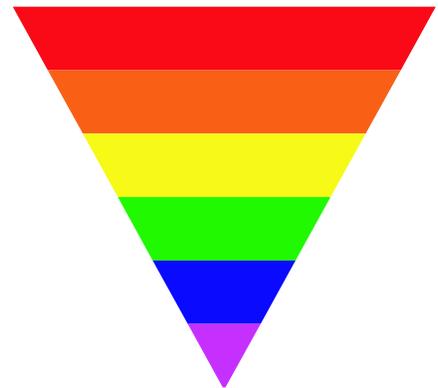


# **YOU LOOK GREAT!**

**LESBIAN, BISEXUAL, QUEER WOMEN  
AND TRANS PEOPLE  
LIVING WITH  
INVISIBLE CHRONIC ILLNESSES AND/OR CONDITIONS**



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**Canada**

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# About the researcher

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# A word about language

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This report is based on a survey. The advertising for the survey requested participants who lived with “invisible chronic illnesses”. The goal was to gather information regarding the challenges faced by lesbian, bisexual and queer women, and transgendered and transsexual people who live with physical invisible chronic illnesses and/or conditions.

Some of the participants took issue with the word “illness” to describe what their bodies are going through. They prefer the word “condition” as a more accurate depiction of what their bodies experience on a regular basis. Based on this feedback, I decided to use both words in this report. Anywhere you see the letters CIC, this means “chronic illness/condition” or its plural “chronic illnesses/conditions”.

One participant took issue with the word “invisible” and how it contributes to an ableist narrative. As I reflected on this feedback, I also realized that “invisible” did not accurately and fully represent the experiences of the participants. Many participants expressed their frustration at the *unwillingness* of their partners, family, friends, co-workers, bosses, class-mates, health care workers, and the community at large to acknowledge the challenges they faced on a regular basis even after being explicitly told about them.

However, after much thought and consultation, I decided to keep the word “invisible” as part of this report for two reasons. First, the issue of invisibility was a central part of why I conducted this survey and the words “invisible” and “invisibility” were used in the survey questions and also by participants in their responses. Second, I could not come up with a better word that would represent the participants’ experience and would not contribute to an ableist narrative. The experiences described by the participants of denial and rejection of their illnesses and conditions are related to what people see and the assumptions they make based on the participants’ appearance.

I believe language will continue to evolve to more accurately reflect people’s experiences and to challenge ableist discourse. However, the final language used in the report is ***invisible chronic illnesses and/or conditions*** or its shorter version ***ICIC***.

Additionally, it was important to have participants speak for themselves. Therefore many quotes from participants have been included where possible to enable them

to relate their own experiences. All precautions have been taken to ensure that the participants' identities remain confidential.

The words *queer* and *trans* are used throughout the report to describe the lesbian, gay, bisexual, transgender, transsexual, two-spirited, intersex, and queer communities. *Queer* and *trans* are used as umbrella terms and are not mutually exclusive. The participants in this report are queer and/or trans identified.

Finally, the report is intended for a wide audience and is written in plain language with the hope that it will spark discussion amongst families (the ones we are born or adopted into and the ones we choose), communities, and health care providers.

# Executive Summary

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This report is based on a Canadian survey of one-hundred and fifty-eight (158) cisgendered women and transgender and transsexual people living with invisible chronic illnesses and/or conditions (ICIC). The majority of participants identified as queer, lesbian and bisexual.

The purpose of this report is to shed light on a situation that remains unacknowledged by the queer and trans communities and society at large, and thereby contribute to efforts to improve services and supports. Queer women and trans people living with ICIC experience a considerable amount of discrimination and lack of services.

There are **seven** sections that summarize the findings:

1. **Participants' experiences of invisibility:** Eighty-nine percent (89%) of participants reported the invisibility of their CIC being a challenge causing disbelief from community members, partners, friends, family members, co-workers, colleagues, class-mates, and health care workers.
2. **The relationship between sexual and gender identity and how ICIC influence these identities:** Participants were asked whether their queer, lesbian, bisexual and/or trans identities had been affected by their ICIC. Fifty-six percent (56%) said "yes".
3. **Participants' feelings of isolation:** Participants related feelings of isolation and lack of community supports throughout the survey. Forty-six percent (46%) of participants felt isolation played a predominant role in their lives.
4. **Why some participants do not have support:** Thirty-two percent (32%) of participants needed support and did not have it. The three top reasons as to why participants did not have support were: "I have always been self-sufficient", "I have a hard time asking for help", and "I am the one who helps others".
5. **What types of queer-positive support free of charge participants would like available:** A significant majority (86%) chose *supplementary health care*. Participants stated that many of these complementary therapies, such as physiotherapy and osteopathy, help manage their ICIC and contribute to shorten the duration of relapses.

6. **Avoidance of health care providers due to discrimination:** Fifty-three percent (53%) of participants stated they avoided health care due to discrimination. They named sexual orientation and gender identity as the primary reasons for discrimination, followed by class, age, body size, race, place of origin, and language in that order.
7. **What health care providers need to know:** Participants were frustrated by the lack of education of health care providers regarding sexual orientation and gender identity as well as feeling disrespected and dismissed by the majority of providers regarding their symptoms.

The majority of participants felt unheard, dismissed, and/or misunderstood by health care providers, queer and trans community members, and sometimes their own friends and families.

**There is an urgent need for the following:**

- Educational materials raising awareness and challenging ableist attitudes for family and community regarding ICIC
- Queer and trans-positive support groups for people with ICIC
- Toolkits and/or workshops to help people organize their own care team
- Queer and trans-positive individual, couple and family counseling that specializes in ICIC

There is a profound lack of understanding in the queer and trans communities - and society at large - regarding the role ableism plays in the lives of people living with ICIC. Many of the challenges faced by participants can be greatly reduced by making workplaces, schools, public spaces such as community centres, and events fully accessible.

Participants want better services and better quality of life. They were tremendously enthusiastic about participating in the survey and are willing to continue participating for change.

# INTRODUCTION

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This report is based on 158 responses to an on-line survey conducted during January and February, 2010. The survey was distributed throughout Canada. The goal was to gather information regarding the challenges faced by lesbian, bisexual and queer women, and transgendered and transsexual people who live with physical invisible chronic illnesses and/or conditions (ICIC).

ICIC share a number of characteristics regardless of diagnosis. Some of these characteristics are:

- Non-observable symptoms such as pain, fatigue, and cognitive difficulties
- Some symptoms that cannot be measured
- Sometimes people appear “well” to others
- Periods of exacerbation where the ICIC gets worse and periods of remission where the ICIC gets better
- There is no known cure

The following is a list of the illnesses and/or conditions cited by participants: adrenal insufficiency, AIDS, ankylosing spondylitis, arterial sclerosis, arthritis (rheumatoid, psoriatic, and osteo), asthma, autoimmune hypophysitis, bilateral foraminal stenosis, candida, cardiomyopathy, celiac disease, cervical spondylosis, Charcot-Marie-Tooth disease, Crohn’s disease, chronic bursitis, chronic fatigue syndrome, chronic GERD (gastro-intestinal reflux disorder), chronic hives, chronic myofascial pain (CMP), chronic pain syndrome, chronic renal insufficiency, chronic sinusitis, chronic urinary tract infection, colitis, diverticulitis, degenerative back disease, diabetes, eczema, endometriosis, epilepsy, episodic ataxia, fibromyalgia, genital herpes, Hashimoto’s thyroiditis, hepatitis, hiatal hernia, HIV, hydrocephalus, hypothyroidism, IGA (kidney disease), interstitial cystitis, irritable bowel syndrome, keratoconus, leukopenia, Meniere's disease, migraines, mixed connective tissue disease (MCTD), multiple chemical sensitivities, multiple sclerosis, myalgic encephalomyelitis, myasthenia gravis, myofascial pain syndrome, multiple system atrophy (MSA), parasites (recurring Blastocystis Hominis), perforated disks, peripheral neuropathy, plantar fasciitis, post-concussion syndrome, postpartum autoimmune hypophysitis, pulmonary disease, repetitive strain injury, retinal detachment, sleep apnea, slipped discs, spina bifida, systemic lupus erythematosus (SLE), thalassemia, and traumatic brain injury.

Many participants disclose having two or more physical ICIC, and the majority have lived with them for more than ten years. Even though the separation between

physical and mental health is an arbitrary one, for the purpose of this report only physical ICIC were taken into account.

The survey could be completed online or printed out and filled out by hand. It was available online for seven weeks. Outreach was done mostly through social networks such as Facebook and online groups interested in health, queer, trans, and/or disability issues.

One hundred and fifty-eight (158) cisgendered women, transgender and transsexual people completed it. Sixty-five percent (65%) of the respondents would like to be contacted for further research. This demonstrates the enthusiasm for this kind of research and the desire for change. As one of the participants put it, "it's about time someone did research like this".

According to the *Canadian Coalition for Public Health in the 21<sup>st</sup> Century*<sup>1</sup>, half of all Canadians live with a chronic disease. Chronic diseases affect millions of Canadians. There is a scarcity of research regarding the impact ICIC have on the lesbian, gay, bisexual, transgender, transsexual, two-spirited, intersex and queer communities in Canada.

This report is a snapshot of a situation that remains unacknowledged and under-researched. Its aim is to spark discussion amongst families, friends, communities, and health care providers and to encourage organizing so that appropriate services and supports can be provided.

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<sup>1</sup> <http://www.cpha.ca/en/programs/ccph21.aspx>

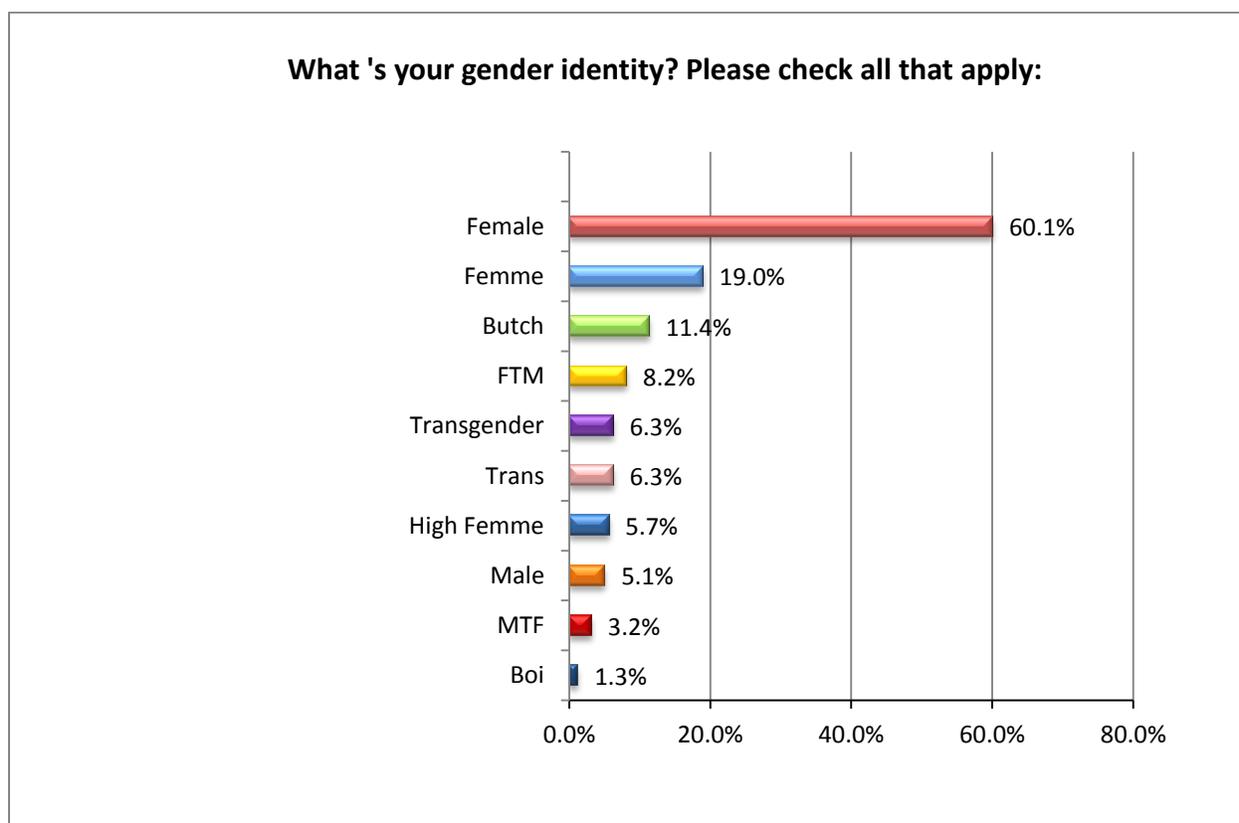
# WHO PARTICIPATED IN THE SURVEY

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Responses were sought from participants all over Canada. The respondents were mostly from the province of Ontario (66%). The second largest group was from British Columbia (23%). The remaining respondents were from: Alberta, Quebec, New Brunswick, Nova Scotia, Yukon and Northwest Territories. Most participants lived in urban centres (97%).

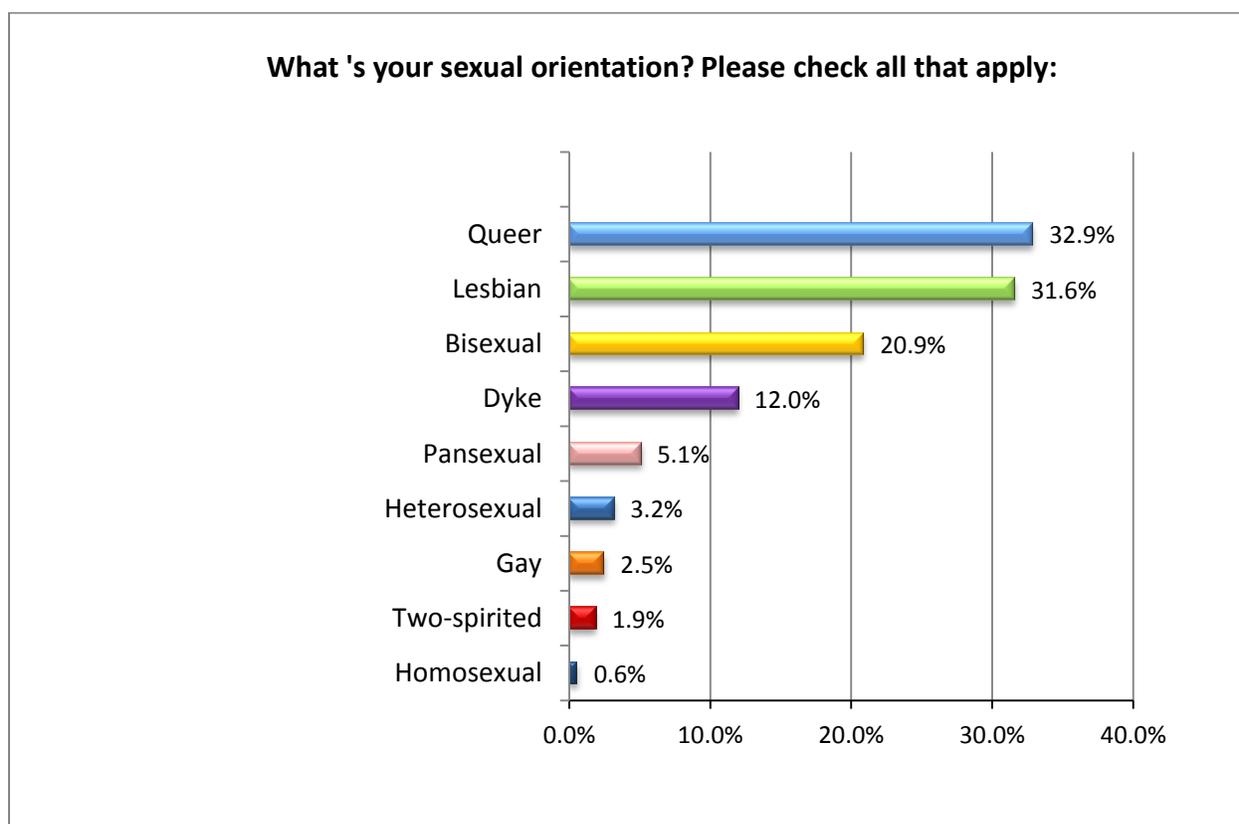
## Gender identity

Participants were asked to identify their gender. Outreach was done to cisgendered women, transgender, transsexual and trans people. Fifteen percent (15%) of participants identified as trans, transgender, FTM, and MTF. Please note that the numbers below do not add up because participants could select more than one choice.



## Sexual orientation

Participants were asked to identify their sexual orientation. They were given the option to select more than one choice. The majority chose queer, lesbian and bisexual. See chart below for details.



## Age

Seventy-four percent (74%) of participants were between the ages of 18 and 49 years old, with the largest age group being between 30 and 39 years old.

## Racial identity

Participants were given a blank space to identify themselves racially, no multiple choices were provided. Based on the responses, I grouped participants into the following categories:

- First Nations and Métis: 4%
- Racialized: 17%
- White: 74%
- Did not answer: 5%

## Parenting

Thirty-six percent (36%) of participants identified as parents and had children ranging from under 1 year-old to adult children in their 40s.

## Financial security

To challenge the normative assumptions around income and perceived financial security, I chose not to ask how much money participants earned. Instead, the question was framed regarding potential and actual loss of income due to illness. I was interested in finding out how much of an impact ICIC have on financial security.

Seventy-five percent (75%) of participants stated that they lost the ability to increase their income, lost some or all of their income, or were on fixed incomes from social assistance or pensions. It is important to note that participants who are unable to increase their income due to ICIC face a loss of earnings due to inflation over time.

In response to this question, participants wrote at length of the financial burden of their ICIC and some related the levels of poverty they live in throughout the survey. They mentioned the employment instability brought upon by remissions and relapses of their ICIC with consequences ranging from having to stay off work for months at a time without pay to being passed over for promotions to losing jobs altogether.

Twenty-two percent (22%) of participants stated that they had *not* lost any income due to illness. Three percent (3%) did not answer the question.

# WHAT WE LEARNT

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The following seven sections summarize the major findings of the survey. These include:

- Participants' experiences of invisibility
- The relationship between sexual and gender identity and how ICIC influence these identities
- Participants' feelings of isolation
- Why some participants do not have support
- What types of queer-positive support free of charge participants would like available
- Levels of discrimination and avoidance of health care providers
- What health care providers need to know

# INVISIBILITY OF CIC

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The vast majority of participants, 141 out of 158, responded that the invisibility of their chronic illnesses and/or conditions was challenging. This means eighty-nine percent (89%) of participants struggle with the invisibility of their CIC. They related experiencing disbelief from community members, partners, friends, family members, co-workers, colleagues, class-mates, and health care workers. Disbelief was expressed directly by telling participants they were “faking” or indirectly by “forgetting” that participants were sick even after being told of ICIC repeatedly. Because of this attitude, participants are labeled as a “whiner, jerk, lazy, antisocial, nagging” by people they know.

Participants struggled with the possible impact of being “out” about their ICIC as well as their sexual orientations. Some participants remain in the closet about both for fear of discrimination.

Participants also reported incidents of verbal and physical harassment by strangers who assumed they were healthy and/or able-bodied. This harassment usually occurred when participants were using an accommodation such as parking reserved for people with disabilities or when they were using an aid such as a cane.

The following quotations from participants exemplify how ICIC can have a tremendous impact on relationships and the ability to make a living. They have been divided in themes.

## Experiences of disbelief from others

Participants make the connection between invisibility and being silenced. Their ability to speak up and seek accommodation when needed is challenged by the widespread notion that if you look fine you must be “faking”. In the participants’ own words:

“My lovers are great now but one long-term partner was continually dismissive, insisting that I didn’t have an illness, that I wasn’t *really disabled* and that my accommodation needs were bullshit.”

“The fluctuation of symptoms, and therefore needs, combined with the invisible nature of my illness is a huge challenge. Classmates, friends, co-

workers are constantly questioning my illness and symptoms based on what they see.”

“People think I am phony or lazy because I can do some things and not others. I am tall and look strong so people don’t understand why I back off certain things.”

“I feel like I cannot talk about my pain. People think I am whining.”

“Invisibility is the big issue. Most people just don't get that if you don't look sick - that what you are dealing with is a legitimate and highly debilitating illness. My own father thinks I'm milking the system, even though I make an effort to work part-time while living on disability. It is still hard to disclose to people - because I always wonder if they are going to think I'm a hypochondriac (which I've been called a lot over the years - even since diagnosis) and also because my illnesses have stigmas attached to them.”

“People only see me when I am well enough to be out. So I could be sick in bed for 3 days and then be meeting someone for lunch on my first day up and have them tell me that I look great (which is nice) but also ask if I might be able to work part-time at least. They don't understand that while they got up and got ready for the day and have worked for 3 hours - I have just managed to shower and dress and meet them at noon and am going home to rest while they work another 4 hours. I don't blame people for that. It's a confusing illness. But it's challenging because of people's perceptions.”

“At work, it appears that I am less committed, instead of just more likely to get sick if I overwork myself to meet arbitrary and ambitious deadlines.”

The testimonies above make it clear that participants are profoundly affected by people’s perceptions based on how they look and behave.

## **Being out or in the closet about ICIC**

Participants expressed uneasiness about disclosing their ICIC for fear of the consequences. Some made the connection between being in the closet about their sexual orientations as well as their ICIC. Here are their comments:

“I haven’t finished my degree yet, and other students (who I am not close to) openly question why. This is extremely stressful. My department is the most competitive department in my discipline.”

"I have been unable to work for many years and have recently re-entered the work force. It has been an uphill battle but I don't feel comfortable bringing up my limitations at work, partly out of pride and partly out of fear that I will be misconstrued. I manage to get through the day and then go home and suffer."

"I tend to isolate and not share who I am with colleagues – both my chronic condition and my sexual orientation."

"At work, I don't get along with my supervisor who is somewhat sexist so the last thing I want to let him know is that I have brain fog in the morning. I write everything down so that when I need to remember things I can always consult my files."

"My co-workers think sometimes that I am anti-social, but really, I just need to sleep during my lunch hour and that is how I get through the afternoon and hold my job."

"I feel exhausted about having to talk about how sick I feel all of the time when I mostly look okay. I feel like I'm making excuses, or that's how people are reading me. I worry about taking up space of people with 'real' disabilities and I wonder how to define disability for myself. I have to constantly out myself, not just as being queer, but as not being able to work full time not because I'm lazy or inept or, or, or..."

These stories relate the burden of having to constantly decide whether to disclose or stay in the closet and the consequences attached to either choice. Sometimes not revealing the ICIC is the better strategic choice but it has a greater toll on the participants by increasing their isolation and denying them the opportunity for accommodation.

## **Lack of accommodation due to invisibility**

Participants expressed frustration at the way they are treated when asking for accommodation as well as the assumptions that are made about them based on the way they appear. The lack of accommodation affects all aspects of participants' lives. Here are some examples:

"People don't understand that I need to be close to a washroom at all times. People don't understand that I am often in discomfort."

"I get weird looks [when I ask for accommodation]."

"The Disability Awareness Centre at my school has put advertisements counting how many people per hour take the elevator in certain locations and saying: 'How many of those people do you think REALLY need the elevator?' The advertisement had the wheelchair symbol all over it, and it seemed to be implying that only people with visible mobility impairments should use the elevator. Now I feel ashamed to use it."

"I think my boss thinks I am crazy [...] She says things like: 'Let's make sure that we don't take any more sick days over the next 3 months.' Or: 'you take a lot of sick days – let's just watch that, shall we?' I find it really condescending, and I feel strongly that she doesn't actually believe me."

"Sometimes I borrow a wheelchair from the store that I am shopping at, but people often have negative reactions to seeing an apparently able-bodied person sit down in a wheelchair."

"I do not qualify for the help a person with a visible disability would get."

"Being denied use of the wheelchair accessible door/elevator particularly when they are operated by an attendant. Being denied the right to vote for the same reason – not being able to walk up the stairs and having to wait – standing for 30 minutes while someone who 'felt like it' finally took me up the locked elevator."

"People almost always assume that I am non-disabled and rarely, if ever, consider the accessibility of a location/event prior to inviting me. As a result, there are a lot of house parties, dinners, movies, etc. I can't go to because of physical barriers or timing."

"I asked to have the fresh food box delivered because I could not carry it home and was told that I didn't look disabled."

These examples make it clear that accommodation is denied often to participants either directly or indirectly by not acknowledging the ICIC.

### **Specific struggles of young participants (ages 18-29)**

Young participants expressed sadness at the inability of peers and older adults alike to accept their ICIC. The expectations placed upon them to be energetic and youthful clashed with the reality of the participants who often felt in pain and fatigued, but nevertheless appeared well. Here is what some of them wrote:

"[My illness] is a really rare thing for people my age to get, people associate it with old age. I often deny the pain I am in in order to appear 'normal', 'fit', 'youthful', etc. [...] I feel like people are judgmental about how dependent I am on my parents because it's a sign that I am immature or 'spoiled'. Because people don't always know about my illness my dependence is read in that way."

"As I've been diagnosed with my ICI at a relatively young age, I find that I sometimes feel left behind by peers who have much more energy and vitality than I do, and it's hard for people to understand why I can't always participate in the same activities as they do. Because it's invisible, I suspect that people think I'm faking it or can't understand the constant level of pain I deal with on a regular basis."

These testimonies revealed an added assumption made about these young participants who are judged as spoiled or immature because of their ICIC.

## **Aggression and harassment by strangers**

Some participants revealed being harassed by strangers because of their ICIC. Sometimes the aggression happened because they needed to use a cane, for example, and this did not match the way the participants looked.

"I get told off for falling on people [when I am trying to get on or off public transportation]"

"I had a woman once stop me as I walked down the street using my cane and ask me if I really needed that."

"Having able-bodied people approach me on the street (when I am using my cane) specifically to ARGUE with me about 'making it up', and having these same types demanding my personal medical history during the confrontation."

"I have a handicapped sticker for my vehicle. If I am having a really bad day, I will use it. I have been called names and screamed at because I LOOK healthy!"

These examples demonstrate the stress participants can suffer just by going out in public and the profound misunderstanding of ICIC by society at large.

## Relationship to self

Participants expressed a range of feelings in relation to their own self and the invisible nature of their ICIC. Here is a summary:

- having to put on a “game face”
- feeling “embarrassed and uncomfortable”
- having to “deny my own symptoms”
- not wanting to look like a “complainer”
- feeling like “I am letting everyone down”
- feeling like “I have no right to access supports”

This participant relates how people’s reactions can affect her own sense of how sick she feels:

“If I am not feeling well, I usually get the ‘*you are always sick*’ or the ‘*you look fine to me*’ routine. Sometimes, it makes me feel like maybe I am just exaggerating and letting everybody down, even though I know I do not feel well.”

As stated at the beginning of this section, the vast majority of participants felt the invisibility of their illnesses or conditions was a major factor in their lives. The testimonies in this section exemplify how deeply participants are affected by people’s perceptions of their ICIC and how participants are discriminated against because of those distorted perceptions.

# RELATIONSHIP BETWEEN SEXUAL AND GENDER IDENTITY AND ICIC

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Participants were asked whether their queer, lesbian, bisexual and/or trans identities had been affected by their ICIC. Fifty-eight percent (58%) said yes and expressed a wide range of feelings and thoughts about it. Some spoke of what being “strong” meant and how to reframe strength in the face of disability. Others made links between how some illnesses are attached to certain genders, for example migraines are often viewed as a “woman’s condition”. Many spoke of their frustrations regarding losing their sense of autonomy, the erosion of their self-esteem, and the significant changes to their appearances and their ability to perform sexually due to their illnesses.

Participants were eloquent regarding the layers of complexity and intricacies in the relationship between femininity, masculinity and having an ICIC that impedes a certain performance of sexual and gender identity and challenges assumptions made by others about it. Ideas of masculinity and femininity were deconstructed in the context of disability. Ideas and expectations of beauty from the queer and trans communities as well as ableism were mentioned as barriers to social life and full participation in community events.

Here are some examples divided by themes and/or identities mentioned by participants.

## **Bisexual identity**

“I am often too tired or in pain to participate [in community events]. I feel both isolated and sad about it [...] if I were able to participate, I would benefit from the self esteem building that participation in such events offer [...] I don’t have a lot of bi-pride, and [participating] would help me overcome my own internalized self-hatred in regard to my bi-identity.”

“I am bisexual, bipolar, and I have a learning disability that affects half of my brain [...] However, I am gifted verbally. I feel like my whole life is an oscillation between two sides [...] I wish society could accept all the sides of me so I could integrate these all together instead of feeling like I’m flipping between the two.”

## Femme and high femme identities

"This may sound silly. But, I identify as High Femme. And it breaks my heart that I can't wear high heels or corsets. Both of these items just put me in so much pain. I hate when my partners go on about how sexy high heels are."

"So much of my femme identity is about not being passive or incompetent, but when I'm not able to do things because I'm not strong enough and it hurts, then I have to ask for help, and that's really changed my ideas of what being strong and femme means. Asking for help and being vulnerable is strength - but that's a hard one to always remember. I hate asking my butch roommate for help with carrying things!"

"As a femme looking my best has always been a big thing for me yet I've had to accept that I can't do that as I'd like. I've had to basically give up my heels (yes it may sound funny but it's a big thing for me) And I always look like I'm tired, which I am. [...] I'm feeling like I'm not really a femme at times because I seem to look frumpy more often than not."

"It affects my social life. I am a femme lesbian, there is pressure to be beautiful and 'clean' and I have irritable bowel syndrome."

"As a queer femme, my femmeness for a long time was all about being tough, independent, and self-sufficient. What differentiated a femmeness that was about freedom and queerness from mandatory, sexist femininity to me was that I was invulnerable. Because of this, it was basically impossible for me to ask for help when I was sick, because then I wouldn't be that fun tough sexy femme, right? [...] Changing my definition of femmeness to one where asking for accommodation, instead of struggling alone, is what's really strong and sexy, has been a revolution."

"I'm a high femme ~ but am unable to wear any shoes other than my hand-made orthopedic numbers and I can't really wear the kind of dresses, lingerie or "slut-wear" I would like to in some instances because of my braces...so I've had to find very creative and personal ways to give expression to my diva self. In those instances when my braces are visible or I'm using a cane, I'm generally seen as asexual, if I'm seen at all, by the queer and non-queer communities."

## Butch and androgynous identities

"Another major challenge is that I can't exercise with the pain. While gender queers are not the only ones who think about body image, it messes with my identity if I can't stay within a particular weight range. I need to look androgynous or butchy in order to feel like myself. I don't feel like having sex when my body is curvy, I lose confidence, I don't want to be seen, I get paranoid about whether people like me or not...all because I lose my gender expression when I can't exercise. I'm 'forced' to look more feminine (breasts, hips, etc.) and that is just. not. me."

"The hardest issue for me has been the loss of strength: physically, mentally and emotionally."

"Sexual intimacy is sometimes very difficult and then there is the mental difficulties with the whole ableism thing, isn't there?!"

## Trans, transgender, and FTM identities

"My sick time at work is slightly higher than others because it takes me longer to get better - because people read me as a man, they begin to insult my identity by saying I'm a "wuss" or "pussy" because it takes me longer to get better."

"There is much I could say about masculinities and care, physical ability, strength, dependence, assumptions about physical vitality / virility / desire, social connections and how gender identities impact the way that a given condition is experienced. I am not sure that any of it would be specific to an ftm as compared to a person raised as male, but certainly it is less expected that I will behave in a stereotypically masculine way around chronic pain and illness. This can be confusing because some of these behaviors are mal-adaptive for anyone, but for me they are both easy to miss and correct and also correcting them (for example, asking for help, admitting weakness) can threaten my social identity. I do not personally feel like these chronic conditions change my identity, but sometimes the person perceiving me will respond in ways that make me feel unrecognized as male - making it hard to require care or accommodation or even empathy."

"People see the extremes first. Either they notice that I'm transsexual first & base everything on that, or they see I'm disabled & treat me like a cripple, ignoring WHO I am, for what I have."

"I feel too ill to transition."

## Two spirit identity

"It actually made me look at my life and learn to know I was trans two spirit."

## Lesbian and dyke identities

"When I experience homophobia from friends or co-workers my condition gets worse [...] because of this I am not an out and proud lesbian."

"I view lesbians as more self-respecting, independent-minded, and socially non-conforming than most heterosexual women, including many feminists. Because these traits are wrapped in valorization of autonomy and self-assertion, the erosion of autonomy caused by illness is, perhaps, harder to bear [...] I think it is especially problematic given my linkage of lesbian identity and independence."

"The onset of my condition was after my first child was born. One of the first symptoms was no breast milk. It made me feel very inadequate and triggered some internalized homophobia, that maybe I wasn't as real a woman as my straight friends who had lots of breast milk."

"I came out to my family and friends as a lesbian. I had no longer the energy to hide it; I didn't care anymore, what their reactions would be. My illness was worse to me than their [negative] reactions."

"Going out as a 'hot' dyke to the women-oriented events isn't half as easy when you are unable to shower more than once or twice a week, and completely unable to brush or take care of your hair."

## Coming out

"I've just been coming out in the last year. So my ICIs are actually a part of forming my identity whether I want them to be or not. For example, I am queer but I am not well enough to socialize much and am discouraged that I can't date. I don't know how my identity would form (but think it would be different) if I were healthy."

“My HIV diagnosis came at a time when I was first coming out as a lesbian and had felt ready to seek out relationships with other women. I felt like other dykes would never accept me, let alone want to sleep with me or have a relationship with me... who has heard of lesbians with HIV? Gradually over time this fear has lessened as I've had positive experiences dating and disclosing. But it was hard for a long time to not feel like a fraud as a lesbian since I got my HIV from sex with a man.”

“I came to my queerness later than I came to my ICI, so the relationship is quite complicated. I believe I would have been more butch... or a ‘harder’ butch had I not had an ICI. It is also quite possible that I would have identified as a high femme, as I’d been very femmey before I came out, but I had to stop wearing the high heels because of [my illness]. I started to wear ‘sensible shoes’ before I came out, and so when I did it just seem easier to pursue the butch path... which is also an ‘authentic’ identity for me.”

## Sex life

“I am a top generally, and like to use my hands to fuck. However, the fact that I have these increasingly regular pain flare ups means that my hands... just can't, for sustained periods, anymore. It's frustrating [...] I haven't figured out an alternative yet.”

“My knees went out once... during a private moment with my partner... It's hard to be all strong and sexy when your knees give out.”

“My sex life has changed very much – again because of the pain (positioning, strength, endurance, etc.) It has been kind of depressing.”

It is clear from the examples in this section that sexual and gender identity is influenced by ICIC depending on whether participants were out to themselves and/or others before or after they develop their ICIC.

There is also a desire to be fully accepted as both queer and/or trans and having an ICIC, to have both worlds integrated and especially to have the queer and trans communities understand ICIC.

# FEELINGS OF ISOLATION

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One participant thought the survey did not address the isolation issue and its ramifications, and in many ways this was echoed by others. Participants related feelings of isolation and lack of community supports throughout the survey. Connections were made between well-being and the ability to socialize, as many participants felt alone. Twenty-three percent (23%) of participants felt isolated daily, and another twenty-three percent (23%) felt isolated at least weekly. This means that almost half the participants felt isolation played a predominant role in their lives.

Others felt angry at the loss of their abilities to participate and just be with others.

Fatigue, pain, and lack of financial resources were mentioned repeatedly as obstacles to having a social life combined with the lack of accommodation at community events. Many felt that queer community members were fully unaware of how inaccessible most events are for people with ICIC.

Here are a couple of those comments:

"I do get very frustrated by the ableism and lack of disability perspective within the queer community [...] I find that even when 'included', disability is produced through a medicalized discourse."

"Chronic pain and fatigue are a terrible burden. I can't have an active social life. People don't usually understand why I can't be active with them, can't stay out late, can't tolerate alcohol, smoke or stressful/stimulating environments such as a loud restaurant. Social activities usually take more energy than I have to spare [...] my pace is slow and frustrates the people around me. They can't see how painful it is to do simple things."

And here is a statement that clearly demonstrates the difference it makes to have community:

"Having a queer disability community kicks ass and has helped me transform my shame and isolation into fierce advocacy, but like I said - it took me a decade to get here."

However, it is important to note that the vast majority of participants do not participate in or have a queer disability community.

## SUPPORT GROUP OR CARE TEAM

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A support group or care team can be invaluable to someone with an ICIC. The group or team can be formally organized or simply be an informal network of people. The care needed can range from emotional support (i.e.: phone calls, visits, and counseling) to physical tasks (i.e.: cooking, cleaning, bathing, and shovelling snow).

Participants were asked whether they had a support group or care team.

Fifty-one percent (51%) of participants stated they had some type of support. This support is provided mainly by partners, friends, and some family of origin members such as a parent or sibling. Additionally, some respondents participate in online or in-person support groups geared to their conditions – but not necessarily queer-friendly groups – and have health care providers such as doctors, massage therapists or naturopaths provide additional support.

The next question asked participants why they did not have support. Participants who did have support could skip this question. Sixty percent (60%) of participants answered this question. They were given multiple choices to explain why they did not have support and they were allowed to choose more than one answer.

Forty-six percent (46%) stated that they did not need support right now. This means that thirty-two percent (32%) of *all* participants needed the support and did not have it.

The three top reasons why participants did not have support were:

- I have always been self-sufficient: 56%
- I have a hard time asking for help: 45%
- I am the one who helps others: 45%

These responses were consistent with comments made in other sections of the survey. Autonomy and independence were repeatedly mentioned as valued by participants and society, as well as the need to stay away from being perceived as “weak” or “dependent”. One of the participants clearly expressed this in the comments section of this question:

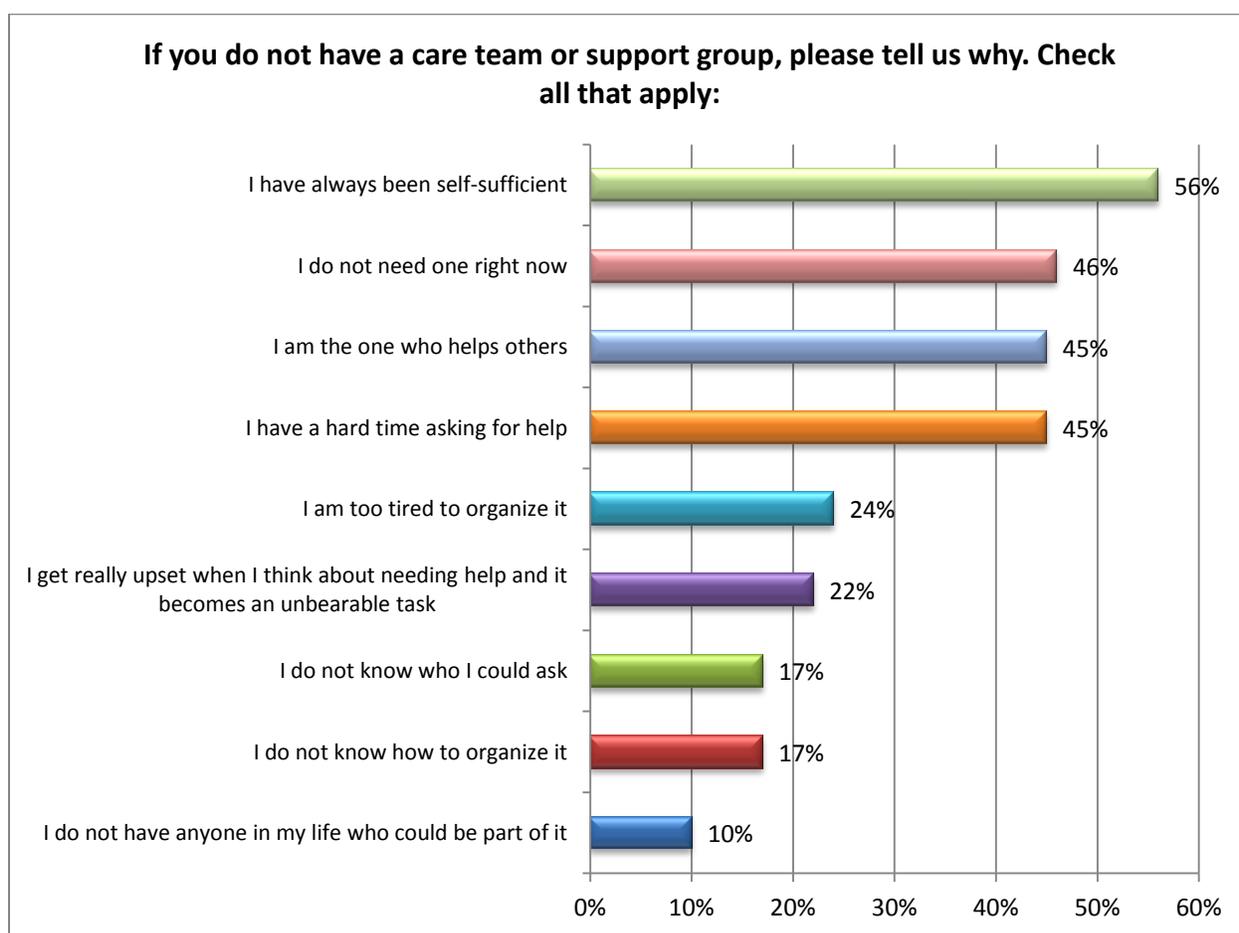
“I checked these even though I do have a care team because all of these are feelings I struggled with for ten years - and still do. For a decade, arguably when my illness was a hell of a lot worse than it is now, I was too self-sufficient, exhausted and challenged by folks who didn't get disability or

flaked out to really have one going on. Also, one thing to remember is that asking for help when you're sick is very vulnerable, and so many queer folks' self-esteem comes from not feeling "broken" or "wrong". When we have more or less invisible illnesses, it can be really tempting to just hide when we get sick so no one sees it - as isolating, exhausting and crappy as that is."

The above participant summarizes the feelings of many others and makes the link between pervasive societal prejudices about queerness and disability. Coming to terms with both identities can be challenging and therefore affect people's ability to seek help, especially for those who are discriminated against as well for other reasons such as class or ethno-racial background:

"I'm already queer and brown and a woman and working class. I am really struggling with this extra label of having a disability and I am not really sure I want to own it."

Here is a detailed chart of the answers:



# QUEER-POSITIVE SUPPORT FREE OF CHARGE

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Participants were asked regarding their specific needs for queer-positive support free of charge. Multiple choices were presented with the option to add comments. The vast majority (95%) answered this question, and twenty-five percent (25%) added their own suggestions and comments.

A significant majority (86%) chose **supplementary health care** as needed services free of charge. This included physiotherapy, naturopathy, and osteopathy as examples. Participants stated that many of these complementary therapies help manage their ICIC and contribute to shorten the duration of relapses. It is important to note that coverage for most of these therapies is either not available or very limited under provincial health care coverage.

This participant makes the connection between the role of complementary therapies in her well-being and the financial burden it has taken on her:

“Physiotherapy and chiropractic, homeopathy and massage have helped me tremendously over the years in managing and improving my condition - yet financially the strain has been huge - and I am still in debt - and due to financial constraints can still not get the proper therapy often enough to keep up the recovery. Seeing a GP helps, but many times, they refer to a specialist - some of whom are not covered - so this is where there is a big gap. The fact too that the health care system does not support mental health (unless it is administered through the care of a psychiatrist) is ridiculous and frankly ignorant. Counseling is HUGE when it comes to recovery - and god knows I have had to be resourceful finding [...] counseling to deal with my health and mental health over the years. Again, the financial strain has been HUGE and at times probably counter acted the benefit I received from the help I was getting just because of the emotional stress related to the financial burden.”

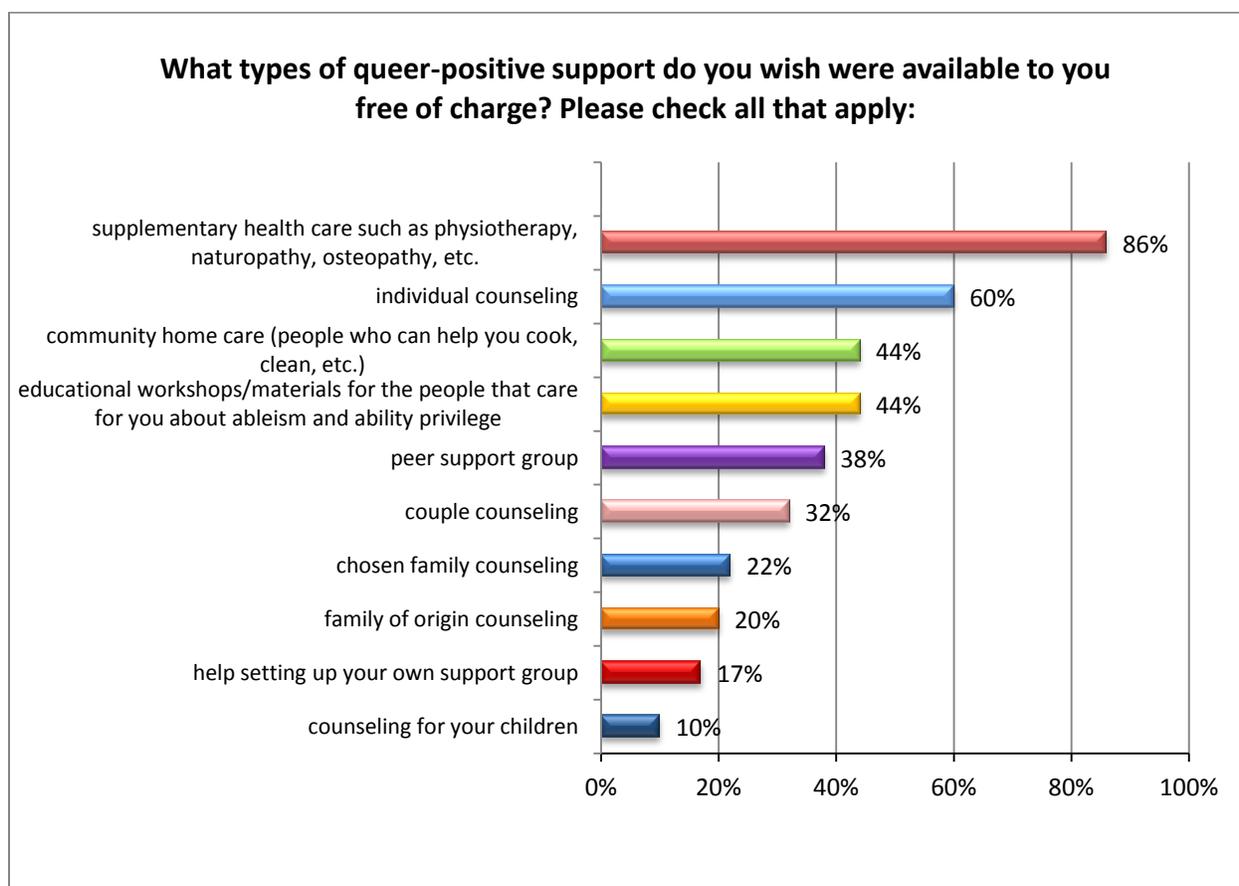
The second response was **individual counseling** at sixty percent (60%), also mentioned by the participant quoted above. Consistently, participants spoke of the emotional difficulties of dealing with ICIC in relationship to their own sense of self as well as the impact on their relationships.

The third answer at forty-four percent (44%) was **community home care** together with **educational workshops/materials for the people that care for you about ableism and ability privilege**.

Participants related quality of life stories regarding **community home care** and how much their lives would improve if this support were readily available free of charge. Community home care includes, but is not limited to: cooking, cleaning, grocery shopping and delivery, doing laundry, shoveling, etc. Some participants spoke of the difficulties of qualifying for the few services that are actually available for free because they either weren't "disabled enough", didn't "look disabled", or did not have a diagnosis.

Regarding **educational workshops and materials about ableism and ability privilege** participants spoke throughout the survey of the lack of education regarding ICIC and how often they were questioned as to whether they were "really sick". Please refer to the invisibility section on page 16 for more on this subject.

This chart includes all of the participants' responses.



# AVOIDANCE OF HEALTH CARE DUE TO DISCRIMINATION

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**F**ifty-three percent (53%) of participants stated they avoided health care due to discrimination. They named sexual orientation and gender identity as the primary reasons for discrimination, followed by class, age, body size, race, place of origin, and language in that order.

When asked about the impact of the discrimination on their health, 109 participants (83%) responded with comments. Some of the stories related by participants speak of blatant discrimination. Others simply have stopped interacting with the health care system. In the participants' own words:

"I have not gone back to the doctor that put 'sexual deviant' in my medical file when coming out and I resist going."

"Denied treatment by several doctors, including one who stated, 'I do not feel comfortable touching you'."

"I first had symptoms of [my illness] when I was 19, for 8 years I was sent from Doctor to Doctor (all male) and although sometimes I could hardly walk, it was suggested that things would improve when I got married (had sex) never figured that out and did not pursue it!!"

"I have ceased seeking medical assistance completely and have resigned myself to my suffering."

"Avoidance and hesitancy seeking medical assistance, negative self image - harm to my mental and emotional health. Lack of attention due to discrimination: i.e. not taken seriously or indirectly blamed for my ill health."

"[Discrimination] caused me to not trust many in the medical field, which also [almost] cost me my life a number of years ago when I refused to go to a walk in clinic for new pain, trying to wait instead for the upcoming doctor appointment I had with my own doctor the following week. It turned out that for close to a week my appendix had ruptured."

Participants cited exacerbation of symptoms and deterioration of general health as clear consequences of discrimination. Participants felt they had to work much harder to receive appropriate treatment by advocating for themselves regularly.

# WHAT HEALTH CARE PROVIDERS NEED TO KNOW

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Participants were asked how they could be more effectively cared for by health care providers. One-third of respondents were satisfied with what their providers knew and had no comments. The other two-thirds had plenty to say. Participants took the opportunity to address their comments directly to health care providers.

The following are the main themes that emerged from the participants' comments. Each theme reflects the participants own words:

- ⦿ Financial burden from the hidden cost of disability is a huge issue as well as poverty and quality of life. Help us access the supports available in the community such as disability benefits, home care, subsidized housing, etc.:

"I wish they had more knowledge of free support services to help me, of local support groups, ideas of things I can do to improve my health (not just 'you have it; get used to it'), support for queer folks, ideas of supports I can put in place so I can maintain my housing and independence but have support so that I don't starve, etc."

- ⦿ Treat us like human beings. Be respectful of who we are:

"I am not just an illness. I am a whole person with lots of other identities and that affects my relationship to my body and how I want to receive/access treatment."

- ⦿ Trans people are often shamed for our bodies and illness can have a re-traumatizing effect:

"[they need to know] the pressure trans people's bodies are already under to present in certain ways and how that can interact with chronic illnesses."

- ⦿ Educate yourselves about queer identities and challenge your prejudices so that we can come out without consequences to our health.

"[They need to know] that presumption of sexual orientation can be offensive and should not have an impact on illness management (i.e. 'get your husband to do the heavy lifting')"

"I would like them to know how hard they make it to believe that: a) our lives or safety is not at risk if the information about one's gender expression or sexual preference is revealed, b) revealing this information will not temper their actions and, c) how desperately positive health care spaces and health care providers are needed"

- ◎ Listen to us: we are not lying about our symptoms, we are the experts of our experiences, and each body is different and complex. We want to make informed decisions about our bodies. Take us seriously.

"I would like a doctor who actually listened to what I say."

"I deserve to know what you think about my body and be involved in the decisions about tests / treatments / specialists, just because I'm sick doesn't mean I'm an infant."

- ◎ Educate yourselves about determinants of health such as racism, poverty, ableism, sexism, and discrimination based on class, as well as lesbophobia, biphobia and transphobia.
- ◎ Be open to different types of healing.

Participants expressed frustration at the lack of willingness by most allopathic doctors to consider the benefits of complementary therapies. Participants want a holistic approach where western and non-western medicine are considered together since they found that complementary therapies such as naturopathy and osteopathy can help manage symptoms, reduce duration of relapses, and contribute to lengthen remission times.

- ◎ Coordinate with other health care providers.

Participants felt that there is a pronounced lack of coordination and knowledge, especially between specialists, as to what is going on with their health. The majority of participants have more than one ICIC and therefore proper follow up and coordination is crucial. Some felt they did not have the energy to keep track of every interaction with health care providers and advocate for themselves when information was not shared.

Many of the themes identified in earlier sections were also highlighted in relation to health care providers. For example, invisibility, being believed, lack of understanding of financial burden due to having ICIC, and heterosexist assumptions by providers were all cited as problems to access adequate care.

## Providers are starting to change for the better

Some participants pointed out that – after much searching – they had found health care providers who did not discriminate against them, who did not dismiss their symptoms and concerns, and who cared. Here is one of those examples:

“I have a wonderful specialist for the musculoskeletal pain who whenever I minimize my pain she is the first to respond and recognize that living with chronic pain is very challenging. This makes a huge difference because it makes me not minimize my own pain.”

This comment summarizes the relief felt by others when they finally found a good service provider. However, it is important to note that when participants find a good provider (usually a GP) they are reluctant to interact with any other health care provider due to the discrimination suffered in the past.

# CONCLUSION

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**M**uch more research needs to be done to understand the conditions in which lesbian, bisexual and queer women, and trans people live with their ICIC.

The majority of participants felt unheard, dismissed, and/or misunderstood by health care providers, queer and trans community members, and sometimes their own friends and families.

The lack of supports available intensifies the isolation many feel and contributes to diminishing participants' self-esteem and sense of belonging as many feel blamed for and alone with their ICIC. Mental health issues can arise in this environment and therefore future research needs to explore the relationship between ICIC and its influence on mental health.

There is an urgent need for the following:

- Educational materials raising awareness and challenging ableist attitudes for family and community regarding ICIC
- Queer and trans-positive support groups for people with ICIC
- Toolkits and/or workshops to help people organize their own care team
- Queer and trans-positive individual, couple and family counseling that specializes in ICIC

There is a profound lack of understanding in the queer and trans communities - and society at large - regarding the role ableism plays in the lives of people living with ICIC. Many of the challenges faced by participants can be greatly reduced by making workplaces, schools, public spaces such as community centres, and events fully accessible. For instance, flexible work time or being able to work from home would help some to remain employed or return to work. Adopting scent-free policies for all gatherings would allow people to participate more often. These are just two examples of things that can be done. However, having space that is accessible for all does not mean that one approach works for everyone. Therefore,

along with accessibility there is an acknowledgment that accommodation is also important and critical.

Future research on ICIC and queer communities must make an effort to include historically marginalized communities such as aboriginal, racialized, intersex, trans and genderqueer. For instance, in this report the number of respondents from racialized communities was *not* consistent with the racial statistics of the province of Ontario where two-thirds of the participants reside. Further research needs to take into account this discrepancy and ensure better outreach to aboriginal and racialized communities.

Queers living in poverty are also often under-represented and we already know that there is a correlation between poverty and chronic health conditions in Canada<sup>2</sup>.

Another group under-represented in this report was rural Canada. Only 3% of respondents were from rural areas.

Participants also requested inclusion in future research about parenting and being a caretaker (to older family members, sick partners, etc.) in relation to being queer and/or trans and having an ICIC.

Further research needs to be conducted in Canada to explore the relationship between sexual orientation, gender identity and having an ICIC. Participants clearly stated that sexual and gender identity is influenced by ICIC depending on whether participants were out to themselves and/or others before or after they developed their ICIC. To provide better services and supports, we need to understand the layers of complexity and intricacies in the relationship between femininity, masculinity and having an ICIC.

Finally, the enthusiasm and support for this survey demonstrated by participants clearly conveys their willingness and desire for change. Participants want better services and better quality of life. It is up to everyone who reads this report to bring up these issues at their workplaces, their schools, their communities, and with their families. It is important for readers to commit to educating themselves and to discuss ICIC with everyone they know and to advocate for change.

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<sup>2</sup> *Poverty is making us sick* report:  
<http://wellesleyinstitute.com/files/povertyismakingussick.pdf>

# APPENDIX

## WHAT YOU CAN DO (No matter who you are)

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Here are some ways to challenge ableism at different levels.

### **Individually:**

- ✓ Challenge your thinking about chronic illness and disability. Make a commitment to learn more and move away from the medical model where people have little or no power to make decisions about their bodies. Check out the list of internet resources at the end of this list.
- ✓ Think about your own body's abilities and how you relate to them. How many daily activities do you take for granted?
- ✓ Be supportive when someone comes out to you about their ICIC and/or disability: do not dismiss, deny, and/or downplay their experience.

### **Socially:**

- ✓ Initiate conversations about people's assumptions about ICIC. Pick an example from this report where you felt challenged about an assumption you have made in the past and share it with someone you know. Discuss how you came to make that assumption and where you learnt to think that way about people with ICIC.
- ✓ Think before you organize or attend an outing or event: Is the venue accessible to all? Think about things that are usually not taken into account such as fatigue, pain, and environmental allergies. Is the event scent-free? Are there quiet places for people to rest?

### **Work/School/Community Centres, etc.:**

- ✓ Approach your Health & Safety committee, Disability Resource Centre, etc. and bring up ICIC and episodic disabilities. Ask them to organize an educational event about it. If the committee or resource centre does not exist then start one.

- ✓ Challenge “survival of the fittest” attitudes and expectations such as working long hours, impossible deadlines, pulling all-nighters, etc:
  - If you work in a social service agency, challenge “sacrifice/victimhood” attitudes about working long hours to “serve the community”.
  - If you are in a position of power at work or school, foster and advocate for healthy working conditions. Encourage workers and students to go home at reasonable hours, take vacation on a regular basis, and take regular breaks during the day.
- ✓ Advocate for scent-free environments.
- ✓ Do an audit regarding physical barriers. Contact your local disability rights group to perform the audit or help you find a consultant with expertise.
- ✓ Examine attitudes that create social barriers and impede people to come out as having a disability. For instance, host an informal discussion during lunch about ability privilege and talk about all the physical and mental activities people take for granted.

## Selected Resources

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- ❖ Disabled Women’s Network Canada: [www.dawncanada.net](http://www.dawncanada.net)
- ❖ Disabled Women on the Web: [www.disabilityhistory.org/dwa/](http://www.disabilityhistory.org/dwa/)
- ❖ Eli Clare: [eliclare.com/background/queer-disability-resources](http://eliclare.com/background/queer-disability-resources)
- ❖ Understanding accessibility – Ministry of Community and Social Services, Ontario:  
[http://www.mcscs.gov.on.ca/en/mcscs/programs/accessibility/understanding\\_accessibility/index.aspx](http://www.mcscs.gov.on.ca/en/mcscs/programs/accessibility/understanding_accessibility/index.aspx)
- ❖ Sins Invalid: [www.sinsinvalid.org](http://www.sinsinvalid.org)
- ❖ Wanna be toxic free:  
<http://www.womenshealthyenvironments.ca/programs/wtf>

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