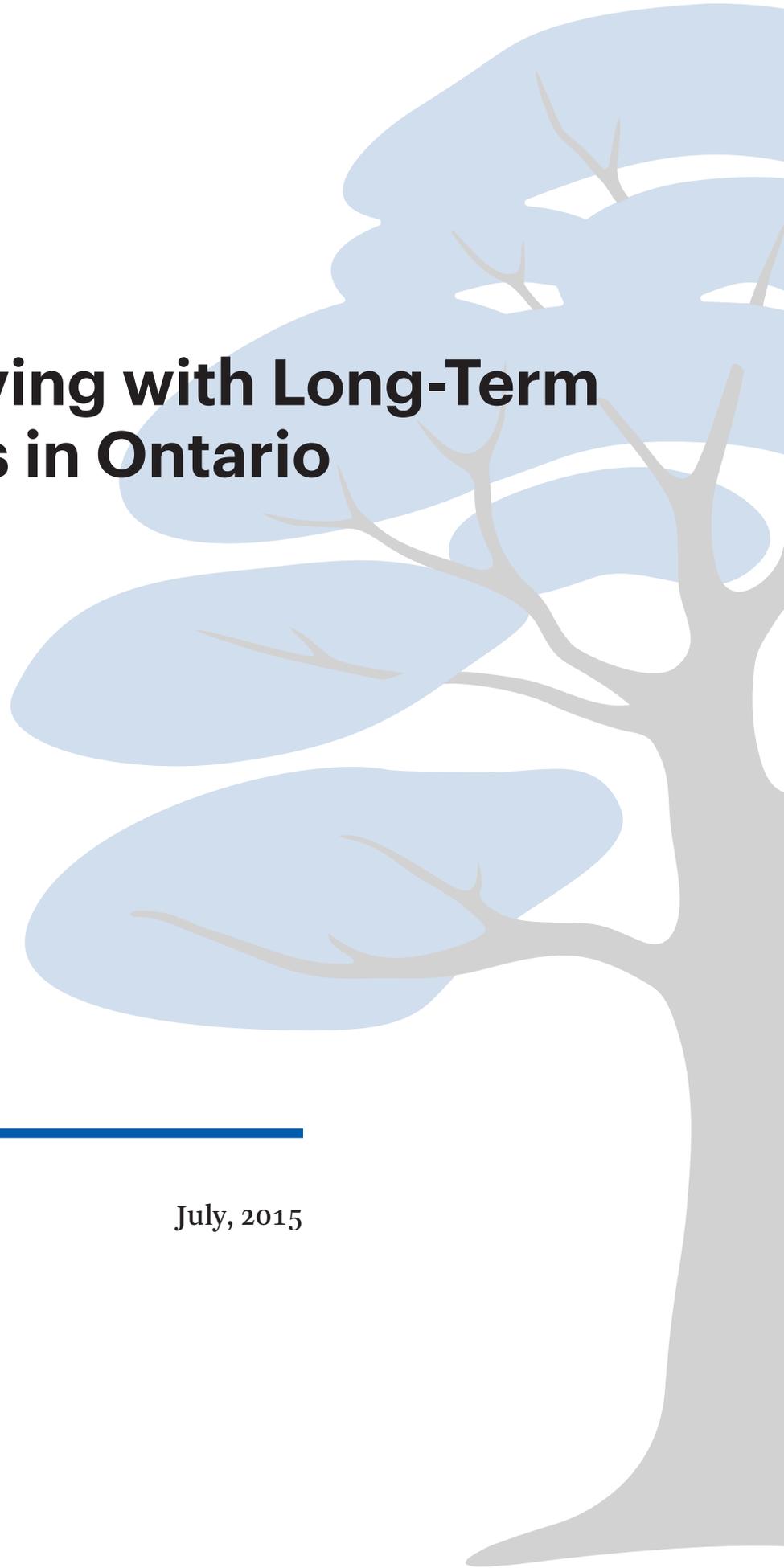# Women Living with Long-Term Disabilities in Ontario

The Wellesley Institute engages in research, policy and community mobilization to advance population health.

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# Introduction

The onset of long-term physical or psychological disabilities has substantial impacts on everyday life for individuals across the social determinants of health. In addition, access to ongoing health care and economic and social support may pose specific challenges for individuals dealing with a disability. Disability support in Ontario has been the focus of recent health and policy research (1). As discussions surface about prospective changes to public or private sources of disability support, there is value in learning from people with lived experiences of an illness or injury that prevents them from working.

Despite a strong body of research on experiences of people with disabilities, there is limited research on the experiences of individuals receiving long-term private or public disability support (2). We know that in Ontario there has been a rapid growth in the rates of people seeking support related to disability (3) and that working age people with disabilities are twice as likely to be living below the poverty line (1). Women have a higher prevalence of disability than men across all age groups (4), including higher rates of chronic conditions such as arthritis, chronic pain and issues with mobility (5), and there may be gendered differences in the experiences of receiving support to help deal with a disability.

To gain insight from those with lived experience we spoke with a small sample of women living in the Greater Toronto Area (GTA) about their experiences of receiving disability supports over time. We learned about their experiences in navigating complex and often demoralizing systems of care and spoke with them about their recommendations to service providers and policy makers moving forward. Following this research, we met with policy and advocacy professionals who work with people receiving support for dealing with disabilities, to present our findings and discuss recommendations offered by the women in our study. To complement this work we also conducted a high-level policy review of the official pathways to disability support in Ontario, and the policies related to disability coverage and eligibility (6). Together we consider how community research and policy analysis can help sharpen our understanding of issues facing individuals receiving private or public disability support over time and how these insights may help inform policy and practice moving forward.

## Study Aims

Our aim in conducting this pilot research was to explore opportunities for people with lived experiences of receiving disability support to contribute to policy discussions and debate. Women who are on disability support experience economic as well as socio-emotional impacts on their lives. There is significant research which indicates that, in Ontario, the amount of disability support many receive is not enough and many people are living at or below the poverty line (3, 7). There is a rich body of literature on experiences of dealing with various stages and circumstances relevant to disability, but a limited body of work that looks at the specific experiences of engaging with long-term disability supports for individuals. What exists may speak more to specific practice-based issues for different support programs (8), different physical or mental health conditions, or addressing the needs of particular populations (9). Our study approaches disability support from a wider lens. We wanted to hear from women about their experiences navigating systems of support (across support programs), as well as the impact of coming to terms with being on disability supports over time, on their sense of self and their relationships. Within this exploration we

were also identifying challenges and opportunities. As the province of Ontario grapples with changes to its program of disability support (Ontario Disability Support Program), learning from individuals who live with the impacts of policy decisions is critical as changes in policy decisions have a direct impact on the quality of these women's lives.

## Methods

We conducted a small qualitative study to learn about women's experiences of disability support through semi-structured interviews in the Greater Toronto Area (GTA). Key informant interviews were conducted with women who were currently receiving public or private support for dealing with a disability in the last 12 months. The use of semi-structured interviews allowed for in-depth conversations with women that aimed to capture the breadth and uniqueness of each of their situations.

### Recruitment

Participants were recruited through a range of community-based organizations, including community and hospital-based health centres and NGOs, as well as professional and community-based network listservs throughout the Greater Toronto Area (GTA). The study used purposive sampling to recruit informants based on pre-determined qualities (10). The participant criteria used in this study included: self-identified women, over the age of 18, either currently on or have received support for dealing with a disability in the previous year, and a history of having participated in the work force. Women self-identified as potential participants. Twenty women expressed interest in taking part in the study, of whom 15 met the criteria outlined above and were interviewed. Women who were excluded from taking part either reported that they lived outside of the GTA or had not been receiving support for dealing with a disability over the past year.

Using a semi-structured interview guide, one-to-one interviews were conducted and covered the following content areas: demographics; women's experiences of accessing disability supports; the process of receiving disability supports over time; the health and social impacts of being on disability; and recommendations from the women on what changes they would like to see in how and what services are offered. While our team worked from a shared set of interview questions to guide the interview process, the questions themselves were qualitative in nature (framed as open-ended rather than closed questions). Working with a shared set of questions also allowed for consistency in the topics being explored across interviews. Each interview took approximately 40 minutes to an hour to complete and was audio recorded. Informed, signed consent was obtained from each participant prior to the interview. An honorarium of $25 was offered to each participant in appreciation of her time and knowledge, and participants were reimbursed for any travel expenses. Following data collection and analysis of the individual interviews all 15 participants were invited to attend one of two focus groups. The purpose of these groups was to report back our findings and recommendations based on the analysis and confirm that our interpretation and representation accurately reflect what the women shared. Eight women attended in total. Women attending the focus groups were asked to give written informed consent. Honorariums of $25 and travel expenses were reimbursed in appreciation of their time in the focus groups. Ethical approval was received from the Research Ethics Board at Ryerson University (REB# 2014-141).

## Approach

Consistent with participatory community research, this study brought together and was informed by the expertise of individuals with research, policy and lived experience. All members of the research team contributed to the design, implementation, analysis and write up of the research. Together we conducted a thematic analysis of transcribed interview data. Similar to grounded theory, thematic analyses requires an active engagement with the data that is collected in a systematic way. Thematic analysis is a flexible and accessible approach that is well-suited to participatory research (8).

Interviews were reviewed individually to identify common themes and trends. The team then came together to discuss their observations from this initial reading, and determine an open coding framework to be applied to the transcribed data. Next, we applied these codes to the data using a qualitative data management program (NVivo 10). Once the data was coded, the research team met and reviewed patterns and observations that emerged through this second level of coding. This second, more focused coding allowed us to take the earlier ideas and refine them, identifying a set of coherent and consistent themes throughout the data. The process of constructing and refining codes allowed us to consider themes and patterns in women's accounts of the lived experiences of being on long term disability (11).

Methodological guidance in qualitative research has supported samples of a minimum of 10-12 participants to reach saturation of themes (12). In the process of data collection and analysis for our study clear, consistent themes surfaced across the interviews and saturation was quickly reached. Once we had identified core themes and patterns in the data, we summarized these to share with participants. We invited the women who had taken part in interviews to come together for focus groups where we reported our analysis and observations of the findings to the women. The inclusion of focus groups served two core purposes. First, the groups allowed us to confirm the accuracy of what we heard from women, and clarify if any key points were missing from our analysis. Second, the groups served as a source of additional data. Through group discussions women were asked to help identify and prioritize the findings and key messages they felt were important in shaping policy recommendations. Participants were given a brief presentation summarizing the data from the interviews (with all identifying information removed). In order to elicit additional insights and impressions from participants, selected quotes were presented to the women for discussion. These quotes focused on policy-relevant and practice-relevant ideas that had surfaced in the interviews. Using these as a starting point ensured that the discussion remained closely aligned with the data and emphasized concrete options that could translate into action items for various stakeholders. Women were asked as a group to help identify options that they felt were important to prioritize.

In this brief report we provide an overview of the findings from the individual interviews and some of the recommendations that women suggested for policy and practice changes to disability support in Ontario.

## Findings

Interviews were conducted with 15 women living in the GTA who met the inclusion criteria. The participants' ages ranged from 31 to 65 with an average age of 47. The sample included women experiencing a range of conditions and reflects a diversity of communities across the GTA. At the time of the study, all of the women were receiving disability supports, with length of time ranging from two and a half years to

20 years. Nine of the women were on government-sponsored disability support, five of the women were on private long-term disability support with additional funds from a government program, and one received benefits exclusively from a private provider. Most women receiving government-sponsored benefits were on the Ontario Disability Support Program (ODSP) (n = 7), while only two women received income support from the Canadian Pension Plan disability benefit (CPP-D) alone. Participants with private long-term disability (LTD) benefits also received support from CPP-D, with the exception of one woman who received benefits from one private provider.

While each of these systems of support came with challenges, all of the women expressed gratitude for the support they received. Where women were working prior to receiving support for dealing with a disability, they noted employers' efforts around accommodation and support as positive and welcomed. However, these efforts often failed to provide adequate accommodation, despite employers' best efforts. This was largely due to a mismatch between knowledge and awareness of conditions women were facing, and the requirements of job settings. For a number of women the rapid onset of conditions made work accommodation unrealistic.

Many of the women found health professionals to be supportive. Namely, physicians were identified as important allies in the process of securing disability support. However, women also noted the challenges of working with health professionals who were unfamiliar with the process of applying for or confirming a disability, and how addressing the administrative side of disability support programs could prove frustrating and lengthy. These challenges coupled with the often rapid onset of conditions could leave individuals scrambling to meet ongoing financial obligations, while coming to terms with a new state of health.

The themes of visibility and invisibility were recurring ones throughout the interviews and focus groups. Women with conditions that were less visible (for example chronic fatigue, pain conditions, or mental health diagnoses) found the process of seeking and acquiring support could prove especially challenging. Women with more visible conditions struggled with the failure of those around them (outside of health care providers) to acknowledge the progression of their conditions over time. A common concern amongst participants included aging and the degree to which the support rules may change once they turned 65.

Three overarching themes emerged most clearly in the interviews and were confirmed in the focus groups: the trauma of dealing with the onset of disability; challenges related to navigating the system of disability supports; and the social impacts of being on disability. First, we explore the emotional impacts of accessing government disability supports and private LTD as described by the women. Second, navigating the system[1] emerges as a central theme across programs and breaks down to the following sub-themes: the application and assessment processes; the role of caseworkers; and the realities of coverage and benefits. Last, in terms of social impacts, we reflect on how women describe the impacts of disability and being on an assistance program in their everyday lives. Stigma, social exclusion and identity are subthemes that consistently surfaced in the interviews and focus groups. Each of these larger themes is interconnected and reflects the complexities that individuals face in reconciling the changes to their status as a result of

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1  In conversation women spoke of private and public disability supports as part of systems of care. However, these programs operate independently of one another with different eligibility requirements, processes, and levels of support, suggesting more of a patchwork of services and programs than a system of care.

an illness or injury, and the challenges that come with seeking to access support for these longer periods of disability. While our sample is small and cannot be described as representative, the commonality and consistency of themes are worth noting and provide some insight into the lived experiences of life on a disability support program.

## Emotional Responses to Long-Term Disability

Women reported that it was often an arduous journey from feeling ill or experiencing an injury, to getting an appropriate diagnosis, to exploring the range of disability supports (from accommodation, to short-term disability, to longer-term disability supports). There were challenges in their day-to-day functioning, well-being, and the realization that they needed support for dealing with a disability. For many the decision to seek support for dealing with a disability was made more difficult by their own mixed feelings. Their expectations for themselves as well as from others (e.g. families, employers, co-workers, health care professionals, insurance company representatives or government caseworkers) led to feelings of frustration and distress. Notably, women expressed stress and fatigue associated with application processes. They felt tremendous pressure to fill out forms correctly and have all their documents properly prepared, but found this difficult to do with the lack of information and support from the system of disability support they interacted with, whether public or private. Other aspects of the process were also described as emotionally draining, including having to repeat one's story to multiple caseworkers and unreasonable demands made by insurance companies. For women dealing with a new disability or a worsening of a pre-existing one, the difficulties of this process were described as added stressors for their health.

> You talk about the story again and again with each person. It might get easier so I'm not sitting here bawling my eyes out but there come the critical point and when you have to do it every month or every time the workers think that you're putting it on but you're not, this is raw emotion. But I'm able to talk to you and see someone and tell them to try but do I have a lot of joy and happiness in my life. Participant 2

As part of the process women feel they are seen with a high degree of suspicion and distrust. This is compounded for those whose disability is not clearly visible. Women at the different stages of the long-term disability process report heightened experiences of stress and anxiety throughout the various stages of the process whether it is when applying, being reassessed or near the end of the benefits. The challenges of working through the application and assessment processes are amplified as women come to terms with long-term illness and what it means for all aspects of their life including their identity.

> The process is dim for me. It was stressful, extremely stressful and I was sick at the same time. Had to deal with LTD and get all the chickens in the row for them to give me money and coping with being ill. It was devastating. The whole long-term disability [process] connotates [sic] that I am not worthy, cannot go back to work again. It was a stressor in terms of own psychological well-being which impacts physical and the rest of the well-being. Participant 1

At the beginning of the application process women describe being unable to absorb the quantity of information provided. For many this initial period remains the only time when information is made

available. Throughout the process of adapting to the new reality of seeking disability support women find information on supports and benefits limited. Yet these are opportunities — specifically those at periods of routine assessment and re-assessment — that are clearly underutilized.

> It's the system; it's the lack of knowledge about the system. You have to deal with your illness and everything happening with it, that's quite stressful and sometimes an unhappy place to be, how it's affecting you and your family and then deal with LTD. You need to know everything and there's no information here. Participant 3

The challenges of trying to access and work through the process of gaining support for dealing with a disability were clearly articulated by women. The process of reassessment and appeals, whether applying for government or private disability supports, were described as difficult. In many of the interviews, participants said that most people applying for disability supports expected to be denied and have to appeal. The appeal process was described as cumbersome and involved more waiting and uncertainty on the applicant's part.

## Navigating the System

Women in the study received benefits either from the government (via ODSP or CCP-D), a private insurer, or through some combination of the two. Most of the participants received disability support from a government program. Whether on a public or private long term disability plan, there are consistencies in how women described the process of navigating the system of disability supports. The substantive difference between forms of support centred on the amount of income support rather than the process itself.

The initial process of applying for disability assistance was one that women described as taxing and not supportive. Administratively, the process was seldom straightforward and instead was described as lacking clarity and transparency. As well, forms were often described as difficult to work through, with limited information guiding the applicant or her health provider. The time for processing applications was described as lengthy and administrative delays were frequent, at times leading to applications being denied.

> Everything was waiting and waiting and waiting. The way they write things is not how it works out. They say they make decisions at three months which, by the way, the court decides. They go by 90 working days. They give themselves four and a half months instead of three. Things like that are terrible frustrating. There are always expectations instead of what they tell you up front. Participant 4

> The process of going on ODSP is hard, very hard. There are so many forms to fill out and there is a long waiting period. That was very stressful, extraordinarily stressful. I remember being quite frustrated. I didn't understand things at the time. Participant 5

Similar frustrations were found with private insurance companies:

> The insurance company was pushy, gave me a really hard time…. We don't empower the patients to give them all the information they need to know their rights and know how to navigate the system so the companies can abuse and prey on their economic needs.

> So they push and the patient is fragile and afraid, perhaps doesn't have any other type of support that can allow them to fight. Participant 3

> [I] had to fill out a bloody big form myself…It felt like there was a right and wrong answer to the LTD question and that fear of getting it right. The little boxes — if you put the wrong thing in the wrong box or not give enough information then you are screwed for another three months and you get lost in the system. Participant 1

If their initial application was denied, applicants were typically not informed of the reason why and had to deal with an arduous appeal processes.

As the first point of contact in the public system (ODSP), caseworkers were frequently identified as a source of concern. When caseworkers were supportive it was acknowledged by women as helpful and critical to their adjustment to being on disability support. There was a common perception that the outcome of their application relied on the decision-making of a singular caseworker, which could be rescinded if that caseworker left. The high turnover of caseworkers amplified concerns about the stability of the support they received. Women reported frequently retelling their stories to different workers, and experienced a lack of consistency in the assessment processes. This fuelled concerns that new caseworkers might make decisions that could alter the continuation and amount of support they received.

> The process was quite painful because the case managers are not really knowledgeable about what it means to have a chronic illness like cancer that is not just broken bones that just gets good in two weeks. And surprisingly they didn't consider all the side effects of the treatment. Participant 3

Even when women recognized the challenges faced by their caseworkers, they saw their decision-making as focused on cost-cutting.

> The workers are all different, they're all humans. The one I have now is ok, but he likes to make a lot of cutbacks. Participant 6

Women on private LTD plans experienced similar difficulties with caseworkers who managed their files. Participants described experiencing great scrutiny and perceived private insurance companies as less willing to believe their disability, which placed a greater burden on them during the application process. In the interviews, women spoke about poor communication from the employer and/or insurance company, as well as demanding application processes. Describing the process for private LTD, one woman said,

> For the first one through the private it was a long process. They want this document and this document. They want the hospital record, the doctor record. It was hell. It was very complicated for me on top of having to adjust and heal from incidence and then had to deal with that. It was complicated and overwhelming. Participant 7

When women started receiving benefits, they felt as if they were under constant scrutiny by the insurance company to verify that their disability was still present. They also felt pressure to return to work whether or not they were ready to.

> Right now I don't find Canada Pension applying the same pressure as the insurance company. [but] Sometimes they would come to my house and say "oh, why don't you be

a babysitter." I had been a senior test analyst, it was sort of insulting. Participant 8

Women felt that assessments could "feel personal" and that they lacked empowerment because the caseworkers and/or insurance companies held all the power and made all the decisions, regardless of whether the disability support program they worked with was private or public. The system's many barriers and difficulties meant that women faced an added vulnerability of trying to navigate the process of disability support while also dealing with a challenging disability. On this issue, one woman said, "it was difficult. It was kind of you were already sick but at the same time they were making it harder for you to do that" Participant 9. For many women these challenges led to increased experiences of stress and anxiety.

## Types and Amount of Support

Overwhelmingly women spoke about the inadequacy of the support they received in dealing with a long-term disability. With the exception of one woman, all the participants noted that the support they received, whether private or public, was insufficient to meet their daily needs. While most women said they were grateful for the money, they expressed the need for more income support to cover day-to-day expenses.

For people on ODSP income is determined by family size, income, assets, and housing costs and a single person on ODSP receives $1,098 per month. For many women this amount is not always enough to cover their needs.

> It meets my bills some months. I try to save if I don't have an expense one month. Some
> months it covers, other months I might have to dip into my savings. Participant 8

Recipients of private benefits generally said they received more money from their programs than they would on a government program. Women felt they had little choice but to deal with the difficulties of the program due to this higher, but still inadequate, income.

Some women found the financial limitations of disability support also had implications for their everyday health and well-being. Women with special dietary needs were unable to afford the food they required, as one participant observes: "[I] don't eat as well as when I could afford to eat properly and well. My health has gone down as well, this goes with poverty." Participant 8

In some of the interviews, women felt that they "fell through the cracks" regarding access to health benefits. Women on ODSP have some access to health benefits from government programs (e.g. the Ontario Drug Benefit), which includes prescription drugs, basic dental and vision care and medical devices. While participants noted their appreciation of these benefits, they also cited the limitations of these allowances and how they worked against recipients. As one woman put it,

> ODSP contributes $30 towards glasses. You get a dental card but try and find a dentist will
> take it and they cover hearing aids but that isn't what it looked like. ODSP does allow you
> to make some money but being self-employed they don't allow to deduct expenses. Found
> I was barely breaking even. There is a really booby trap if you are turning 65 everything
> you make the year before is deducted for GIS. They claw it all back. The ODSP has already
> taken on half of it. Participant 5

Health benefits coverage for private LTD, on the other hand, varies depending on the plan purchased by employers, which meant that some women received benefits while others did not. Those who did not

receive benefits from their private plans also were not entitled to public health benefits. Added to confusion surrounding private plans, most plans were described as time sensitive, meaning that recipients' access to benefits would expire after a set period of time. Some women did not know how long their benefits would last for or what they could or would do after this happened.

Women on private LTD programs said that they could not work or volunteer while on the program. If their insurance provider found out that they were working or volunteering, they would be deemed fit to resume full-time employment, which would put their disability benefits and security net at risk. Participants receiving ODSP coverage said they could work but identified high claw back rates and confusing rules about returning to work as barriers to gaining employment. In our sample, only two women were working, either part-time or self-employed. Those women who were not working said that it was not in their best interest to do so. When their disability income was adjusted to accommodate their employment income, women said that they would maintain the same overall income or even end up with less. For this reason, interviewees made it clear that they saw little or no financial benefit to gaining employment. Women on ODSP did not face barriers around volunteering.

The lack of a safety net provided by the private LTD system made it difficult and sometimes impossible to return to work. Rules for returning to LTD differ among private insurers in cases where a person decides to leave private LTD to return to work but her disability once more becomes an impediment to continuing work. Some may allow her to apply to return to the program, while others may consider the case to be one of a pre-existing condition that disqualifies her for LTD coverage. The uncertainty and ambiguity of this system makes it difficult for women to return to full-time employment because of the risk that help might not be available should she need it again. She can, however, switch to the public disability support programs (i.e. ODSP), but will likely experience a reduction in her income benefits. The public system is a little more forgiving and women can return to the program if need be, however there will likely be a gap in the resumption of benefits, which would put them in a precarious situation. For women with episodic disabilities, the rules around employment and volunteering leave them largely unable to take advantage of periods of greater functioning and less disabling symptoms without jeopardizing the stability of their support.

There was a general sense of uncertainty among participants about what would happen to their disability benefits and income after they turned 65. Some women clearly understood the new classification they would be transferred to and even looked forward to the increased money they expected to receive from a combination of public programs. Others were unsure about their financial futures and worried about having sufficient income to meet their needs after the age of 65.

## Social Impacts of Long Term Disibility

All of the women interviewed identified social impacts in their lives as a result of going on/being on disability supports. Perceived stigma, a decline in their social networks and social activities, and personal changes in their sense of identity were consistently raised by women as some of the impacts they experienced in everyday life.

For those women who had experienced stigma, they described more situations where they felt judged if their disability was not visible.

> [I] feel like others think I am taking advantage of the system. Participant 10

> [Being on disability assistance]… it immediately puts me in a class, I am now disabled in society's eyes… You become invisible to society because the main important thing you ask is where do you work. Participant 1

> People who know you are on government assistance think you are a drain on them personally… We are thought of as cheats, bad people, failures as human beings. Participant 4

Social isolation was described as another negative impact of the low income women received. After paying for everyday necessities, women barely had enough left over for transportation or other costs associated with social engagement. Participants also expressed embarrassment of their situation and finances, which also hindered their ability to interact with others. The inability to afford transportation kept some women homebound and restricted their social life to online activities and phone calls.

> My social life has decreased by about 90 percent. Because of the disability, people avoid me, I'm not included and I'm not financially able to join in. Participant 11

> I don't go to the movies or out to eat. I don't have any social things to do. My money goes to rent and the foods I have to eat. So there's nothing extra. If I want to go on the subway it's because I have my token, I don't have a bus pass. It's how I have to plan things. Participant 2

Not all participants experienced social isolation in the same way. One woman maintained the same social life with support from other people. Further, a handful of women also took the opportunity of not working to engage in other activities, such as conferences, classes and support groups. Such stories were few, however, and the uptake of these activities varied among women as some found it difficult to participate in activities due to lack of information about them and financial and transportation limitations.

Finally, limitations placed on participants' abilities to work or sometimes volunteer also contributed to their experiences of social isolation. Restrictions placed on women's abilities to gain employment or volunteer opportunities separated them from co-workers and other friends. Many women said that working was a part of their identity and viewed it as a way of contributing meaningfully to society. The inability to work then had strong, negative impacts on how they defined themselves and how they thought others defined them. As one woman put it, "we are such a work driven society, if I wasn't working I was nobody" Participant 1.

While some women said that they were entitled to some disability support and benefits, often because they paid into some type of program, others said that it felt like a handout. One woman commented that "the main surprise is even though you have that income security you still feel invalid… For me I still feel like I shouldn't take money unless you work for it" Participant 7. The majority of women we interviewed had a strong identity based in their work, making it difficult to go from an active work history to an identity shaped by the experiences of not working due to disability. In addition to the challenge of reconciling these competing identities, women found their social life was often structured around their work lives. This was something that was damaged or no longer existent in their new lives on disability support. Whether long term disability was viewed as an entitlement or a handout, all the women experienced changes to their self-identity as a result of receiving the benefits. Some spoke about having to present as disabled to receive benefits, and if they started to look or feel better they were worried about how it would affect

their entitlements. There was an idea that you would be penalized for looking good or living better which created a disincentive for actually getting or presenting as "better."

## Policy and Practice Discussions

Following data collection and analysis the research team invited all of the women who took part in the study to come together to be part of a focus group discussion. Two focus groups were held. The groups were an opportunity for women to learn about the progress of the study and the findings of the research, and to engage in a discussion about the policy and practice recommendations that had been raised in individual interviews.

Discussions in the group echoed the findings of the interviews. The lack of clarity on navigating systems remains a critical concern. This ranged from working with health care professionals to complete forms, to receiving information about supports and supplementary care in the community . The amount of financial support was consistently described as inadequate, which for most women meant that they lived in or near a state of poverty. In addition, while women acknowledged gratitude for the support they received, they were also conscious of the complex arrangement of disability support and the growing urgent and unmet need across communities, as well as the human component of the experiences of people on disability may get lost or overshadowed.

Women noted that neither system of support, whether public or private, provided adequate support. Critically, the income levels offered remain inadequate for most people. While some systems (ODSP) allow minimal supplementary income, it is subject to claw back. For the women, this meant that there was little support for them when looking to returning to work. From the women's perspectives the rules impose a rigid definition of disability that sees people as wholly disabled or wholly able bodied. This definition fails to reflect the realities of women's lives. Unaccounted for in this all-or-nothing definition is the episodic nature of some disabilities (including mental illness, immune disorders, and other chronic, recurring disorders).

The lack of ability to move from a state of being unable to work to being able to work over time was described as problematic. In practical terms it left women unable to take steps toward re-joining the work force without compromising the stability of the support they received. Instead some women spoke of the pressure to return to work regardless of their health status and current level of functioning.

The process of managing their disability or working towards improved functioning was generally constrained by a lack of information and guidance about supports from disability support programs and the wider community and health services. The lack of information was pervasive, impacting all aspects of the disability support journey from the ability of health providers to complete forms, to the ability of people on support to access information about supplementary care or services that could be useful in their recovery or enhance the ability to adapt to life with a disability.

Some women articulated the concern that lack of access to information was largely driven by fear and apprehension. Claimants were seldom given full information about which supports they could access or apply for, or services external to disability supports that could be of use (community, social, legal for example) for fear that these would "be taken advantage of and abused" Focus Group 1. Others noted that services tended to be compartmentalized by sector or by geography, which added to exclusion. The lack

of consistency in accessing services, or in acquiring information about services prompted women to call for coordinated, comprehensive care:

> I wish there was an umbrella organization so that you could define the functions of it and then everyone would fit into these organizations and then we would know exactly what is needed. They are all so scattered and they are all over the place. I think it is intentional that they are all scattered and all over the place and you don't know where to go. Focus Group 1

The lack of system-level supports and the ongoing need for support to navigate services and programs is further amplified by the fact that many are dealing with ongoing social, emotional and physical impacts of disability. Many noted these impacts were subject to change over time, particularly as they aged.

Women were asked to consider and prioritize their recommendations to policymakers and service providers working with NGOs and community health services about ways to improve systems of support relevant to disability assistance.

A variety of recommendations emerged and were specific to the process of seeking disability support. There was a call to streamline the systems of support, providing clarity and transparency to the process of seeking support and information about disability support. Women spoke of the need to improve the systems (whether private or public), to make them more efficient, and to raise the amount provided. Finally, women spoke of the need for an evolving system of support to work across sectors and respond to the unmet needs of individuals over time.

## Discussion

'LTD is hostile to people with disabilities'
    Participant, Focus Group 1


The impact of physical and psychological disability on women's health is substantial. Women have a higher prevalence of disability than men across all age groups (4). In addition, long-term disability is more severe, as well as more frequent for women than men, including higher rates of chronic conditions such as arthritis, chronic pain and issues with mobility (5). However, a noted gap in the literature has been attention to the lived experience of being on disability assistance (rather than experiences of disability more broadly) (2). What limited research exists points to systemic barriers. For example, in a study of barriers to ODSP experienced by homeless people in Toronto, the findings reported: people with cognitive and mental health challenges struggled to follow telephone instructions; people trying to shift from Ontario Works (OW) to ODSP struggled to adequately explain their situation to OW caseworkers; and getting medical forms accurately filled out was difficult in some cases (2). The same study noted that delays in administrative processes resulted in a lag in applicants' access to benefits, a high denial rate, and resulting financial burden for applicants who had to appeal the decision (2). The barriers to and delays in benefits negatively impacted people's health and well-being.

The stories told in this study speak to the difficulties women experience with disability assistance programs. Most notably, the application processes for disability support are not friendly or easy to navigate. The resulting disempowerment and delayed access to benefits was harmful and difficult to handle, especially

when added to dealing with a disability. For individuals with certain forms of disability (i.e. less visible conditions, chronic or episodic conditions), this may be even more pronounced as they struggle to justify and gain (or confirm) the institutional recognition necessary to receive public forms of income support (13). Confusion about how to navigate the systems of health and social support can magnify the barriers that exist in identifying entitlements, accessing and maintaining support, and understanding when or whether a return to work is wise or feasible (14) .

Women reported a significant gap in the information available related to disability support programs and often find they stumble upon entitlement and program information (15-17). Consistent with the findings in this study, in a small study of ten Ontario women with disabilities, nine of the women said they did not have access to current and relevant information about the ODSP (16). The challenges of navigating this system can be made more difficult by a rapidly changing array of workers, whose role is perceived as a gatekeeper to support. Moreover, the perceived judgements that women described point to a strong sense of stigma in their everyday lives, which can affect their self-identity.

## Conclusions and Recommendations

Women who are applying for and living on disability support experience a diverse array of impacts starting from the process of applying for support, maintaining support over time and coming to terms with the broader impacts that result from this transition in their lives. For the majority of the women this was a time of upheaval, stress and anxiety which was unnecessarily exasperated by different aspects of securing and maintaining long-term disability support.

Their recommendations include:

**1. The process for accessing disability supports (through private and public support programs) should be streamlined to be more client-oriented, consistent and transparent.**

- Application forms should be redesigned with clear language and design principles.
- Information systems should ensure timely updates and appropriate information throughout the process, providing information about the supports, and educating clients on how to transition from disability assistance to other financial supports (e.g., Old Age Security for people over 65).
- A Human Resources Strategy to recruit, train and retain knowledgeable and compassionate staff that understand issues related to disabilities to help support applicants and the health professionals that are treating them.

**2. Whether on private or public disability support programs, the current levels of income support are insufficient to keep people with disabilities out of poverty.**

a. Disability assistance rates need to be raised to ensure a basic standard of living for all people.

b. Policies should be developed that allow women receiving disability support to participate in some way in the work force or in the community without losing benefits. The current claw back rates and employment rules are significant barriers to women who want to seek employment. The barriers are even greater for women on private LTD who are not allowed to work at all while receiving benefits.

**3. Disability assistance recipients would benefit from greater support in navigating the process of disability.** Women spoke about their difficulties in accessing information and navigating an often complicated process. Having an advocate through a community organization or NGO could help people navigate the system and make use of community supports that could minimize experiences of social exclusion and

stigma. In addition, suggestions were made for support throughout the process of receiving disability support, including follow-up meetings to ensure the process is going smoothly and to review again the supports and benefits available. As time progresses and women further adjust to having a long-term disability and their "new" reality becomes their "new" normal they might be interested in hearing again about the diverse supports and benefits available (particularly social supports) as they might be ready to access them at this point in time. When women are transitioning off of disability support because of age (reaching 65) it is imperative to have a meeting which includes a review of supports and benefits available at this stage.

## Limitations

This small qualitative study offers a glimpse into the lives and experiences of women receiving disability supports in the GTA. As a small community-based research study, the study has limited ability to inform policies or to shape practices in the area of disability supports.  However, there are consistencies in the stories that we heard from women that warrant greater attention. In our sample we strived to ensure that we had broad representation of women from across communities. As our study is limited we only heard from a fraction of women affected by issues related to physical and mental health disabilities. Further research is needed to ensure that research in this area creates opportunities to learn about the experiences of those individuals who may be more vulnerable, and less likely to volunteer for research of this nature.

While the sample size in this study is small, the response from women receiving disability supports is worth noting. Recruitment for the research was relatively brief due to the strong interest we received from women. We heard from interested women from across the province and from some nearby provinces. Those women who did take part expressed a strong appreciation of the opportunity to do so. Specifically, they articulated a sense of powerlessness about the processes of seeking disability support and the lack of a safe space where they could voice their concerns with their disability supports provider. Although some women found it difficult to tell their stories in the interviews, they felt that it was important to include their voices in discussions about disability supports and to hopefully affect change. What this process showed us was the critical need to ensure that public consultations are built into the discussions and debates around systems of disability support in the province. These processes need to be accessible and open to people who are receiving or have received disability support in Ontario.

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