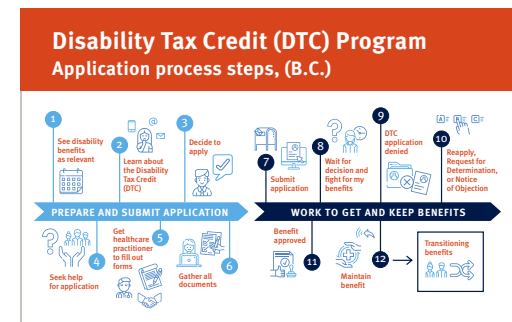


“Hello. I’m an adult survivor of childhood abuse and neglect, and I’ve been receiving [disability assistance for a designated Person with Disabilities (PWD)] for just over a year. I was approved [in September] 2019. I started trying to pursue these benefits in early 2017. Due to some bad experiences with the application system in 2017, I gave up for a couple of years and went back to trying to manage my symptoms and my life without support.”

Understanding the disability benefits application process

Our research focused on the federal Disability Tax Credit and the B.C. Disability Assistance program. For these benefits, applicants must obtain formal disability assessments from multiple healthcare professionals and navigate many application steps and forms – more than are typical for other types of benefits. Through first-hand interviews, we developed a composite map (encompassing diverse disability benefits) of this general process from the perspective of people with disabilities and organizations that support them.

View DTC application steps



Research findings

Four main barriers generally underlie disability benefit application processes.

The following barriers are cross-cutting in nature and manifest in different ways along the applicant journey:

Barrier 1

Benefit application processes are complex and unclear

The unpredictable disability benefits process makes it extremely difficult to take sustained action to get these benefits. Throughout their journeys, people with disabilities need to carefully use their energy for the greatest impact on their application process, while facing an unclear process where they often don't know how to best engage the people they need to, whether they need to wait or to act, how long the process will take until they get the benefits they need, and what they should do in the meantime if their application is denied.

- **Benefits approvals are a “black hole” of uncertainty and apparent inconsistency**
It is unclear to both people with disabilities and professionals whether an individual will be approved for benefits by the government or not, and many shared stories of people with similar applications and in similar situations where one was rejected and the other was accepted. Applying feels like sending documents into a void and waiting to see what comes back, leaving some people hesitant to make the effort.

- **Participants feel the system is designed to keep them out, not help them**
While benefits are supposed to help create financial stability, some participants felt the steps and work needed to qualify made it feel like the government was actively trying to persecute people with disabilities.
- **If at first you don't succeed, try, try, and try until you're too burnt out to care**
People who did eventually get benefits shared many stories of wrong turns, leads that went cold, and a process that dragged out over years, until they happened upon a person or organization that could unlock the process for them.
- **Getting denied is part of the process**
Navigation staff actively normalize the fact that an applicant's first application will be declined, because denials are common but also because a first denial seems to have little bearing on whether an applicant will qualify in the end.
- **Not wanting to risk other benefits**
Benefit interactions are very unclear, leaving many people unwilling to apply for benefits for fear that they will lead to other benefits being taken away.

“What should have only taken 3 months ended up being 2 years because people never volunteered information. We found out piecemeal. It was incredibly frustrating and led to us going homeless after a while.”

– Person with a disability



Joseph's story continued

“ In early 2017 I sat down with an advocate at an outreach centre and he helped me complete the application for income assistance [from the Government of British Columbia] online. It took us roughly three hours. [He] said I should expect a phone call from the ministry within a couple of weeks.

After a month of not receiving a call, I phoned him to ask if he had heard back from the ministry, and he said that he hadn't. He advised that I call the ministry with my application number and try to talk to someone. I did that, and I was told I would get a return call from a worker. I never received that call.

After two full months of not hearing back from them I decided that if the ministry wouldn't even return a phone call or contact me in any way, I wasn't going to bother.

Maybe not the wisest choice, but my mental health was deteriorating and I had just lost my job and my residence in the same week, and had nowhere to go. I ended up living in my car that year for several months, which was not unusual for me.



It was extremely frustrating that the ministry had my application and contact info, I had followed up with them, and they still weren't responding for some reason. If they had even contacted me to explain that I had been denied, that would've been something. I gave up on the process and tried to move on with my life. I never did hear back from them regarding that application, however two years later (2019) when I applied the second time, I noticed that the 2017 application was still in the 'My Self Serve' online system, shown as 'processing'. It's still there to this day, unprocessed, which is frustrating.

The difference for me personally between 2017 and 2019 was that I had worked with a handful of advocates and I had learned the language of advocacy along the way. Which gave me the tools for self-advocacy. Basically I went into the process in 2019 with the mindset that I wasn't going to take 'no' for an answer. I don't think most of us applying for this stuff initially understand how to do this, and we tend to roll over and give up in frustration when we hear it once or twice.”

Research findings continued

Barrier 2

The burden placed on healthcare providers gets passed on to people with disabilities

Benefits programs position many doctors as unwilling gatekeepers, ultimately creating more work for people with disabilities. Doctors (and sometimes other healthcare providers like Nurse Practitioners) are required to play a critical role in many of the steps a person with a disability must take to gain financial support. However, this position is an uncomfortable one. Fears of liability, lack of clarity on qualifying criteria for benefits, suspicion of patients trying to exploit the system, and the challenge of conducting disability assessments without any training or a long-standing patient relationship can lead doctors to avoid the role of gatekeeper that is thrust upon them. This means that people with disabilities and navigators must also learn to work with doctors to get them to do what they need.

- **Doctors are afraid of getting it wrong**
Doctors often are not trained to complete government and private sector disability assessments and may not feel comfortable committing to a functional impairment opinion on a benefits application.

They may not be an expert or specialist in a patient's disability, particularly if that person has multiple disabilities. This means patients have to 'coach' their doctor or, if that fails, find another doctor to get what they need.

- **Doctors suffer from fatigue from completing forms**
The time and effort to complete disability benefit application forms is a deterrent for some doctors. The relatively small fee doctors receive for this service may not be enough for them to carve out time from their busy schedules. As well, many patients cannot afford these fees, leaving them at an impasse.
- **Lack of existing medical relationships**
Many people with disabilities do not have a family doctor. Finding a doctor for the first time and one who is willing to complete benefit forms is a big stumbling block. Searching for the right doctor significantly slows the benefit application process.

“I can't emphasize enough how important it is to have a doctor (or doctors) who is both experienced in the applicant's health conditions AND experienced in how to “speak” the language that the government disability assessors need to hear.”
– Person with a disability



Joseph's story continued

“ Now that I was receiving income assistance, I had 90 days to meet several requirements to apply for [disability assistance]. I started working towards those requirements in May of 2019. The biggest challenge was coming up with a diagnosis (because I was applying due to mental health issues). I had been trying to get screening and diagnosis for several years prior to 2019. I had asked several mental health professionals to help me better understand what the hell was going on with my brain, and I was consistently denied. [In May 2019] I made a few dozen phone calls around [my region] (and beyond) looking for a doctor that could see me within the next three months to help me work on a diagnosis for the claim. I couldn't find anyone initially, and I was starting to panic.

As anyone reading this is probably aware, it's incredibly hard to find a doctor taking new patients and even those that are, typically have long wait lists.

I was consistently being told it would be much longer than 90 days wait to see a given psychiatrist. Also, I kept hearing that even if I did find a psychiatrist or clinical psychologist, there was no guarantee that individual would diagnose or even try to. Hearing this several times was very dis-heartening.

In the end, it was a friend who was able to hook me up. His dad was a psychiatrist working several cities away from where I was living at the time. I'm not convinced that I could've found a doctor in such short time without that friend/family contact. I lucked out.

During our session he asked for my detailed mental health history. By the end of that session he strongly agreed with me that I was dealing with C-PTSD [Complex post-traumatic stress disorder] and he issued a written diagnosis on the spot. He said he'd get some forms filled out and mail a copy of the diagnosis to me ASAP. He also asked me to send him my [Person with Disabilities Designation Application] forms once I got my section filled out, and he would complete section three.

As it turned out, when I got my forms back from him a few weeks later, he had in fact filled out both sections two and three for me, as his professional status as an MD (as well as a mental health professional) allowed him to do that. I was very grateful, as he saved me the hassle of trying to find a medical doctor (I've never had a regular or family doctor, because I've been so transient all my life).”



Research findings continued

Barrier 3

Every step requires time, energy, connections, and access to resources that many applicants lack

This means that the barriers to accessing disability benefits are greatest for the most vulnerable and marginalized people – those that these systems are intended to support. People with multiple disabilities, cognitive impairments, mental health challenges and those living in Indigenous communities face some of the largest barriers, because the system requires you to: be comfortable working with government systems; digest and navigate complex information and requirements; schedule appointments and travel to meet with healthcare professionals and government agencies; and advocate for yourself until you find allies that can unlock the process for you.

- **Literacy requirements are high**

Most information on disability benefits and support is written in complex language. As well, the process is easiest for those who have a high degree of ‘systems literacy’ – those who know how to work with systems to get what they need. Those who lack these abilities face a daunting challenge.

- **There are gaps in supports for people with multiple and cognitive disabilities**

We heard that there are many organizations dedicated to helping people with physical disabilities navigate the system. However, people with multiple disabilities and those with cognitive impairments may not have access to as many benefit navigation supports. They may also not have the energy or cognitive ability to ‘fight for their benefits’ effectively.

- **People in rural and remote communities may have few local supports to turn to**

Rural and remote communities, including many Indigenous communities, may lack many of the resources people need to help them apply for benefits, particularly local doctors or support agencies. Community members may also be suspicious of ‘free money’ and government institutions and, by extension, nonprofits.

- **People who do not identify as a person with a disability, despite meeting the criteria, miss out on disability benefits**

Misdiagnosis, or no diagnosis, can cause some people to not identify as a person with a disability or to feel entitled to disability benefits.

“Being in constant 24/7 pain, along with tremendous fatigue, made it very difficult to think straight and drum up the clear thought process that’s needed to complete the application process.”

– Person with a disability



Joseph's story continued

“Earlier this year, 2020, I wanted to sign into CRA ‘My Account’ to do my income taxes as well as try to send in my application for the Disability Tax Credit (DTC). I was locked out of My Account again. The system advised me to phone in (which would mean they’d send me a code by mail). Unfortunately, this was right after COVID started, and CERB, so to actually speak to someone at CRA was taking most people several straight days of waiting on hold.

I didn’t even bother trying, to be honest. Which means I didn’t send in my DTC forms.

I’m not happy to admit this, but one of my C-PTSD symptoms is a form of self-harm when I get stressed out or agitated.

I disclose this to say that basically four out of five times that I’ve tried to deal with the CRA over the past five years, I’ve left the exchange triggered bad enough to self-harm.

Last month (September) I finally got through to CRA on the phone to try to unlock My Account. After about 90 minutes on hold, I was transferred to three different people before I was told that there would be yet another security code (third one in three

years) sent out via snail mail and that I could expect it in three to six weeks... which meant that I was going to miss the deadline to apply for DTC that would’ve qualified me for a one-time \$600 benefit related to extra COVID expenses. The deadline was Sept[ember] 25th, and I received the code in the mail three days ago (Oct[ober] 8th). I had to hang up from the call while the woman was still speaking, because I had started hitting myself in the head.

I mention all this to say; what would really help support me financially is making some of the required systems that every Canadian has to interact with more supportive and easier to use. The steps and delays and strange convoluted language

on the government websites are challenging for neurotypical people... which means they’re doubly so for some of us with mental health (and other) challenges.”



Research findings continued

Barrier 4

Benefit application processes are dehumanizing

The dehumanizing effects of benefit application processes give people a strong reason to avoid them altogether. All steps, from becoming aware of disability benefits to potential denial and appeal, can be exhausting, traumatic and stigmatizing. On top of everything, the low dollar value of disability benefits also makes people feel as though Canadian society sees them as inherently worthless.

- **Government departments are communication silos, creating more work for applicants**
People with disabilities must often fill out exhaustive forms with largely the same information over and over for multiple programs in the same government, or even the same ministry. On top of dealing every day with a disability, the added burden of proving your disability repeatedly for different benefits can be exhausting and defeating for a person with a disability.
- **Retraumatizing yourself for a handout?**
Application processes include probing questions that can be painful for, or even re-traumatize, applicants. As well, people are marginalized by constantly having to prove and re-prove their

disability and that they are worthy of financial support – even when there is no possibility their condition will change or improve. Benefit programs are designed to judge them and their situation.

- **Indifferent bureaucracies just don't care**
Government offices can be difficult to access or hard to travel to for people with disabilities. We also heard stories of government staff, federal and provincial, giving inaccurate information and verbally abusing clients. Government websites are complicated and difficult to navigate even for those with no cognitive impairments. Rules, processes and deadlines feel rigid, despite the unique needs of people with disabilities. All of this makes people feel that governments don't care to help them, at every step of the journey.
- **Demand far outstrips supply**
Advocates who assist people with disabilities who need help to navigate benefit programs are seen as saviours. They bring compassion and humanity back into the process, but there are too few to help the many people who need support.

“ [my partner] did jobs that no person should ever have to do [...] to support his family and himself. And then, when his body broke under the strain, the government denied him again and again and again. They turned their backs on us and said, ‘Not my problem.’
– Person with a disability



Joseph's story continued

“The PWD forms are fairly complex, with three different sections. One to be filled out by me, one by a medical doctor, one by a mental health professional (assessor).

I found each section very emotionally challenging, because I had to disclose a lot of very personal, embarrassing, shameful, traumatic things about myself to several different people.

I realize that the ministry needs accurate information to decide a given claim, but this doesn't diminish the fact that the process itself can be perceived as very invasive in some ways.

In the section that I was meant to fill out, my advocate advised me to write as much detail as I could about my childhood traumas and the consequences of them throughout my adult life. This was a very painful series of experiences to put on paper for (potentially) dozens of people to scrutinize. I don't need to explain that any further, I'm sure.

Prior to COVID-19, I was receiving \$1,235 per month in benefits. Starting in (I believe) April they've been issuing an additional \$300 supplement to help with things like extra expenses and

the fact that there is far less work available (for everyone). As of right now, that extra supplement runs out in December. I would love to see the ongoing benefits stay at \$1,535 or even go a little higher. At this current rate, I have just enough to cover my rent, car insurance, and cell phone bill, and some groceries. I partake of the local food bank every month as well.

Prior to the COVID increase, I often found my cupboards bare at the end of the month as the food bank in this area only allows clients to receive a portion once per calendar month. So, it often happened that I was stretching a full month on around \$100 worth of groceries that I could buy, and the rest from the food bank. Now with the COVID increase of \$300, I can buy upwards of \$200 worth of groceries for the month, and not be skipping meals by the end of it.

I still typically only eat once a day, just to stay on budget, but I'm eating far better.”



Next steps

People with disabilities, like Joseph, face many systemic barriers to getting disability benefits they are entitled to.

At the same time, one of the bright spots we found was the support that organizations, peers, and caregivers provide to help people with disabilities navigate benefit programs.

In Phase 2 of the **Access to Benefits for Persons with Disabilities** project, we will be developing an access to benefits service model for people with disabilities. This service will need to meet the following key principles identified by project participants. As our work progresses we will continue to add to this list:

- **Give me a consistent human relationship throughout this process**

A consistent relationship is so important as people move through all the steps of the benefit application process. Ideally, this person is empathetic and can help people with disabilities learn about and apply for benefits and know where to go for help with difficult situations.

- **Build a roadmap for me to follow**

People with disabilities asked for a clear and plain view on the steps they need to take, pitfalls they may encounter, and ways to navigate challenges. They need information to help decide whether to embark upon this journey and to know what to expect before they encounter it.

- **Humanize my experience with straight talk**
People with disabilities must often deal with incorrect or unclear information, being infantilized, and having to decipher government jargon. They asked for honest, direct, and clear guidance about what they can expect from the process. They want to know when we don't have an answer (e.g., not knowing how a decision is made). They need to be treated like human beings, not objects.
- **Activate new advocates and navigators**
We need more advocates to help people with disabilities to navigate benefit program processes end-to-end. This service should help new advocates quickly get up to speed and to know where to refer clients with more complex cases.
- **Get the word out to the most disconnected people**
Many people with disabilities don't have a close connection to an agency serving people with disabilities. This service will need to work with others in the ecosystem, like legal aid and health-care professionals, to connect with these people with disabilities through established referral channels.
- **Make it accessible to everyone**
This service must be available to anyone who wants to use it, without qualifying criteria. It needs to be useful to people with diverse abilities.

Joseph's story continued

“Having my monthly basic needs met, without having to struggle with toxic work situations, has given me the stability and sense of security I need to finally begin the process of unpacking my past and dealing with it. To put that another way, now that I'm not constantly struggling with daily needs and present-moment stressors, I have the opportunity and energy to face the things that have been holding me back for over half my life.

Over the past 10 months of having continuous stable housing I've enjoyed for the first time:

- Sleeping well when I need to
- Eating healthy every day
- Unfettered access to the internet
- Safe space of my own to unfold into
- Keeping house-plants for the first time in my life
- Owning furniture
- Ability to shower every day
- Knowing that I'll be here next month
- ... this list could grow extremely long.

Benefits have given me the ability to step back from toxic survival jobs. For the first time, I have the opportunity to break that cycle. I'm now able to make good choices about whether or not to take a given job based on how healthy it will be for me... or not. For the first time in my life, I can choose to earn money in ways that accord with better mental health. It may sound like a simple thing to many people but it's truly a revelation, for me.

Sometimes I feel genuinely surprised that I'm being supported [through disability benefits]. Over a year into it, I still work at wrapping my head around it. I feel supported. Every month? Yeah. Every month. I feel safe. I feel humbled. I feel appreciated and cared for by my community... which is traditionally a very rare thing for me.

It's a very daunting thing as a man in my 40's (and for anyone, at any age, facing any different-ability challenge) to contemplate giving up a huge amount of independence and autonomy by effectively asking a government organization for support that we can't get anywhere else. We know that it will open some doors but close others. I knew going in, that they would have access to my banking info, my detailed history, and that I would have to report to them about my month-to-month activities. The government now has documents detailing dozens of very uncomfortable aspects of my past, and just as many about my current challenges. This is an extremely obvious power dynamic, and in the sense of gatekeeping I have entered into a relationship with this organization for the rest of my life.

If they don't handle their side of this relationship with respect and empathy, where does that leave me as a client and user of this system?"



Get involved

Income benefits and other disability services are critical supports that can help enable people with disabilities to live with greater dignity, participate more fully in society, and more actively realize their human potential.

Too often, however, processes to access and retain these supports discourage, thwart, and dehumanize people seeking help, rather than opening up a path to a better life.

Joseph's story clearly outlines what is at stake. We can and must do better.

If you would like to join or support us in this work, please let us know. We welcome individuals and organizations who wish to collaborate in the second phase of our work – developing and piloting a new benefit navigation service in B.C.

If you are interested in working with us or learning more about this project, please contact:

Galen MacLusky

Manager, Program Delivery & Integration
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Additional resources

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