Co-Design as Applied to Accessibility in Health Care

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Abstract

This research study is a participatory exploration of the experience of people in accessing health care. The study highlights barriers and personal accounts from people who were excluded in accessing health care during the Covid-19 pandemic in Ontario, Canada.

The study employed two qualitative research methods to gather information: storytelling and co-design. People with lived experience of health care exclusion shared stories of barriers they experienced in accessing and receiving health care during the pandemic.

As part of the co-design sessions, participants (who are referred to as 'co-designers') designed and participated in collaborative design exercises aimed at developing improvements to existing health care barriers. Co-designers worked together to design approaches to address common barriers, and developed recommendations to support meaningful consultations with the disability community.

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I acknowledge the land on which the Ontario College of Art and Design University is situated and where this project work was conducted. I myself am an uninvited guest on this land, the traditional terrority of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples. This land is still the home to many Indigenous people from across Turtle Island.

I am thankful and privileged to reside, work, and learn on this land.

Tables, Figures, and Illustrations

Preface

This research paper does not make assumptions about the experience of people and their barriers. It is a compilation and design exercise in which important voices shared their stories and came together to build something meaningful. This research paper and the recommendations enclosed within do not seek to solve healthcare inequities or barriers experienced by all people. Instead, the research is a start towards building a more inclusive and accessible health care system.

Introduction

The Covid-19 pandemic changed many aspects of life as we know it, and immediately impacted health care systems and resources across the world. The pandemic worsened some existing health and societal barriers, and created new barriers that heavily impacted how, when and if persons across Canada could access health care. The term "social determinant of health is often used to refer broadly to any nonmedical factors influencing health, including health-related knowledge, attitudes, beliefs, or behaviors." (Braveman et. al, 2011, para. 4). An improved understanding of individual and social determinants of health is vital in moving us towards greater equity in health care, and storytelling as a research method is an effective tool for conducting health equity research. The benefit of storytelling is that storytelling helps participants take a more active role in the research process and can help build connections and relationships between researchers and communities (Banks, 2012). These benefits also are applicable to co-design as a research method. This is especially important towards creating a more inclusive research practice. A more inclusive research practice creates many benefits, and one very important benefit not to under look is citizen participation. Arnstein defines citizen participation as citizen power, whereby power is redistributed to enable those who are excluded from current processes to be deliberately included (Arnstein, 1969). Increasing the practice of co-design can create greater opportunities for a more deliberate shift towards citizen power-sharing and social reform.

An Overview of Known Barriers and Exclusions

Covid-19 has negatively impacted the lives of many people, but the pandemic has had disproportionate negative impacts on the lives of people with disabilities, and those experiencing exclusion. This section shares information on some of the barriers that were experienced around the world as a result of the pandemic.

People who require personal care assistance and routine medical care have been adversely affected by the global pandemic. In particular, the impacts may have been greater for those managing conditions that may not be sufficiently cared for through digital health and socially distanced practices (Drum et al., 2020).

Many institutional barriers that currently exist may have been exacerbated by Covid-19, impacting the ability of persons with disabilities to access information and services. Due to these barriers, people with disabilities may be at greater risk of contracting COVID-19. Public health information on prevention measures is not being provided in accessible formats, creating barriers to access for many people, and in particular persons with visual disabilities (Meaney-Davis et al., 2020).

An increase in virtual therapies may introduce new barriers and exclusions for people who need access to a therapist. Important factors like Internet access, device availability, the digital accessibility of virtual meeting tools, a person's comfort and perceived safety, and the ability to navigate technology are just a few notable barriers (Simpson et al., 2020).

People who are hard of hearing and or deaf experienced barriers to receiving important and timely information regarding pandemic health care measures. In many jurisdictions where key public health information was shared, not all live broadcasts provided sub-titles or sign language interpreters (Ned et al., 2020).

Given the frequency and volume of information related to Covid-19, there may be difficulty for many people, not just persons with disabilities in understanding and accessing the information that they need on a daily basis. People with intellectual, learning and mental health disabilities could be at greater risk of becoming overwhelmed by the volume and frequency of information related to Covid-19 in the media and on social media (Courtenay & Perera, 2020).

Targeted responses were not deployed with the Covid-19 pandemic, and in many places across the world, and in Ontario broad police-enforced and population-wide mandates were implemented. This one size fits all approach is not feasible for certain populations, including for people who are incarcerated, detained, living in shelters and for some people with disabilities (Okonkwo et al., 2021).

One size fits all approaches, designed by governments do not adequately address unique needs and provide equitable solutions. To address this in the future, persons with disabilities should be included in decision making, and have opportunities to participate in the design of targeted approaches. Additionally, when designing and creating opportunities for greater participation, it is important that multiple dimensions are analyzed within a specific context. By taking a deeper look at other dimensions of inclusion such as race, sex, or class, there are greater opportunities to see how intersections “mesh, blur, overlap, and interact in various ways to reveal knowledge” (Annamma et al., 2013, p. 5).

In sum, these barriers show that the Covid-19 pandemic has disrupted the status quo and we have much to learn. This unique and challenging time in history presents a great design opportunity to hopefully guide us forward in positive change.

Research Methodology

The research study was designed with two methodologies, storytelling, and co-design.

Storytelling was leveraged as a research methodology to share impacts and people's experiences in a humanistic way. The stories shared within the research have been kept exactly as they were shared to preserve the identity and meaning in which they were told.

Co-design was employed as a participatory research method. This important design tool was used due to the flexibility and ownership opportunities that it offers participants. Co-design for the purpose of this research is defined as meaningful end-user engagement in research (Slattery et al., 2020), and within this project it involved co-planning, co-design, and the co-production of the final research findings. The adapted definition as proposed by Blomkamp (2018) is that co-design involves "Iterative stages of design thinking, oriented towards innovation" (Blomkamp, 2018, Table 1). Co-design has great applicability to health research, as it is helpful in generating creative and design centred methods that could be applied to complex health problems, while preserving agency and respect for participants.

About the Storytelling

People with lived experience of health care barriers during Covid-19 were invited to share a story of their personal experience. No limitations were imposed on participants with respect to what they could share as part of their story. Additionally, participants were invited to share through a format or means that worked best for them.

About the Co-design

People with lived experience of health care exclusion were invited to come together as a group and design approaches to the challenge. There were four group co-design sessions in total, over the course of seven weeks. Additional one-to-one co-design sessions were held for co-designers unable to attend one of the design sessions.

Design Challenge

Instead of guiding the research with set expectations or rules, co-designers were presented a design challenge for their consideration. Co-designers were presented with the following challenge:

> During the Covid-19 pandemic, many barriers and exclusions have been introduced and intensified by health care systems.
>
> ‘How can we reduce or remove these barriers?’

Process of Seeking Co-designers and Storytellers

The process of seeking co-designers and storytellers emphasized learning from and working with persons who had lived experience of health care exclusion. Outreach was conducted with community organizations, groups and individuals working in the healthcare space. Co-designers and storytellers were recruited through the following communities or groups:

- Inclusive Design Research Centre Community
- Canadian National Institute for the Blind (CNIB)
- Community Health Care Providers/Advocates
- Working for Change
- March of Dimes
- ARCH Disability Law
- Ontario Disability Support Program (ODSP) Action Coalition

The co-design recruitment materials were also shared amongst the personal networks of some of the storytellers and co-designers.

Recruitment Process

The recruitment process occurred over the course of four weeks, starting on January 28, 2022, and ending on February 28, 2022.

There was some initial difficulty in recruiting co-designers and storytellers for the research. A representative from a community advocacy group shared that the research method of storytelling is not always effective. They shared that they have found there may be some reluctance to share stories as they may be painful and traumatic experiences for people to recount. While this is true and important to note, the researcher does hold an important role in informing their practice with trauma informed approaches to create emotional safety. Important principles include, “establishing emotional safety, restoring choice and control, facilitating connection, supporting coping, responding to identity and context, and building strengths” (Wilson et al., 2015, p. 1).

Using an Inclusive Design Approach to Design the Study

An inclusive design approach was employed in the design of the research study. The approach followed certain principles to ensure that the research process was as inclusive and respectful as possible. The approach aimed to follow open community practices where participants are emphasized as co-designers and have an important role in maintaining the project's outcomes. Additionally, the inclusive design approach was non-prescriptive in the design methods that the co-designers selected (Clark et al., 2016). Also notable, is that the inclusive design approach to the study was not rigid "because inclusive design is about diversity, variability and complexity" (Treviranus, 2018, para. 1).

Lived Experience

At the very core of this research is the focus on lived experience as being the guiding factor to this work. First-person accounts and stories shape the framework and direction of the research.

Ownership

An important aspect about inclusive design is that people are experts in their own experience. The research efforts for this study centred and valued that experience by providing ownership opportunities to participants in many aspects. The study was designed by making a conscious effort to avoid a traditional approach to research where participants are considered to be subjects.

The study was designed to provide ownership opportunities to co-designers in the following ways:

1. The study was driven by research questions, a challenge and theme instead of a hypothesis.
2. Participants were not considered to be subjects but instead designers who were involved with the agency to make decisions as much as possible. Throughout the research participants were not referred to as participants, but instead as co-designers in the process.
3. Participants were given the opportunity to co-design the activities and approach that would be used for building the recommendations.
4. Participants were invited to review and recommend changes to the research outputs before publishing.
5. Participants were invited to review the draft paper and propose any recommendations or edits to the content.

Flexibility

The study was designed for flexibility within the limitations of the Research Ethics Board at OCAD University. Flexibility in design enabled new opportunities to pivot and change direction according to the voices of persons with lived experience. If new themes and areas emerged, there was opportunity to focus on the aspects of most importance to the co-designers.

Storytelling and Research Design

Interested individuals were invited to share their story about how they experienced health care barriers during COVID-19. Participants were invited to contribute their stories about how they experienced healthcare barriers during COVID-19 in a format of their choice. Some suggested options included a written story through email or by mail, drawings, over the phone or through a virtual meeting.

There was greater uptake of this option, and the stories were varied and diverse. While the format for such sharing was left open to participants' own interpretation, a few participants requested some questions to guide and structure their storytelling. The following prompting questions were prepared to support this request. Participants were told they did not need to answer any or all of the questions, and that they had been provided purely to guide and support reflection on the topic under consideration.

Prompting Questions as Supports

- Tell me about yourself.
- Tell me about your general experience in accessing healthcare over your lifetime.

- Tell me about your experience accessing healthcare during Covid-19.
- What barriers did you experience?
- How did those barriers make you feel?
- What impact did those barriers have on your life?

In total, eight stories were collected from participants. Some of these participants were also engaged in the co-design sessions. The stories were all collected by phone, or through a virtual meeting conversation.

Barriers that Emerged through Storytelling

The stories have been organized thematically, and quotes have been included to show personal impacts that healthcare barriers have had on their personal lives.

There's a Limited Understanding of Disability

The extracts from stories presented in this section shed light on the theme of 'Limited Understanding of Disability'. These stories illustrate the disconnect in understanding between health care professionals and persons with disabilities. The stories show that barriers can be worsened by those in health care through limited understanding of disability and their specific needs.

> However, in everyday life we who live with a disability are not sick! We are not sick! We live with a disability. At the same time, most of us do not suffer from our disability. This is a question that is raised to us once in a while. It's a term that's used about us. Well, unless we are in pain, I don't suffer from

> being blind. I suffer from being discriminated against on a regular basis. – John Rae, Blind Rights Activist
>
> I said, ‘Didn’t the staff tell you that I’m low vision and I’m legally blind?’ She said, ‘Oh. Do you wear hearing aids?’ I said, ‘No, when you have low vision you don’t wear hearing aids’. I wondered if that was a nurse. – Sharon Dever
>
> Some people aren’t very good at verbalising directions or information. ‘Just move the thingamajig to the left’. A lot of that in the operating room when I was trying to transfer to the bed. They don’t realize words are what I need to hear to visualize what they want me to do, or what they are going to do! – Sharon Dever

A limited understanding of disability could result from willful ignorance, societal design or many other factors. Ignorance in this regard, in the health care space impacts health equity and contributes to systemic discrimination and exclusionary processes. Notably, the attitudes of health care professionals and how these professionals interact with the personal characteristics of their patients are a concern when identifying factors that can result in healthcare disparities. This may include differences in the quality of care provided to their patient and influence the health care professionals’ behaviour and actions (Meade et. Al, 2015).

Policies are designed to ‘exclude people with disabilities’

The extracts from stories presented in this section shed light on the theme of ‘Exclusionary Policy’, illustrating how the design of policies, programs and services can create barriers and exclusions for persons with disabilities. These stories are particularly concerning, as they demonstrate how policies can unintentionally or intentionally cause significant harm.

> I managed to get hold of information from the government that if it came to a point where healthcare resources, which are already limited health care resources, had to be rationed, that disabled folks would die. And I think that's an indication that our lives simply don't matter now. – John Rae, Blind Rights Activist

> Multiple health care agencies, since COVID, have worked together and used public resources to deny services to, and discriminate against, persons with disabilities, whether it is the triage policy to deny those with reduced activities of daily living access to ventilators in ICU if they develop severe COVID, or whether it is creating policies to whittle down the number of persons with disabilities who are medically exempt from the vaccine. [And there are ongoing questions about the use of medical assistance in dying (MAID) that point to the same types of concerns, where resource allocation is used in oppressive ways against persons with disabilities.] These deliberate and often punitive acts of bringing together scientists, policy-makers, politicians, regulators and insurance lawyers to squeeze vulnerable people out of access to necessary public health services, access to their communities and mobility and other human rights are disturbing and need to be addressed from an inclusive perspective, by advocacy groups and those who want to advance our rights. The problem is not just that the system is over-taxed and is too busy to solve the problems persons with disabilities are raising. Rather, they are organizing to use resources needed for quality of life in ways that oppress persons with disabilities. – Cybèle Sack

> I know what you mean about narrowing vaccine medical exemptions. Public health officials say doctors want to give exemptions at 2% (or 1 in 50), but the government thinks that number is 1000 times too high. That means about 99.9% of people doctors don't think it's safe to vaccinate, the government wants to vaccinate anyway. And the policy direction isn't coming from one official – it's from the province and the feds. The direction is very top-down. So who falls in that 99.9% – tens or even hundreds of thousands of patients in Ontario – who the government wants to vaccinate against their doctor's advice? Do we not count? Do we hide – and if so, for how much longer? Now Public Health expects us to register on a targeted site that

> specifically tracks medically exempt patients and lets them contact us at any point in the future, if they decide to coerce us. It's not a safe registry to be on, but there's no system to protect us from it. And if we don't register, our doctors' notes don't count anymore – to get access to things like work, schools and universities, transportation, recreation and mental health, even some medical buildings. We don't have access to society and we're in hiding. The last I heard, fewer than 300 people registered on the exemption site, because we don't trust it." – Anonymous Person One
>
> "Should doctors be the arbiter of bodily autonomy? Is that in line with disability ethics? Consider persons who are unvaccinated because they don't have their own family doctor or nurse practitioner they trust, which happens more to some populations than others. There are also those with complex mental health needs and trauma experiences, or who have various other health reasons for not being vaccinated that doesn't fall under the medical exemption category. Persons with many types of disabilities have been advocating against the need for medical notes to access education and employment for years. Are we setting that work backwards?" – Cybèle Sack
>
> "Vaccine exemptions are an exclusionary tool that perverts the concepts of inclusion and accessibility. Medically vulnerable persons (including immunocompromised people and those who can't be vaccinated for medical reasons) may need social measures in place to reduce their chance of infection, so they can fully participate while mitigating their risk of getting sick. Vaccine accommodations should have been designed to account for these needs but instead they have been designed to do the exact opposite. The paternalistic view of persons with disabilities (keeping them locked away and preventing, reducing and limiting their participation) has resulted in discrimination against them.- Cybèle Sack
>
> If you have a driver's licence – which you can imagine, I don't – you can renew your health card online. So, since I don't, I had to go out during the height of Omicron 'cause it was in December that I did this. – John Rae, Blind Rights Activist

These barriers show the significant negative impacts on the lives of people with disabilities. A consequence of exclusive policy design is that "people with disabilities are more likely to be poor, because of the systemic institutional, environmental, and attitudinal barriers encountered in their daily lives, which in turn results in their entrenched social exclusion and their lack of participation in contemporary society." (Groce et. al, 2011). These inequities are also a direct consequence of continuous exclusion of persons with disabilities due to limited representation in positions of power and therefore limited decision-making capabilities in defining public policies and systems.

Inaccessible Healthcare Equipment

The extracts from stories presented in this section shed light on the theme of 'Inaccessible Health Care Equipment'. These stories illustrate how health care equipment in public spaces or at home is not always designed for use by all.

> What we want is for Health Canada to stop approving for use in Canada devices that aren't usable by the blind. – John Rae, Blind Rights Activist
>
> As someone with diabetes I have this little machine in my hands and a sensor and I wave it and the machine doesn't talk. This is the same problem with diabetic pumps. And the same with at home Covid tests. Covid tests do not provide any auditory or tactile information, so they are useless to a blind person who lives independently. – John Rae, blind rights activist
>
> I took a taxi to the hospital with my scooter. First person you would meet was a security guard. You then take your health card over to some scanners which are up high with small print. I'm sitting down, with low vision and I can't read the screen. I'm not sure which way to put the card. So, I went to one of the staff, and she said, 'No, no you can't come here'. – Sharon Dever

Inaccessible Formats

The extracts from stories presented in this section shed light on the theme of 'Accessible Formats'. These stories illustrate how receiving important medical information in inaccessible formats creates barriers. These stories make it especially clear how these pose barriers for persons with a visual disability.

> When I was discharged there was a piece of paper. Sending a patient their discharge plan electronically shouldn't be an issue. – John Rae, blind rights activist
>
> It was about four days later when I got to the operating room. One doc came out with an agreement they said I had to sign. It was a legal-size form with printing on both sides. Imagine how small the print was. So I couldn't read it of course. I couldn't read it so I asked them to read it. Which is what I normally would do. What now? They had no clue. It was a new team, and when I said, 'Can you read it?', they said, 'Right now?' They said, 'The whole thing?' That annoyed people because they wanted to know what the hold-up was. – Sharon Dever

Inaccessible Physical Spaces

The extracts from stories presented in this section shed light on the theme of 'Accessible Physical Space'. These stories illustrate how the design and location of things and the organization of physical spaces in health care settings may create additional barriers. These barriers range from navigating a space successfully, to visual only indicators, and to secure and comfortable waiting options.

> They didn't have a chair with arms – and I really need arms. My walker is on lock and the floors are very slippery and I would have appreciated a chair with arms. – Patricia Smiley

> In a clinic setting, the numbers appear somewhere on a screen with your name. That’s what I’m told, of course I couldn’t see it. – Sharon Dever

> Once I got to the registration desk, in emergency and there were two chairs in front of the desk. She wanted my health card. I couldn’t reach across the chairs and desk to give her my health card. I had to toss it on the desk and she grabbed it. She was asking about my address, and I asked if I could get closer, and she said, ‘Just move the chairs’. She couldn’t hear me, I had a mask on. She kept asking me questions and I just kept nodding. By that point I was almost out of it. – Sharon Dever

> While I was in that room, most of the staff complained about the scooter. They said, ‘Who left it? Why is it here? Can you leave it in the hall?’ – Sharon Dever

> Being in an open space that is so cold and uninviting makes my mental health even worse. I already had problems and that was why I went in there but seeing and feeling the coldness and lack of warmth from staff completely broke me down even further. – Anonymous Person Three

Inaccessible formats, physical spaces and health care equipment may seem like very specific problems; however, these problems exist due to systemic barriers in health care. Although some of these barriers may seem small or even insignificant to someone who does not experience them personally; they significantly affect a person’s independence, their agency, and add to the already inequitable cognitive and physical load experienced. In order to move towards greater inclusivity in health care, we must apply an inclusive design approach to identify and resolve these barriers.

Barriers to Care

These stories illustrate how the design and organization of systems creates barriers to access. The stories demonstrate the difficulties in access to public services that arise due to limited resources, closed services and inadequate care. Barriers that were introduced during the Covid-19 pandemic prevented and amplified how people might access care.

> During Covid-19 is when I started to experience mental health problems and found it extremely difficult to get immediate help. Numerous times I tried to find in-person help with a therapist and was not able to because of the Covid restrictions. When a phone call was scheduled instead, the doctor fell behind schedule and never did call me. – Anonymous Person Two
>
> I think that the long wait times, and the fact that most doctors were not even open to seeing new patients was very discouraging. This made me feel hopeless and not important. Health care was very hard to access, especially mental health care during Covid 19. Perhaps if it was more accessible, I would have not let it get as bad as it did. – Anonymous Person Two
>
> Finding a family doctor was especially hard during Covid. They [the hospital doctor] gave me a website to find a doctor and because of Covid I kept calling offices, and no one was answering the phones. For you to find a doctor at this time is near impossible. – Stacey McLean
>
> I've been waiting to see a specialist for five months, and I'm in excruciating pain. My doctor won't do anything for me until I see the specialist. She won't even start me on physio because that may make things worse. Also, because I haven't seen the spine specialist, I was not approved for CPP-disability which impacts me financially because I can't work right now. I can't even sleep at night. I sleep maybe two hours per night because of the pain I'm in. – Stacey McLean
>
> I can't get access to safe health care anymore, as a medically exempt unvaccinated person with additional factors that make me more at risk from the virus. The government removed many of the COVID protocols from walk-

> in clinics, during the “re-opening phase” and refused to provide me with accommodation, despite provisions under the Human Rights Code. For example, they now do lung exams on symptomatic people just before people at risk from the virus come in the same exam room. Symptomatic people were sent to other locations in 2020 for safety reasons, but they started bringing them in again in August 2021, because they said most people were vaccinated and therefore didn’t need protection from exposure in health environments. I had an infection in my foot and the virtual walk-in doctor told me to come in – but then said maybe it wasn’t actually safe for me to come. So, I had to sort out my infection on my own. – Anonymous Person One
>
> “Some persons with disabilities may need extra time for observation during vaccination, as well as extended recovery and convalescence afterwards. However, no extra supports were provided by the government. What if they need a month of sick leave from their employment or mental health or child supports while they recover? If the government doesn't want to supply this kind of support, should they have developed such a heavy-handed policy pressuring people to get vaccinated?” – Cybèle Sack
>
> If you have a driver's licence – which you can imagine, I don’t – you can renew your health card online. So, since I don’t, I had to go out during the height of Omicron ’cause it was in December that I did this. – John Rae, Blind Rights Activist

Systemic Harm and Neglect

The extracts from stories presented in this section shed light on the theme of ‘Systemic Harm and Neglect’. The stories demonstrate the difficulties in access to public services that arise due to limited resources, closures and inadequate care. In addition, the stories emphasize how neglect, misdiagnoses and limited attention within medical care can result in systemic harm.

I was misdiagnosed three times, and by the time I was correctly diagnosed, it was October 2021. I went into the hospital, and I couldn't walk. It was determined that I had three compression fractures and a chip in my disk. – Stacey McLean

During the pandemic, I felt that many health care workers were not as passionate about helping you as they once were. (This could be as they too have been affected by the pandemic.) I feel that once you get in to see someone the appointment is literally two minutes and then you are passed off to figure things out on your own. – Anonymous Person Two

They had given me a temporary prosthetic. When the swelling went down, I stuffed it with socks. I was ready in March and had monthly follow-up visits. The swelling went down, and I was ready for a more permanent prosthetic. They closed ADP in March and so I had to wait until ADP was open again so I could get my prosthetic. So that left me with a temporary prosthetic until, I think, June. I think this left other disabled people in a worse situation. I remember reading about a woman who needed a wheelchair, just to even go to the toilet. Talk about independence. – Patricia Smiley

With walk-ins, when you're walking in with something. You know there is something going on. Maybe they should listen a little. For me to go in four times, after the first two, the other times I said, 'You've already done an x-ray on my leg, there is something else causing this pain'. Basically, they just pushed me off: 'Ok, we did the x-ray on your leg again, ok, bye-bye'. – Stacey McLean

I had many times over the last two years where I needed to see someone urgently. But they [the healthcare system] make it so hard for you to see someone. I tried to check myself into the hospital last year but they sent me home. They thought I was ok even though I knew I wasn't. I guess they couldn't handle the amount of people that needed help. But can you imagine having something get so bad that you ask for help but they don't even acknowledge your needs. – Anonymous Person Three

I don't know who a nurse is, whether they are a Personal Support Worker, or a member of the public. Nobody is wearing a uniform. I'm told there are name tags. Very unnerving sometimes. Imagine that you're vision and hearing impaired and these people are not wearing anything specific. I felt scared and knew my gallbladder was in real trouble and I knew they had to

> do something. Each person was wearing a double gown and a yellow gown on top. That gown was probably covering their nametag on their shirt. I assume that everything gets covered up. You don't know why they are there. – Sharon Dever

Ableist and Attitudinal Barriers

The extracts from stories presented in this section shed light on the theme of 'Attitudinal Barriers'. These stories illustrate how stereotyping, stigma, and discrimination impact access to health care.

> Oh, attitudinal barriers? Some vaccinated people are not knowledgeable about science and took the vaccine only to "return to normal". An immunocompromised friend was told, "It's not my problem if I make someone sick, I've done my part by getting vaccinated and it's survival of the fittest. "I also heard a few people say things about medically exempt people, including "Is their disability legitimate or are they faking it?" What is a legitimate disability? Are other disabilities bastards? This rhetoric is being constructed by the government and amplified by the press, without skepticism." – Anonymous Person One

> I was barely sitting up in the hospital, and luckily my boyfriend came. They wanted me to talk about my symptoms. They said to him, 'No, you can't share. We have to hear it from her'. He started to stand up, and they said, 'No if you don't sit down, we will call security'. So, he left. I'm then left there alone. There were a couple of nurses standing there at the computer. I had brought in a paper pre-printed with my medications. And they said, 'No, you tell me'. And I said, 'No, it's on the card'. – Sharon Dever

> I had a fall in the kitchen one night and I broke my femur in one leg (amputated leg). I ended in rehab in Hamilton and it was a bad experience with the PTs and Ots there. It seemed to me that neither the physio or OT understood what it meant to wear a prosthetic – and it was almost as though they disliked the fact I wanted to be independent. I made a comment about playing basketball with wheelchair advocates and the PT found this terrifying. – Patricia Smiley

> As an unvaccinated medically exempt person, I feel like I'm constantly at risk of discrimination, as I'm medically exempt and unvaccinated, given the ongoing rhetoric of politicians and the media, who suggest all unvaccinated people should just get the shot and that we don't deserve life-saving health care and should be triaged out of hospitals and ICU if we get COVID. When you read this all the time, it makes you feel unsafe going to the hospital even if you need it, in case the staff are mean about it when I need them. I'm also worried that they'll give me Covid from their not following protocols and then blame me for catching it because I'm unvaccinated. – Anonymous Person One

> In trying to park the scooter and transfer to the stretcher, that's where some of the problems begin. These are not suites, they are shoe boxes. I go in with the idea of the best place to park, the safest area, kinda thing. The first thing they say is, 'How do you do that at home?' I must have heard that about 50 times. 'How do you manage that at home?' – Sharon Dever

> The correct term is legally blind, and it's when you have lost 90% of vision. The general public doesn't know it or understand it. As soon as they mention it they start to question you. 'How do you drive that thing?' 'How do you manage at home alone?' 'How did you get here?' 'How do you go to the bathroom?' – Sharon Dever

> 'It made me feel small, insignificant, [like a] second or third class citizen. 'Are you sure there is no one to help you?' You don't have to ask me three times. It's like I have no credibility'. – Sharon Dever

These barriers are particularly dangerous, especially given that the core role of many health care professions is to support people with achieving greater independence in their lives. In particular, the profession of occupational therapy is an important role in supporting their patients to gain greater independence in their activities of daily living. Occupational therapists should work closely with their patients to understand how personal and environmental factors impact their patients lives, and support their patients with living in accordance to their personal definition of independence (Bonikowsky et al., 2012). It is concerning that from the stories collected, that attitudes in health care significantly impact the care a patient receives.

Recommendations from Storytelling

Through the stories, many themes, barriers, and recommendations became apparent. Included below are some of the salient recommendations regarding actionable concepts to improve the medical system.

> No public health policy should ever be designed without co-design with communities of persons with disabilities. The government told the public to take various measures and even sacrifice lifestyle to protect persons with disabilities (including immunocompromised people and seniors) but haven't been working directly with communities to plan their response. – Cybèle Sack
>
> Make sure there is a segment in the training for doctors, nurses, nurse practitioners and other professionals with an opportunity to meet real life advocates as guest presenters. – John Rae, blind rights activist
>
> As far as the medical system, I honestly feel that there should have been more people in healthcare that are designated to deal with the pandemic, and others that are designated to deal with other critical illnesses as well. People are getting really sick; some people are waiting in pain. People are dying because they're not getting the proper treatment they need. – Stacey McLean
>
> People with disabilities should not be used as poster children for government policy that harms us. Vulnerable people with disabilities – including people who are unvaccinated for medical reasons – don't fit the government narrative. – Anonymous Person One
>
> Sending a patient their discharge plan electronically. – John Rae, blind rights activist

> As far as CPP, I wish they could give me more help since I've been denied. I told the adjudicator that it's not my fault I haven't seen the specialist yet. All I can do is wait. – Stacey McLean

About the Co-design Sessions and Co-designers

The group co-designers consisted of four individuals with lived experience of disability and health care exclusion. Their profiles are below:

John Rae [1]

John Rae was totally blind, and a long-time disability rights and broader human rights activist, who joined his first co-creation project to promote positive change and greater accessibility throughout the health care sector for persons with various disabilities. The greatest need, as in most other aspects of life, is greater involvement of disabled consumers throughout the entire process, from the training of medical practitioners, to how individuals are dealt with when in a doctor's office or hospital, to the discharge process and plan, where providing needed information in formats other than just a printed page would be really helpful to a blind person.

Patricia Smiley

I have been on the Ontario Disability Support Program (ODSP) since 2009 (after a 2 year wait!) originally for a serious mental health issue. I added a physical disability in 2019 when my right leg (below knee) was amputated. While bouncing around from one survival job to another, and going on and off Ontario Works (OW), I was actively involved in housing advocacy. To add to a considerable formal education in political science and legal studies, I was able to take advantage of every free opportunity for professional development in advocacy and community development. Since being accepted to ODSP I have become actively involved in the ODSP Action Coalition. For the past 10 years I have been the recipient co-chair of the Policy and Research Committee and sit on the Steering Committee. I also belong to Defend Disability.

I moved to Hamilton after being renovicted from my apartment in Toronto. I had lived in the neighbourhood for 15 years, 12 of them in that building. My daughter and her partner bought a little house for me and I pay an affordable rent. One of the things I really like about my new city is that it seems most Hamiltonians can wait for me to get across the street with my walker, will help me pick up stuff I drop – whether in a store or on the street, give disabled people access to the marked disabled seats on buses and are willing to wait while they get themselves and their mobility devices strapped in.

Sharon M. Dever

I chose to become involved in this study for personal & professional reasons. As a person with a congenital disability, every aspect of life has been impacted, most recently with medical services.

I chose to participate because accessing medical intervention and care, throughout emergency triage, care and surgery was more complicated due to disability logistics at a Toronto hospital.

The biggest change I would like to see in healthcare focuses on disability awareness and training as part of their practical experience. Including individuals with disabilities as part of a diverse, hands-on, functional experience prior to becoming a patient would streamline / civilize a traumatizing encounter.

On a personal note, most contact with the system has been negatively magnified by the healthcare ‘professional’ stigmas about disability being the illness. As a self advocate, I've encouraged medical practitioners to include detailed file notes, regarding the disability, as many levels of staff will be reviewing the file.

Cybèle Sack

Cybèle is a consultant, researcher, writer, and editor with a focus on social innovation, inclusive design, and accessibility. She is invited to speak as an expert about structural barriers faced by people with disabilities and envision spaces of greater belonging. Cybèle works collaboratively to support equity-based system transformation, including efforts to dismantle ableism in post-secondary education and healthcare. She is an award-winning social advocate and led a coalition to call for access to information about systemic failures and patient safety in Ontario hospitals. Cybèle contributed to the development of international digital accessibility standards and research on the social impacts of smart technology. Her work has been published in a textbook, journal articles, conference presentations and in the press.

Co-designing the Co-design Approach

The first co-design session was held on 4 March 2022, for one hour, during which the co-designers came together to meet each other and discuss the challenge. The purpose of the first session was to plan a co-design approach to determine how the group can develop recommendations to improve healthcare information and services for people who experience barriers to accessing health care.

To start off the session, each of the four co-designers introduced themselves, and shared why they were interested in this work. There was a great deal of alignment in desires to improve the healthcare system.

The next priority was to discuss what safe and inclusive involvement looks like for the co-designers. Co-designers were asked to discuss and build a set of group norms to guide the work over the coming sessions. The group norms are as below:

Safeguarding Information and Privacy – Agreement / Group Norms

- There will be no newcomers to the group
- We will respect one another and the input in this process
- We will respect each other's experience
- We will actively listen to all the participants
- We will have sensitivity for each other's health information
- We will hold the weight of each other's health experiences
- We understand there is wisdom from our experience that deserves care
- We will take care when responding to those of different experiences
- We will not invalidate others' lived experiences
- We will exemplify the best of disability culture
- We will hold compassion

Once the group determined and accepted the ground rules, the group discussed different approaches and activities that could be used to develop recommendations that healthcare institutions and service providers can use to create more accessible services.

Discussion on Activities and Opportunities for the Co-design

The group then took the rest of the session to discuss different approaches and tools. There was a difference in preferences for digital tools. Certain co-designers preferred to use digital collaboration tools, where other co-designers preferred note taking and sharing through email after the sessions.

It was agreed that a mixed approach would be used, whereby specific collaboration tools would be used for certain co-designers with specific preferences for these, and alternative tools, such as email, would be used for others.

It was determined that more time would be needed to discuss which activities should be used for the co-design sessions. The co-designers determined that the following approaches should be considered:

Live Mode

Co-designers agreed that the sessions would mostly be in live format, where discussions would occur, and the facilitator would take the work produced away, and pull it together. There was preference for the co-design process to take place collaboratively and through group discussion.

Journey Mapping

There was discussion around considering a journey over time approach to consider how health care and barriers have shifted. Possible activities that would support this, including journey mapping, were considered. There was some interest, and confusion with this approach regarding how it might be used.

Clustering and Prioritizing Themes

There was interest in developing activities that would support co-designers in clustering and prioritizing themes.

Special Focus

The group shared interest in focusing on mental health during the pandemic and how people have been neglected.

Storytelling

Co-designers also shared that storytelling may be effective, as the more that the group works together and gets to know each other’s circumstance and experience, the better it will be for others’ understanding. The group wished to get to know stories, so they can understand where there may be intersecting parts of their experience.

Co-design Session Two

Session Plan

The second co-design session was held on 11 March 2022 and took place over the course of two hours. The agenda for the session included spending the first hour defining the activities and outputs of the co-designers considered to be impactful to them, and the second hour involved continuing the discussion or beginning the first activity.

Session Mode

The group was lively and engaged in the task. While the session was held, a shared document was projected through screen share for the co-designers to follow. One of the co-designers was interested in actively editing and placing comments within the shared document during the session.

Discussion

Co-designers expressed that the group should consider looking at the past two years within the context of the pandemic but also include information regarding problems that occurred before. This was recommended because what can be learned might still be relevant for the future. Each co-designer was asked to share information on what research outputs they were interested in and how we might achieve that output as a collective group. The interests of each co-designer are described below.

Co-designer One

- Interested in refining research to one to two selected areas that have been agreed upon by the group, and dive in more deeply to those focused areas
- Interested in considering how we might balance the needs of certain disabilities as opposed to others

Co-designer Two

- Interested in taking a storytelling approach to developing a set of policy and legislative recommendation documents
- Notes that involving persons with disabilities is a very large theme

Co-designer Three

- Interested in creating a call to action about what needs to be addressed and why it is important to engage in this work
- Interested in identifying a method or process to develop themes, exercises, or practices. Interested in approaching the work differently, for example, bottom-up for producing a proposal
- Interested in storytelling and how collective storytelling might support development of key themes

Co-designer Four

- Interested in considering how consultations with persons with disabilities might support the work, while taking a policy lens

Co-designer Goal's of Participation

As the session progressed, discussions continued to veer into personal stories and experiences of exclusions. A recommendation from one of the co-designers was to focus the conversation on the specific goals of the co-designers through participation. Goals were discussed as a group one by one and through this discussion many themes arose. Interestingly enough, through the discussion, co-designers focused mostly on themes instead of goals. The co-designer who was active within the document highlighted many of the themes as they were noted down. The goals have been condensed below, with themes following.

Goals

- To help produce a final report
- Consider what insights from the last few years can support the healthcare system to better prepare for future emergencies
- Initiate a proposal for a big change

Themes

The themes below have been ordered by priority. Priority themes were determined through co-designer support for the idea.

High Priority

- Consult with persons with disabilities

- Unaddressed mental health needs experienced by persons with disabilities
- Attitudinal barriers within the healthcare system
- Training and disability sensitivity
- People with hidden disabilities and their experiences
- Impact of Covid-19 on the healthcare system

Secondary Themes

- Denial and lack of access to safe care
- Use of technology and algorithms to exclude persons with disabilities
- Negligence in long-term care homes
- Barriers introduced by the Ontario Disability Support Program (ODSP)
- Political advocacy

Discussion on Approach for the Third Co-design Session

After much discussion, it was evident that there were some very prominent and emergent themes that the whole group was interested in working on. The themes that came up most frequently were the impacts of Covid-19 on access to healthcare, and nothing about us without us in healthcare.

For the third co-design session the group was interested in starting work on these two themes. A co-designer recommended that structured and time-boxed design activities might be helpful for the group to think in different ways. It was agreed upon by the group that the agenda for the third co-design session would include activity options that the group could choose from and/or adapt to their needs. Multiple activity options would be prepared for the co-designers to participate in during the third session.

Preparing the Co-design Activities

Co-designers requested that design activities be prepared in advance for them to choose from during the session. Three activities were prepared, and some broad discussion questions were included.

Design Exercise Option One

In this exercise, co-designers would talk about an artefact or experience being re-designed. The exercise is simple: any part of the health care experience could be selected, whether it is a physical object, a process, or a service touchpoint. Then the group would imagine how it could be made more respectful and inclusive. The exercise allows the group to think about how the barriers impacted their lives, and how they might see a future where the barrier has been removed.

Design Exercise Option Two

In this exercise, co-designers would discuss their own experience or another person who they know who experienced barriers, during different stages of the Covid-19 pandemic. Some of the options to focus on included:

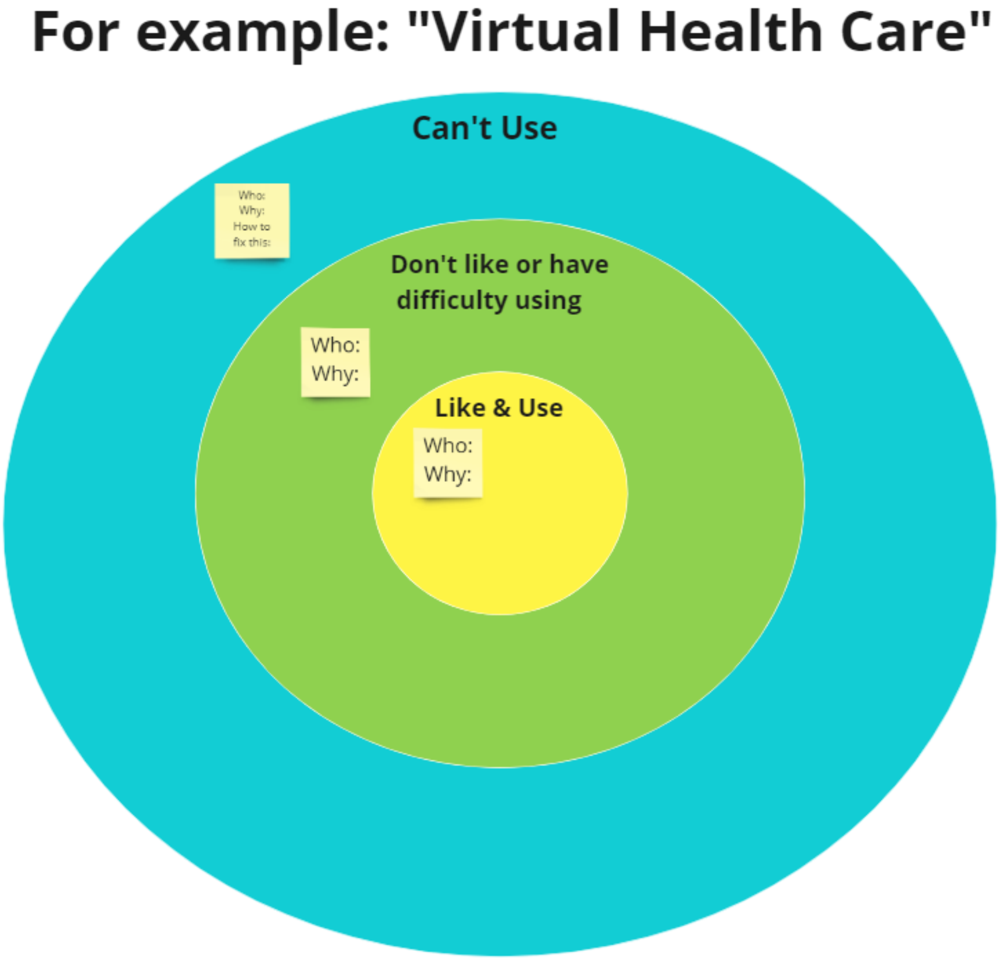
- Covid-19 First Started (Lock-down, social distancing, panic, media)

- Re-opening (transitions)

Design Exercise Option 3: Virtuous Tornado

The third option used the inclusive design research centre’s virtuous tornado as inspiration for the exercise (Treviranus, 2019). A digital whiteboard was prepared to show three circles, one in the centre middle, another circle behind and a final circle at the outer rim. Co-designers would be asked to focus on a specific healthcare issue (for example digital health) and work together to discuss barriers and opportunities for inclusion. In the centre circle, co-designers would focus on those users that like and use ‘digital health’. In the circle just outside of the centre, co-designers would focus on those users who do not like or have difficulty using digital health. In the outer rim, circle co-designers would focus on those users who cannot use digital health.

Figure 1 Virtuous Tornado Activity Example



Co-design Session Three

Co-design session three only had three participants due to the fourth co-designer addressing a health issue. The beginning of the session focused on discussing the design activities the group would be interested in choosing. During the walk-through of the first option, discussion immediately broke out in relation to barriers that co-designers wished to discuss.

Co-designers chose design exercise number one where co-designers discussed an artefact or experience being re-designed. There was interest in beginning this discussion by talking about the discharge and follow-up experience. It became apparent that barriers discussed during the co-design session may not all be a result of Covid-19. Instead, many barriers that were shared were pre-existing barriers that have continued to occur during the pandemic.

Medical Professional Interactions with Patients

Topic: Receiving Discharge and Medication Information

Barriers

- There is a notable difference in quality of the discharge experience across different regions in Ontario.
- Often health care workers did not consider the proximity or the familiarity of a clinic when choosing a follow-up location for the patient.
- Some rehabilitative health care professionals, such as physiotherapists and occupational therapists do not share enough information with their patients on how and where to acquire specific assistive devices and equipment. Rehab professionals should support their patients with more information, including how to navigate social systems, how much the recommended device and equipment costs, and how their patient might acquire the equipment through social service supports such as the Ontario Disability Support Program (ODSP) or Assistive Devices Program (ADP).

- Discharge process issues are often magnified by disability and as a result the paperwork tends to not meet the patient’s specific needs. Many health care professionals do not spend enough time considering the complexities of a patient’s medical situation.
- Health care professionals often will not provide accommodations for patients who require large print or other formats. Alternate formats are not included as part of the discharge plan, preventing some patients from independently accessing important medical information.

The barriers identified in this section by co-designers all existed prior to the pandemic and continue to be a concern.

Recommendations for Improved Discharge and Follow-up

- Patient information must be private and confidential. Take extra care to consider patient privacy in busy environments.
- Ensure discharge information is provided in alternate formats, including large print, electronic, or other formats that are accessible for persons with disabilities.
- Consider a patient’s specific communication needs. Write things down while explaining things for people who are deaf or hard of hearing, people who are anxious or who experience memory issues.
- Leverage alternate communication tools to support individuals with diverse communication needs (e.g., tablet).
- Support patients with their digital accessibility needs, including providing digital access to a patient’s medical records and other important information online (e.g., digital chart system and or access to prompt

copies of records). This is especially important for patients with visual, cognitive or memory related disabilities.

- Provide additional support to patients who wish to better understand their health. Offer the option to have someone explain important information about what is going on with their health.
- Provide additional support for patient's post-discharge. Offer various follow-up options for patients after they have left the hospital.
- Provide one consistent point of contact for discharge patients to reduce complexity and allow patients to access timely support if needed.

Health Care Professional Checking in on Patient's in a Hospital Setting

Co-designers discussed barriers that arose when health care professionals checked in on their patients in a hospital setting. The barriers described are from a range of health care professionals and focus on the service aspect.

Barriers

- Health care professionals do not always introduce themselves when they come into the room, making their presence concerning and sometimes confusing for a patient.
- There is difficulty getting sufficient explanation from health care professionals when a patient inquires in regard to their health.
- Health care professionals may act as though the patient is not participating in their own care.
- While under their care, health care professionals may not want or allow their patients to be independent or manage things the way they have done them in the past.

- Some health care professionals may treat their patients with limited credibility and trust.
- There is limited knowledge amongst health care professionals regarding how to approach certain medical situations for a person with a disability.
- Health care professionals have limited time available per patient, and as a result of this patients are frequently dismissed, ‘I’m busy charting’. Health care professionals should consider that some patients with complex medical needs may require more time and support.

Recommendations for Inclusion in Hospital Settings

- Co-designers shared that the medical community may be reluctant or nervous to ask patients questions about their disabilities. Due to this, in some instances there may be assumptions made by medical professionals about what is best for their patient. Medical professionals should not hesitate to ask their patients for more information about their medical history or disability when they do not know the answer. “It is fine to not know all of the answers.” This is turn would provide a more well-rounded and holistic approach to patient care.
- Allow patients to be more involved in their care by encouraging them to ask questions and collaborate in the development of their treatment plans. Personalized approaches better account for individuality and a patient’s unique needs. This could motivate a patient to be more proactive with their treatment and potentially improve treatment results.

Emerging Barriers as a Result of Covid-19

As a result of the Covid-19 pandemic, there are new barriers that have been introduced impacting a person’s access to health care. Prior to the pandemic, there were limited efforts to be inclusive and use participatory research methods with diverse persons. Given this new health care challenge, the lack of inclusive practices intensified health care disparities for equity seeking groups.

Covid 19 Test Kit

Barriers

People with visual disabilities have difficulty or cannot use the Covid-19 at home test kits due to barriers that the tests introduce. Test kit results do not emit any sound or provide any tactical indicators as to the result. This creates difficulty for those who may have less vision, as the test results may not be legible without support.

Test kit instructions are complicated and not designed for plain language, making them difficult to understand. This can create barriers for those with many types of disabilities, from those with vision needs to those with cognitive needs, as well as for those with intersectional needs, such as language barriers.

The size of the tools within the kit creates additional difficulty for individuals with limited dexterity in their hands to administer independently. This impacts people with many different types of disabilities, from arthritis and Parkinson’s, and cognitive disabilities, including learning disabilities.

Recommendations

- Design and build new technologies and medical tools with people with disabilities
- Consider a wider range of disabilities that may be impacted (and not only a few)
- Consider the sensory experience of the technology and tools (visuals, sounds, tactile, odour, etc.)
- Consider risk mitigation for those with auto-immune and chemical sensitivities, as well as others who may be sensitive to ingredients
- Use large print, plain language, and audio cues to support multiple needs over a range of ages and experiences
- Governments must consider people with disabilities as technologies and tools are procured and released to the public

Nothing Without Us Discussion

A key focus for the third co-design session was to discuss what Nothing Without Us looks like in practice. The session was structured as an open discussion in alignment with the co-designers’ preference for the research approach. To add structure to the session, co-designers were asked three questions, with many opportunities to explore other pertinent areas they felt were important. The discussion questions were:

1. What are some problems that arise from a lack of inclusion?
2. Which areas in health care require greater inclusion?
3. How can healthcare professionals live the ‘nothing without us’ principle? Provide some examples of how this can be applied.

Problems That Arise from a Lack of Inclusion

The co-designers discussed how problems might surface from a lack of inclusion. Research methods that are considered traditional or well established have always disadvantaged individuals at the margins, by eliminating them from research processes or discounting their experiences in data sets where they might be considered outliers or “noise” (Treviranus, 2014). These systematic exclusions in research means that these individuals’ needs may never be considered.

- In the development of public policy, there is limited representation in policy making positions and policies that are developed do not represent the interests and needs of a diverse population.
- There is insufficient training for healthcare professionals in understanding the needs and preferences of persons with disabilities. In medical school and other training programs for allied health care professionals, there is limited exposure to persons with lived experience of disability. Specific recommendations include providing a disability segment in medical training and inviting paid guest speakers with lived experience to share their knowledge.
- People with disabilities are excluded at every stage of the healthcare design process. There must be representation in consultations, and

engagements throughout the design process. This will impact design decisions and results significantly.

What Does Meaningful Engagement Look Like?

Within the discussion, there were many negative comments and a sense of mistrust with engagement and participation in formal research initiatives. A co-designer shared that they had a permanent negative perception of research initiatives due to their transactional nature and poor track record of implementation. I've defined 'transactional research' as researcher-driven initiatives limited in both depth and engagement with participants. Given the sensitivity of this topic, co-designers were asked to elaborate more on what constitutes meaningful engagement and consultations. The following perceptions were shared:

Listening

- The ability for the research team to truly listen and try to understand personal and individual impacts
- Treating the consultation and its impacts as a serious matter
- Seriously considering and respecting participants' input and lived experience.
- Hold trust for sensitive information and stories
- Do not tokenize people with disabilities. Include people fully.

Inclusive Processes

- Including thoughtful, relevant questions, and focus areas
- The atmosphere and environment in consultations is important. Ensure that the presenter or facilitator is an inclusive speaker
- If recommendations are not viable or possible, inform consultation participants exactly why
- Post-consultation, maintain contact and always inform participants about actions taken with their input provided.

Research in Action

- Share the engagement findings and inputs with administrators or people in positions of power
- Strive to implement or consider all input
- Participants want meaningful engagement, not the ‘Here’s your honorarium, we did our do diligence, goodbye’
- If nothing was done with the recommendations or feedback, it is indicative that the process was not inclusive

Areas in Healthcare That Require Greater Inclusion

Co-designers were asked to reflect on specific areas within the health care setting that require greater inclusion. They shared the following:

There are many physical barriers in walk-in clinics, emergency rooms, and in hospitals. Additionally, many of the healthcare spaces are compressed to maximize the space; however, this creates more barriers and complexity with movement. Co-designers shared that it is difficult for persons with mobility disabilities to move around efficiently and safely.

How Health Care Professionals Can Live ‘Nothing Without Us’

The Nothing Without Us principle highlights the need for community participation, and inclusion of the disability community in all aspects of decision making. The Nothing About Us Without Us movement has been adopted by many “disability rights advocacy groups to communicate that individuals with disabilities should be at the forefront of any decision or policy-making that affects their lives” (Franits, 2005, para. 1). This is especially important in the healthcare setting and healthcare professionals have an important and unique role in considering and ensuring inclusion and participatory methods with patient involvement.

Co-designers recommended that in places with physical barriers, healthcare professionals should:

- Ask patients for what they need to move and be comfortable in the space. Support patients with any needed adjustments in the space for their comfort.
- When planning for a public infrastructure, include people with disabilities in design consultations. Designing for a wider and more diverse range of people will help everyone in accessing an inclusive and safe place. Consider the curb cut effect where designing for greater inclusion by introducing curb

cuts in a street benefitted not only persons in wheelchairs, but everyone (Blackwell, 2016).

- Ensure that there is a hospital administration committee with representation of people with disabilities involved in the design of a public space

Co-Design Session Four

The goal for co-design session four was to focus on attitudinal barriers and how co-designers propose that they might be addressed in the health care setting. This was an important topic of interest, as attitudinal barriers arose as a significant theme during the initial co-design planning sessions, and through the individual stories. To align with the interest in co-designing solutions using discussion-based methods, co-designers were asked to discuss and consider the following:

- attitudinal barriers they have encountered in medical settings
- why they think those attitudinal barriers occurred
- root causes of those barriers
- how to fix the barriers

Co-designers were also asked to reflect on the process of co-design as a research method, their thoughts about the co-design process and how they think that co-design could be used within health care research.

Attitudinal Barriers

The following barriers came up through group discussion.

1. An inherent and problematic issue is that medical practitioners have traditionally been taught to cure the sick. With this way of thinking there is a disconnect between medical professionals and some members of the disability community. Medical professionals commonly see a person with a disability as sick with the need to be cured by the medical community. Although a person with a disability may get sick and need help with getting better, they may not wish to be cured of their disability, as it is part of their identity and for many other reasons. 'We are happy and proud of ourselves as we are'. This is true of the medical model of disability where "a person's functional limitations (impairments) are the root cause of any disadvantages experienced and these disadvantages can therefore only be rectified by treatment or cure" (Crow, 1996, p. 3). The opposing argument known as the social model of disability argues people with disabilities are not disabled by their impairments but instead by the disabling barriers in society (Oliver, 2013). It is notable to share that some non-disabled people may presume that people with disabilities' impairments and assumed effects are negative, which in fact may be experienced quite differently by people with disabilities. Listening and engaging openly with the testimony of people with disabilities is important (Goering, 2015). Through open dialogue, patients may share their experience of barriers which may be unrelated to their functional

impairments, and instead are based on barriers that exist in society preventing full participation due to exclusive practices.

2. How people are treated varies depending on how they look, their disability, and who they may be accompanied by. “Health providers favour certain classes of people who are already well supported by caregivers, who have more money and education, and who "look pretty" (by their version of normative standards, and often in racist as well as ableist ways). This causes deep harms to those who aren't on the protected list.”

3. There may be special interest in the person with a disability by medical practitioners, unrelated to the reason they are seeking treatment. A co-designer shared their experience in the hospital where they experienced interest and curiosity about their disabilities, despite seeking treatment for a different, and very pressing medical issue. ‘“Oh, look at your eyes. You have nystagmus, I haven’t seen this before. I’m going to call in other doctors to show them this”. All while sitting in the emergency room with a broken arm’.

4. Attitudinal barriers perpetuate stereotypes, even within the medical profession. Rehabilitation professionals have created barriers to patient independence by recommending mobility aids inappropriate for their patient’s recovery. “My Physiotherapist recommended a wheelchair to get around my community, instead of helping me get comfortable and better learn how to wear my prosthetic.” This highlights the importance of deeply listening to the

patient and letting the patient share what their values and goals are for their recovery and independence.

“Why Do You Think These Barriers Occur? What Are the Root Causes?”

Co-designers shared why they think these barriers are occurring within the healthcare space, and what the root causes are with these barriers.

1. The lives of people with disabilities are not equally valued
2. There is limited educational training on disability
3. When training for professions, in the medical field or others, students have few persons with disabilities as their peers
4. There is stigma associated with disabilities “from the dark ages”
5. People working in health care are overloaded, and unable to support individual preferences and needs at a greater scale
6. It takes time, experience, and exposure to change attitudes
7. Many disabled people are on ODSP, and there are attitudinal barriers associated with people on social assistance. There are assumptions that people on social assistance do not deserve financial assistance.
8. There are significant attitudinal barriers for people with mental health disabilities because they don’t look disabled
9. People at every level in the medical system have not recognized that they have these ingrained attitudes and perceptions, and they are imposing these attitudes on patients, and patients are internalizing them

“How Can We Fix These Barriers?”

Co-designers shared opportunities for barriers to be resolved in the health care setting:

1. Providing greater exposure and the opportunity to meet people with lived experience of disability during medical training. Creating opportunities for medical professionals to ask questions that support them in their training and understanding of disability. To be truly good advocates, “people with disabilities must be willing to answer questions about ourselves and how we cope with our disabilities in our daily life”.
2. Greater representation of persons with disabilities in decision-making positions within the health care system
3. Health organizations focusing more on education and training initiatives instead of “pity-filled fundraising”
4. More educational opportunities and training on disability theories and their impact on communities within health profession training programs
5. Opportunities and barrier removal to increase representation of students with disabilities in medical training programs
6. Creating opportunities for greater representation of persons with disabilities as students, decision makers and peers will support needed attitudinal change to and likely more inclusive practices in the future. This is especially true for persons with physical disabilities in health care.

Reflecting on the Co-designers Experience

Co-designers were asked to reflect on the process of co-design as a research methodology and their experience with the research. Notably, most of the co-designers did not have previous experience with this type of research format.

> ‘In this case, those that have a stake in the outcome were very much involved and that is unusual’.
>
> ‘I liked the small group environment’.
>
> ‘The process worked’.
>
> ‘I didn’t understand the process at first, but I came to understand it. I wasn’t clear on our roles but became aware as time went on’.
>
> ‘I liked that my bio and information was going to be included. Sharing names and personal backgrounds are respectful and gives credibility’.
>
> ‘Very respectful process’.
>
> ‘Often there is too much time producing research, and it is collecting dust in libraries. We need to spend more time implementing recommendations, rather than just doing research’.

Opportunities to Use Co-design in Healthcare

Co-designers shared that there are opportunities to use the co-design methodology within a healthcare setting.

- There are fewer limitations when doing research in this manner
- There are greater opportunities to expand research out beyond defined mandates
- The co-design process tends to be more respectful

- The method provides voice to people who may not be heard otherwise
- Co-design research should focus on action and change

There has been strong community advocacy for change, however with little formal public engagement and involvement in policy responses to the pandemic (McGrail et al., 2022). The power of co-design as a research tool, is that it enables us to take a health equity approach to design when used well in practice. Additionally, co-design as a research tool in health care provides opportunity to influence health outcomes by not only having those in decision making positions set and design policy.

Reflecting on the Process

In retrospect, the design and intention of the process to follow the principles of ownership, respect and inclusivity were very important. It was evident that three of the four co-designers were very new to the process and unsure of how it might work in action.

Notably, three of the four co-designers were unsure about the process and the intent at the beginning of the research. The process of co-design and the opportunities to shape the design of the research were articulated during the first session. Despite this, there were many questions and points of clarification needed for co-designers to better understand their roles within the process. It became evident that spending more time on co-designer understanding of their roles and opportunities to shape the research outcome are very important. For future studies that use co-design as a method, more time, more opportunities to ask questions and a different approach to introducing the project may be helpful in co-designer understanding.

The research approach was designed for inclusivity, which allowed for relationships to be built or rebuilt among co-designers, as well as with myself, the co-design research facilitator. Due to the approach taken, there was a culture of respect, safety, and kindness in the space where everyone supported each other and their ideas. There was limited need for facilitator intervention during the sessions, other than to refocus co-designers on the task at hand and provide space for those not currently speaking to contribute.

The research outputs and stories shared amongst co-designers shone a light on the experience of four Ontario adults with disabilities. The co-designer group was composed of three older adults, and one middle aged adult. Greater time and focus on designing would help with alignment between co-designers and on the desired research outcome.

Adapting the Design of the Research

At many points within the research, I adapted my approach to try to remove barriers for participation.

When the fourth co-designer was unable to make the last two sessions, individual co-design sessions were held to enable the co-designer to provide their inputs. This allowed flexibility for the person who was not well, while still providing the group with the needed momentum to continue the work.

The process of co-designers designing the activities during the session was more complicated than anticipated. There was strong interest in holding low-tech discussions surrounding key topic areas. This itself still does present as co-design and follows the co-design process. However, there was some discomfort amongst a few of the co-designers with the opportunity to introduce research design activities that involve new software. There were varying degrees of discomfort with technology, and even using a videoconferencing tool was an adjustment and learning curve for a few of the co-designers. However, by the end of the sessions there was more comfort and ease with the videoconferencing tool.

There was a notable difference in expectations from the co-designers, and the initial assumptions of how I myself thought the sessions would work. A few of the co-designers also noted that the process was different than expected for them due to the openness and flexibility of the direction of the research. The openness and ability to change direction during the process led to some perceived uncertainty on the co-designers' part. During the sessions I received many questions from co-designers about what I would want from the research. I tried my best to respond consistently, noting that the purpose of the research was to share stories, share lived experiences, and come together to design something as a group. In my not prescribing directions for how the research would go, there was a bit of confusion and complexity added to the process.

Discussion of the Major Research Project Limitations

The research covers the experience of nine people in the province of Ontario, Canada. The research does not claim to cover or address the experience of all individuals within the province of Ontario.

Each of the co-designers and many of the story participants were located in southern Ontario, and therefore many of the findings represented here reflect the experience of a person in an urban environment. This has an impact on the findings, as within urban environments there are generally greater numbers of healthcare professionals, specialists and resources. Exploring the experience of rurally located people will likely result in very different experiences.

Additionally, none of the individuals who had contributed their stories and participated in the co-designs had recent lived experience of housing insecurity. This is notable, as healthcare barriers may increase for those with no fixed address and without identification. There were recruitment limitations given the state of Covid-19 at the time of the research. Recruitment occurred through email, and word of mouth limiting contact with those who may not be digitally connected. For the design sessions, co-designers could participate through video conferencing or by phone. The method of research creates barriers for individuals who may not be comfortable participating digitally or without access to a phone.

The research was conducted within a set time span to produce the final report, as required by the university's guidelines. Due to time constraints, the research process was condensed to ensure sufficient time for writing. The ability to conduct more sessions and spend more time with co-designers on designing the research process and their desired outputs would have been beneficial.

Many of the co-designers, if not all, would be considered disability advocates in their experience. In a way, this made the process easier, as the co-designers were very comfortable in talking about their experiences of barriers. However, because of this, there is an advocacy lens applied to the research findings, which may have produced different findings from individuals who have less experience as advocates for their positions. This could also be defined as strength in that co-designers had experience with considering their lived experience and applying it in context to societal issues and barriers faced by the disability community.

Contributions to the Field of Inclusive Design

This work contributes to the field of inclusive design by modelling an inclusive co-design approach. Throughout the process of the research project, the principles of ownership, flexibility and respect are paramount.

In recent literature reviews, it was found that including users and patients is still low and often at “tokenistic” levels (Ní Shé & Harrison, 2021). The research demonstrates that there are great opportunities to apply inclusive design principles to research that focuses on policy design and development work. This research-in-action project illustrates that design concepts have great applicability to a range of disciplines. Particularly, inclusive design principles and processes can be very powerful. This study shows that inclusive design principles can support building stronger connections to the community. Especially in a space as complex as disability, this study shows that research does not always need to be transactional or researcher driven.

The study shows that providing ownership and opportunities to change processes, design the research and design the outcome and final paper, the research reflects and supports not just the research co-designer/facilitator's bias or perspective. The outcome of the research is reflective of the experience of the whole group. This supports the premise that participants in research are not subjects but instead co-researchers.

Next Steps and Future Work

There are many opportunities to continue this research, following a similar approach. A next step would involve co-designing what future research would look like to build upon the stories and recommendations shared by the group. Inviting others with experience of barriers and exclusions in healthcare would be an important step. An important aspect of research relates to implementation, and there is interest from the group in thinking about how we might move beyond research to implement recommendations

Additionally, a key focus should be on translating results into easy to understand and actionable measures. Greater adoption would be benefitted by creating very easy to understand guidelines and recommendations for healthcare institutions and service providers. Following that, time should be spent sharing results with those in the healthcare field for greater visibility and understanding of the issues.

As noted by McGrail et al. (2022), “Societal issues are not forces of nature that cannot be altered, but instead result from the structures, institutions and policies that form our communities and our local and national identity.” (para, 1). By taking a closer look at the various harmful policies, structures, and institutions that form our society through the lens of lived experience is a powerful opportunity to highlight how we might re-shape and re-design the health care experience. Stories and lived experience in designing health care systems can emphasize a person’s additional risks for negative health outcomes through their connections and place within socioeconomic, political, and cultural hierarchies that exist where they live. The term “structural vulnerability” is the outcome of socioeconomic and demographic attributes, including gender, socioeconomic status, race/ethnicity, sexuality, citizenship status, institutional location in combination with status including health-related deservingness, normality, credibility, assumed intelligence, and imputed honesty (Bourgois et al., 2017). An important future aspect for continuation of research in this space, is to focus on inclusive recruitment where individuals with a diversity of structural vulnerabilities and diverse lived experiences can contribute their knowledge.

An interesting finding by one of the co-designers was that through the co-design sessions and stories, many of the barriers that were shared existed prior to the

Covid-19 pandemic. Additionally, it became evident that Covid amplified some existing systemic problems, and unfortunately introduced new barriers. It may be helpful to consider further developing an understanding of how the Covid-19 pandemic impacted these barriers, through a categorization exercise. It was recommended to consider which policies and programs that were introduced during the pandemic that may place people with disabilities at greater risk of contracting Covid-19. Salient examples include the triage policy and the vaccination passport. Next steps should include co-design work with people who may have been directly impacted by these policies and programs.

Leveraging other research in the field to build upon and design consolidated guidelines and resources would be helpful. The opportunity to co-design together with persons with lived experience of health care exclusions, and healthcare professionals with experience of delivering service, might support more robust outcomes.

Final Word

It is all too apparent that there are massive and widespread barriers that people with disabilities encounter when accessing and receiving health care. As shared through the stories and co-design sessions, these barriers to access prevent the full participation of people with disabilities and can place individuals at greater risk of negative health outcomes. Prominent barriers that emerged through this research included exclusionary policies, programs and services that prevent or exclude persons with disabilities from accessing and receiving equitable treatment. I hope this research serves as an important reminder that it is vital as we move forward and design a more inclusive health care system that people with disabilities are included as equal partners in designing our collective future.

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[1] John Rae sadly passed away during the period between the writing and submission of this study.