MORE THAN A FOOTNOTE

A Research Report on Women and Girls with Disabilities in Canada

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DisAbled Women's Network of Canada

Publishing Information

Credits

Acknowledgement

Disclaimer

This research report represents the opinions and philosophy of our organization, and is not necessarily shared by the funder. We also note that this report is a first step in documenting the conditions and lived experience of women with disabilities in Canada.

DAWN Canada is aware that the photographs used in this report are not representative of all women with disabilities. Indeed, we had difficulties finding images that represented a plurality of women.

Contact

Contents

About DAWN Canada

Established In 1985, the DisAbled Women's Network of Canada (DAWN) is a national, feminist, cross-disability organization that has provided opportunities for self-determination and leadership development for women with disabilities for more than 30 years.

Our mission is to end the poverty, isolation, discrimination and violence experienced by Canadian women with disabilities and Deaf women.

DAWN Canada works towards the advancement and inclusion of all women and girls with disabilities and Deaf women by creating change at a systemic level. This includes building strategic partnerships, developing research reports , curriculum and educational tools, and addressing policy change.

Staying true to our grassroots, we keep women with disabilities at the center of our work. We amplify their voice by ensuring that they are represented at decision-making tables.

Glossary

Brain Injury // Where we use "brain injury" we are referring to injuries to the brain which are not congenital, degenerative, or hereditary (i.e. the result of a blow, substance use, brain events like tumors etc.).[1]

Disability // Throughout this report when we use the word "disability" we are using it in a way that is cross-disability in scope. This is inclusive of a range of disabilities (mental health, mobility, sensory etc.) as well as those who have yet to receive an official diagnosis and/or those who self-identify. We have chosen to be as inclusive as possible when using the term disability as a part of our commitment in this research is to include those with disabilities who remain invisible and uncounted.

Episodic Disability // Where we use "episodic disability", we are referring to long-term conditions characterized by periods of good health that are interrupted by periods of illness and/or disability. These periods can vary in length and severity and change from one individual to another. [2]

Gender Identity // "Gender identity" refers to an individual's concept of self (as female, male and/or neither). [3]

Indigenous // An umbrella term to cover the diversity of Canada's Indigenous population including First Nations, Metis, and Inuit.

Intellectual Disability // Where we have used "intellectual disability" we are using it in reference to disabilities that impact learning and communication.[4] Here again, self-identification is an important factor.

LGBTQI2S // Where we use "LGBTQI2S" throughout this report it is to refer to those who identify as lesbian, gay, bisexual, transgender, queer/questioning, intersex, and two-spirit.

Women and Girls with Disabilities // Throughout this report when we use the terms "women and girls", we use these inclusively for all those who identify in these ways. We have also tried to capture a life course analysis that considers the lived experience of girls with disabilities (under 17) and women with disabilities as they move through their lives (young adults, working age, seniors etc.).

Universal Design // "Universal design" refers to environmental products, programs, and services that have been designed to be usable by all. A key feature of this kind of design is that it can be accessed by users to a great extent without the need for adaptations.[5]

Note about language:

Throughout this report we have used person-first language to be consistent with the organizational practices of DAWN and partner organizations. The use of person-first language throughout this report is also one of the ways we have created a space for intellectual disability and honored the language preferences of our partner organization (People First) and their members.

Forward

This report begins to create, for the first time, a more fulsome picture of the issues and concerns Canadian women and girls with disabilities are facing.

There is limited empirical evidence available from which to draw an accurate portrait of the social, economic and political situation of women with disabilities and Deaf women. Further, although Statistics Canada reports that 1 in 5 women in Canada lives with a disability, while this is not insignificant by any means, because much of the data is based on self-identification, it still represents a significant gap in understanding that the intersection of disability impacts a very high number of women and girls in Canada.

Through this research DAWN Canada has intentionally identified and examined populations that are under the radar in terms of quantifying and identifying 'who are women and girls with disabilities in Canada' including brain injured women, women living with episodic and chronic illnesses or pain, and women with intellectual and learning disabilities, many of whom live a lifetime of un-named stigma and discrimination.

To date, the available information, whether research-based or anecdotal, had never been gathered or analyzed in a comprehensive way that could be used as an evidence-based platform from which coordinated policy and programmatic responses could be developed.

Even less is known about girls with disabilities. One of DAWN Canada's most serious concerns is the complete lack of research, information, advocacy and representation of children with disabilities in Canada, particularly girl children and adolescents.

Women with disabilities in Canada have the highest rates of unemployment and poverty, and lack full access to education and health care, including sexual and reproductive services. There is emerging evidence that they are being criminalized and incarcerated due to their disabilities, and that women are becoming disabled (or further disabled) due to intimate partner violence.
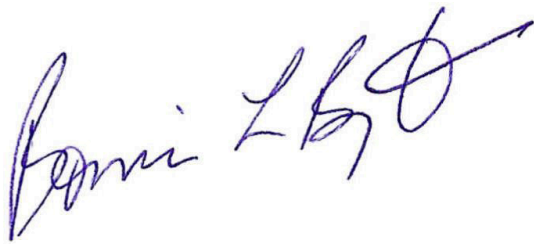
Indeed, the most pressing problem they face is violence. According to the Canadian Centre for Justice Statistics March 15, 2018 report on Violent Victimization (physical assault, sexual assault or robbery), in 45% of all incidents of violent crime, the victims were women with disabilities. As well, victimization among women with a mental health-related disability or with a cognitive disability was four times higher compared to those without a disability.

In May 2017, the UN Committee on the Rights of Persons with Disabilities presented their concluding observations and recommendations to Canada, and identified women with disabilities as a key constituency for action.

The gravity and scope of this situation cannot be addressed through short-term means. Rather, an effective response to the social and economic exclusion of women with disabilities must address the long-standing and systemic gaps in policy, programs and services that have resulted in the current situation. Such a response must necessarily be national, coordinated, inter-governmental, cross-ministerial and cross-sectorial. Such a response must be informed by empirical evidence.

While feminist academics and researchers have built a significant body of work on Canadian girls and women, most of that research has been and continues to be done without an intersectional lens, particularly the disability lens. As a result, there is an absence of analysis of the implications for women and girls with disabilities and Deaf women and girls.

More Than A Footnote: A Research Report on Women and Girls with Disabilities in Canada is a call to action that affirms why the Committee on the Rights of People with Disabilities placed so much emphasis in its recommendations to Canada on the situation of women and girls with disabilities in Canada. It affirms the urgency of moving forward and the need for a national discussion that focuses on the full social, economic and political inclusion of women women and girls with disabilities.

Bonnie Brayton,
National Executive Director
DAWN Canada

1. Introduction

Women and girls with disabilities face unique challenges and barriers that require unique approaches in terms of research, education, policy, and practice. It is from this place that Disabled Women's Network (DAWN) Canada[6] crafted this research project in order to better understand the key issues facing women and girls with disabilities in Canada. This report will summarize these findings, including key aspects from the literature, policy makers, community and activist resources, and partner organizations.

1.1 Importance of Partnerships

As disability itself is often presented as a monolithic experience, and certain disabilities, including invisible ones are often absent in the literature, we have partnered with People First of Canada,[7] **Realize,**[8] and the Acquired Brain Injury Research Lab[9] to ensure attention to important and undertheorized aspects of certain disabilities are covered in this report. We are hopeful that by creating a space and giving attention to these often unseen disabilities we can be more inclusive in terms of both disability and gender analysis. We also recognize that disability itself, specifically invisible disability, can have unique gendered aspects that largely remain overlooked in disability research and policy. An example is burgeoning research around women and traumatic brain injury (TBI) that among other things indicates a high percentage of women offenders with this condition.[10] These are the often times invisible threads we seek to highlight in this report in an effort to make the case that gender and disability do matter and should collectively occupy more space in both gender and disability research.

1.2 Methodology & Framework

We have placed an emphasis on community literature in an effort to bring together the work of activists, policy makers, and community scholars to ensure their insights are included in this analysis. In doing this, we are also working to address concerns that traditional research, both in terms of process and final product, can be exclusionary of community and grassroots perspectives. Furthermore, we have promoted research and resources that are open-access wherever possible as we recognize that paywalls and restricted access often exclude the very subjects of the research. For the purpose of this review then, we have strategically focused on certain kinds of literature. This is not to say that other sources are not of importance, and we have included a larger bibliography in the appendix. Additionally, DAWN is committed to finding ways moving forward to build and share resources that enrich the possibilities for more intersectional and gendered analysis where disability is concerned.

In practical terms, we've pulled from a number of resources that all use different methodologies, yet our goal in doing so is to provide a snapshot of the lived experience of women and girls with disabilities in Canada. We know that women and girls with disabilities face unique challenges and needs, yet in the context of Canadian research a gendered and intersectional lens is missing. We hope this report serves as a call to action and a first step in the active engagement of these issues through a more inclusive and intersectional lens.

As we recognize there are significant gaps in the literature, some original research was conducted. This included 5 key stakeholder interviews on issues related to disability, intersectionality, and gender, interviews with 5 women with intellectual disabilities, and a facilitated session with 25 members of People First to better engage persons with intellectual disabilities in this research process. While our larger group discussion with People First was mix-gender, there was a greater number of women in the room and this initial discussion has helped identify the

need for specific group discussions with women with disabilities in terms of next steps. This report will include highlights from this work. However, because the information we gathered was so rich and our timelines so tight, we anticipate that this report will serve as a first phase in this research process, with other more textured analysis following in our next steps.

As women and girls with disabilities experience a diverse range of barriers and needs, we have organized this report to to examine key issue through a gendered and intersectional lens with specific attention to disabilities that are often invisible. The following sections reflect how the research has been organized:

- **Social Exclusion**

- **Income and Income Security**

- **Education**

- **Employment, Unemployment & Working Conditions**

- **Livelihoods (unpaid labour and other contributions)**

- **Girl Children and Youth with Disabilities**

- **Food Insecurity**

- **Housing**

- **Health Services & Well Being**

- **Sexuality**

- **Gender Identity**

- **Violence & Abuse**

- **Transportation**

While not exhaustive, we acknowledge this report is a first step in better understanding these issues and that these sections will provide a foundation for next steps in these areas. Below are specific considerations we have tried to include throughout this analysis (these include a life course analysis, geography, Indigenous status, and race).

1.3 Life Course Analysis

Women and girls with disabilities experience different things throughout their life course, and where possible, we have tried to include this in our analysis. For example, in Canada more women than men report having an activity limitation and as daily tasks tend to become more difficult as people age (weaker muscles, stiff joints, incidents of chronic illness etc.) women report a steady increase in activity limitation as they age (1 in 3 by their 80's).[11] We know then that where disability rates and aging are concerned, there is the need for a gendered analysis. As such, wherever possible we have sought to include evidence that reflects how a life course analysis matters for women with disabilities. Of note is that this was one of the key gaps our stakeholders shared with respect to existing literature. As many of our stakeholders noted, we know very little about girls with disabilities in Canada and there is also a need for more work addressing the needs of women with disabilities as they age.

1.4 Geography

Where one lives can seriously impact their access to supports and services, and this reality also shapes the experience of women and girls with disabilities in Canada. In rural areas, higher rates of disability and chronic illness are reported.[12] Older Canadians have unique disability-related needs as things like depression may be more prevalent later in life, especially among rural and isolated persons.[13] For women with disabilities who live in Northern communities, needed services and supports may not be available and women may have to leave their homes and travel to access them, additionally, climate itself may present unique barriers as things like snow may be difficult to navigate and being able to afford to pay someone else for removal may be difficult.[14] As such, throughout this report we've

tried to pay attention to the ways in which where one lives influences the lived experiences of women and girls with disabilities in Canada.

1.5 Indigenous Status

While there are major gaps in the literature with respect to gender, disability, and Indigenous issues, we recognize that Indigenous women and girls with disabilities require attention in this research. To this end, in both our review of the literature and interviews with stakeholders we have sought to address these gaps. In terms of situating the overrepresentation of persons with Indigenous status in many of the areas our research looked at, it is important to contextualize this in terms of the role of historical and intergenerational trauma. This begins with an understanding that Indigenous persons have been impacted in unique ways in Canada because of their relationship with the government, mainstream society, and the churches.[15] Thus we start from a place that recognizes the historic and continued violence of colonialism and how this shapes Indigenous lived experience. As there is evidence to suggest that Indigenous people in Canada are reported as having higher rates of disability [16] we seek to draw attention to these important issues throughout this report.

Through our stakeholder interviews the lack of gendered analyses of disability and Indigenous issues was highlighted. Other key issues emerged in our discussions that are important considerations. First, there is incredible diversity in the Indigenous experience in Canada. Experiences are shaped by things like location, place on and off-reserve, language, culture, and governance. As such, there is no one experience of being Indigenous in Canada as these are layered and complex identities. Second, there are inherent tensions between the concept of disability itself and Indigenous ways of knowing that must be acknowledged. Disability, which is often viewed as a marker of difference in western culture, is conceptually at odds with ways of living and knowing that do not see disability as

difference. One of our Indigenous key informants with a disability underscored this when they shared that it was not until they entered university and began to learn about disability through the lens of social work that they understood disability was conceptualized differently by some and as a negative thing. For them, this created conflict as it illustrated the very real differences between how they were perceived in two very different worlds. This is important to keep in mind, and while this report cannot fully explore these nuances, we want to acknowledge these tensions and their importance in future work around the lived experiences of Indigenous women with disabilities.

Finally, as one Indigenous stakeholder noted, there is a need to go beyond this current moment, which is marked by big systemic initiatives (truth and reconciliation etc.) and ground next steps in an anti-racist approach that concretely tackles embedded forms of racism that continue to shape the Indigenous experience in Canada. Here then, it is important to acknowledge the continued role of systemic racism in the experiences of girls and women with disabilities in Canada.

1.6 Race

While the lives of persons with disabilities are shaped by race and ethnic status, there are still gaps in research with respect to these intersections, and the research which does exist tends to be grounded in the needs of service providers (culturally appropriate services).[17]

In terms of the Canadian context, there is a need for less work addressing "culturally competent" services and more work focused on the root causes of inequity.[18] Throughout this report we have tried to include research and evidence of how the lived experience of women and girls with disabilities may be shaped by race, and in particular how racialized bodies are impacted in unique ways.

The four broad areas outlined above have been woven throughout this report. Of note, is that we have tried to be intentional in identifying existing gaps as a means of continually reminding ourselves and the reader what voices and experiences are typically absent. We have done this in part because our literature review confirmed the extent of many of these gaps. We also acknowledge that this report is not exhaustive in terms of the issues and barriers, and instead serves as a starting point where the gendered experience of disability in Canada is concerned.

While the literature is broad in the area of women and girls with disabilities, we have placed an emphasis on the Canadian experience, and worked to highlight research and writing that is illustrative of the barriers women and girls with disabilities face, as well as their capacities as full and equal participants in Canadian life. It is also important to note that the lived experience of disability is both complex and diverse and there is no monolithic experience of having a disability. Additionally, the barriers women and girls with disabilities face are also diverse and there is often overlap and interplay throughout the life course and among various different issues. We must also note that the literature on women and girls with disabilities spans several disciplines and given this we have tried to focus this report on threads within the research that help make up a more complete picture of what it is to be a girl or woman with a disability in Canada. As such, there are pieces that while useful fell outside of the scope of this initial report, yet we see these as integral to work in this field and next steps.

2. Unique Needs

In general, disability research has failed to fully appreciate gender dynamics and their influence on the experience of disability. Conversely, many gender-based research initiatives have failed to include a disability lens. As such, our goal in this report is to highlight the often invisible nature of the experiences and contributions of women and girls with disabilities, and draw attention to those spaces where their inclusion is critical. We seek to fill noted gaps where the intersections of gender and disability are concerned.[19] Women with disabilities are uniquely situated as they face discrimination linked to living in a male-dominated society as well as oppression rooted in living as a person with a disability in a society geared to able-bodied needs.[20] In Canada, statistics reveal that a greater number of women than men report having a disability, 15% for women and 10% for men,[21] thus a gendered analysis is important. Additionally, for women, the experience of disability may be different and require unique insight and solutions. As an example, because men tend to experience traumatic brain injury (TBI) at higher rates, there is a real gap in examining the impacts of TBI on girls and women, yet the frequency of injury indicates that millions of women are injured in this way annually.[22] This speaks to the unique needs of girls and women in this space and the need for more gendered analysis.

Throughout this report we will draw on resources, literature, and research that help illustrate the complex, layered, and valued experiences of women and girls with disabilities in Canada. It is important to note that there are many of these experiences that overlap, both in terms of the life course itself and because women and girls with disabilities lead holistic lives that are not always easily categorized. As such, we will endeavour to make connections between these areas throughout the report.

3. Social Exclusion

Social exclusion can be defined as the process of being denied opportunities to participate in various aspects of Canadian life, and we recognize that specific groups experience this at higher rates in Canada[23], including women and girls with disabilities. Social exclusion is experienced through four unique aspects which include: barriers to participation in civil affairs like laws and regulations, barriers to social goods like health care, exclusion from social and cultural opportunities, and economic exclusion.[24] In Canada, persons with disabilities experience exclusion in all these areas, and as this report illustrates, these lived experiences of exclusion are often times unique for women and girls with disabilities. With nearly half (49%) of all discrimination complaints in Canada grounded in disability, there is ample evidence that social exclusion continues to disproportionately impact persons with disabilities.[25] This was underscored by one of our stakeholders who noted social exclusion remains one of the most important areas for them as "it's hard for some women [with intellectual disabilities] in a social area or a social place… they are quite shy...they don't know how to open themselves up to other people...I want to crawl into my little shell…" We spoke about how a lack of inclusion fueled these feelings as some women we spoke to didn't feel they were ever given the skills they needed for inclusion early in life. Another stakeholder touched on this and noted there is very real isolation for many women with disabilities because of these dynamics.

Social exclusion is a process that can be very different depending on one's disability. For example, women with intellectual disabilities or mental health disabilities may experience the threat of institutionalization differently as persons with intellectual disabilities are still institutionalized, including in large institutions, long-term care facilities, nursing homes, and other residential facilities.[26] With episodic disabilities, stigma can be experienced uniquely as health conditions that can, in combination

with the environment, result in episodic disabilities including some conditions that are highly stigmatized. For people living with mental health related disabilities and/or HIV the experience of stigma can be a very regular occurrence. Stigma is also known to have an impact on the well-being of people living with HIV.[27] As well, women living with HIV face additional intersections of stigma, particularly if they are also members of an ethno-racial minority, are LGBTQI2S and/or are sex workers.[28] Women living with mental health conditions also experience stigma related to their episodic disabilities. For women living with stigmatized episodic health conditions, social exclusion can be increased as individuals seek to avoid stigmatizing interactions by avoiding social situations.

With our attention to invisible and episodic disabilities, we also acknowledge that stigma may impact lived experiences in unique ways that exacerbate social exclusion for some individuals. Of note is how the interplay between stigma, social exclusion, and invisible disability may impact disclosure (the process of sharing one's disability and/or disability related needs), an often integral process of accessing disability supports. As most episodic disabilities are invisible, decisions about disclosure must be made on a day-to-day basis and person-to-person basis. In research related to women living with fibromyalgia, disclosure decisions were likened to "impromptu disclosure dances" where women must decide if and how much information to share depending on assessments made regarding the risks involved.[29] Throughout this report it is important to remain mindful of the women with disabilities who may be invisible within the research because of these complex dynamics.

Social exclusion can have important impacts on individuals and their ability to thrive, as strong social support, particularly for women, has been linked as a strong determinant of health.[30] It is because of this that the issues explored throughout this report are of such importance, as gaps and barriers here perpetuate forms of social exclusion which lead to greater inequality and marginalization.

4. Income & Income Security

Income has been called one of the most important determinants of health as it shapes overall living, as income security measures are designed to protect individuals as their lives shift.[31] Together, income and income security measures speak to the ability of individuals to thrive and have access to needed supports and services. Yet for women and girls with disabilities, there are real barriers with both income and income security.

Poverty rates in Canada begin to shed light on the unique needs of women and girls with disabilities. In Canada, persons with disabilities are twice as likely to live in poverty.[32] Of Canadians living in poverty, between 26%[33] and 33%[34] are women with disabilities. Women thus remain more likely than men to experience poverty[35] and the risk factor for poverty increases when compounding factors like disability are present.[36] We also know that the risk of living in poverty increases for persons with disabilities if they are also women, racialized, Indigenous and/or lone parents[37], so intersectionality does matter. For children and youth, we know that poverty disproportionately impacts racialized groups,

"Out of those who live in poverty between 26% and 33% are women with disabilities."

Indigenous persons, recent immigrants, those with disabilities, and children in households led by lone parents who are women.[38] Age is also an important factor where poverty is concerned as young women with disabilities who are poor are almost two times as likely as their male counterparts to be recipients of social assistance (23.3%).[39] For persons with intellectual disabilities, rates of poverty are

three times that of persons without disabilities, with these rates highest among persons with intellectual disabilities not living with family (75%).[40] Poverty rates for women and girls with disabilities speak to the precarious income and income security experienced by many women and girls with disabilities. These realities are one of the most damning indications that women and girls with disabilities remain underserved and under supported within the Canadian policy landscape, and that an intersectional analysis is key to understanding these lived experiences.

4.1 Income

In Canada, 23% of those who report having a disability experience a low-income compared to 9% of those without a disability.[41] Where income is concerned then, disability is a significant factor. The following analysis draws on data from the recently released Women in Canada: A Gender-based Statistical Report [42] and begins to shed light on the gendered dynamics of income:

- Wages remain the most frequently reported source of income for women with disabilities aged 25-54 (49.4%), while the second most frequently cited was (16.3%) social assistance. Of note is the reliance on social assistance among women with disabilities as we received overwhelming feedback from participants that existing social assistance support was not nearly enough.

- Women with disabilities report lower levels of personal income with those aged 15 and over working full-time reporting on average $37,070 in income ($2,250 less than women without disabilities). The pay gap continues to be a significant barrier for women with disabilities.

- There are shifts across the provinces with Atlantic Canada seeing the largest personal income gaps between women with disabilities and women without disabilities (women with disabilities report $3,640 less), while British Columbia

reflects the largest gender gap in terms of personal income with women with disabilities reporting $10,320 less than their same-aged male counterparts with a disability. This indicates that across the country there are notable disparities in terms of how women with disabilities fare and in different economic climates women with disabilities require more support.

- While women with disabilities 15 years and older in both Alberta and the territories report the highest household income, they still average less than their counterparts without a disability ($27,250 and $25,960 less respectively).

- Women with disabilities who live alone and/or are a lone parent report the lowest average household income as compared to women without disabilities ($25,690 versus $34,000).

Women with disabilities appear disadvantaged where income levels are concerned and given the importance of income to the social determinants of health, this creates added stress and barriers.

"Women with disabilities report lower levels of personal income with those aged 15 and over working full-time reporting on average $37,070 in income ($2,250 less than women without disabilities)."

While research and literature do not always apply an intersectional lens, where income is concerned we know this is an important factor as:

- The median annual income for trans individuals is only $15,000.[43]

- Among Aboriginal people in Canada aged 25-54, the total median after-tax income is just over $20,000 (compared to $27,600 for non Aboriginal people)[44] and in one analysis the median income for Aboriginal women was noted as generally less.[45]

- Women who are visible minorities in Canada also report lower incomes compared to women who are not visible minorities ($39,330 versus $42,848 respectively).[46]

- Among adults with intellectual disabilities 71.8% are out of the labour force, 6.0% are unemployed, and there is only a 22.3% employment rate (the lowest of any type of disability).[47]

- While there is no breakdown available in terms of gender, the median income for working aged adults with intellectual disabilities was reported as only $10,800, with 71.9% of adults relying on government transfers as their greatest source of income.[48]

- For those with episodic disabilities there are additional barriers to qualifying for provincial and national income security systems as definitions of disability often rely on being either fully disabled or fully able to work which leads to conditions that make poverty more prevalent.[49]

Where income is concerned then, women with disabilities are not a monolithic group but rather one whose lived experience is deeply shaped by multiple complex factors. This speaks to the need for research and policy to engage the issue of income through a more intersectional lens to better understand the needs of all women with disabilities.

4.2 Income Security & the Social Safety Net

Income security and the social safety net refer to various government programs, benefits, and supports that address the support needs of individuals over the life course. For the purpose of this report, we will focus on federal programs and benefits that have the greatest impact on women and girls with disabilities. While this is not extensive, it provides a snapshot that is illustrative of the unique barriers

facing women and girls with disabilities.

Income assistance is an important piece of the disability and income dynamic and for many persons with disabilities in Canada and is often a 'last-resort' as they have little to no access to income from other sources like employment or income programs grounded in labour force participation.[50] For the purpose of this report, we will focus on the Canada Pension Plan and Employment Insurance as they relate to women with disabilities. Additionally, as women with disabilities are more likely to experience lower incomes the impacts of these programs can be unique.

"Young women with disabilities who are poor are almost two times as likely as their male counterparts to be recipients of social assistance (23.3%)"

In general, women are more likely to experience invisible and/or less visible conditions like pain and chronic fatigue, which are less likely to be covered under programs that compensate for work-related disabilities.[51] The application process itself can also be full of barriers specific to women with disabilities. For example, the application process has impacts on women's self-identities as definitions of disability used in the application process often fail to account for the wide range of lived experiences, including a feeling among some women that feeling or even looking better will affect their access to needed disability supports.[52] Additionally, women with disabilities have shared there is stress and anxiety associated with the application process and the completion of forms along with a long period of waiting to find out if they are eligible.[53] Unsurprisingly, the process to qualify for and apply for income support is often a significant barrier for women with disabilities.

4.3 Canada Pension Plan

The Canada pension plan is a contributory federal social insurance program, and because it is contributory component both gender and disability are necessary in any analysis as women with disabilities face unique barriers that often prevent them from maximizing their contributions in the same way as their male and/or non-disabled counterparts. Both women and persons with disabilities are more reliant on public rather than private pensions [54], with 14.4% of Canadian women with disabilities aged 25-54 reporting the Canada Pension Plan Disability Support Benefit (CPPD) as a source of income, and 80.4% of women with disabilities aged 65 and older reporting Canada pension plan (CPP) as their source of income.[55]

Of specific concern for women with disabilities are recent reforms to the Canada Pension Plan (Bill C-26) which exclude provisions meant to protect workers who are impacted by either child raising responsibility or disabilities, both of which influence ability to contribute to CPP. While Bill C-26 recently was framed as strengthening the CPP, critiques illustrate how this measure fails both women and persons with disabilities. For example, a protection for a "child rearing drop out" or "disability drop out" would protect women from being penalized for low and/or no income periods stemming from care labour and/or disability needs.[56] While there has been a commitment by the finance minister to consider the impacts of these drop-out clauses, as it stands reforms to the CPP fail to account for the lived experiences of many women with disabilities. This serves as just one example of how a failure to include an intersectional lens can create policies that exacerbate experience of poverty and marginalization.

4.4 Employment Insurance

Employment insurance (EI) provides temporary income support for unemployed workers while they seek employment and/or skills development. This issue is significant in terms of both a disability and gender lens as women with disabilities are uniquely situated with respect to employment. While the section on employment helps illustrate some of the disparities faced by women with disabilities, there are barriers specific to EI that are worth exploring.

Women remain far more likely than men to take time away from the workplace because of illness or disability.[57] Additionally, women are far more likely than men to work part-time and thus less likely to qualify for EI benefits. Among Canadian women, those from racialized groups, those with disabilities, Aboriginal women, and immigrant and refugee women remain significantly disadvantaged with respect to labour market participation.[58] Some of the most pressing barriers for women with disabilities with respect to EI include:[59]

- The duration of benefits is insufficient for those with disabilities as they often need longer periods of support;

- The benefits are limited to those who participate in the labour force (which excludes many women with disabilities);

- Criteria related to end-of-life is stringent in ways that make it difficult for those experiencing terminal conditions to know when to apply.

EI insurance is thus structured in ways that penalize women in specific ways as they fail to account for the lived experiences of various individuals.

4.5 Summary

In addition to the "tangible" aspects of income and income security, women with disabilities find support in different ways. For example, family living within the household is the most frequently cited source of help for women with disabilities (63.6%), followed by family living outside the house, and a much smaller percentage from friends and/or neighbors. Of note here is that in terms of support from outside of the home, these numbers increase substantially based on the complexity of one's disability.[60] Thus the more complex one's needs are, the more likely one is to report accessing support from sources outside of the household. These unpaid sources of care are an important consideration and while we will explore the unpaid labour of women with disabilities later in this report, we must also recognize that inequities noted throughout this report in part exists because of a lack of formal supports for women with disabilities and that a lack of income and income security shape these. For women with disabilities then, disability supports must be conceptualized more broadly to include informal networks that are necessary. Additionally, there need to be efforts to even out inequalities women with disabilities experience, especially as they age. As the federal government has jurisdiction over both EI and CPP, as well as supports for Indigenous persons, there is a need for them to explore how they can better support women with disabilities through these frameworks.

Throughout this report we will try to touch on these often invisible aspects of the daily lives of women and girls with disabilities. Yet, where income and income security are concerned, women with disabilities face inequities in terms of access. For some women with disabilities, including those with episodic disabilities, income security measures have been crafted in ways that are inherently exclusionary as they fail to account for either a gender perspective or the diversity of the disability experience.

5. Education

Education is seen as a key social determinant of health as there is a high correlation between education and other determinants of health like employment security and income.[61] Indeed, education was one of the most frequently cited priorities in our work with stakeholders as stakeholders often cited the foundational role education plays for girls and women with disabilities. Of particular importance to our stakeholders were:

- The experiences of girls with disabilities in early education settings and the many ways these experiences shape access and opportunities throughout the life course.

- The specific barriers certain groups of girls and women with disabilities experience in education including persistent marginalization and unequal access for those with intellectual and episodic disabilities.

Our stakeholders reaffirmed the importance of education for girls and women with disabilities and expressed concerns that broader work around accessibility and inclusion continues to leave some girls and women behind.

Women and girls with disabilities' experience with education is thus a key factor to consider when examining existing barriers. It is important to note that while this section will explore education experiences, there are certainly issues related to 'unschooled' and out of school girls with disabilities. While we do not have the space in this piece to explore this dynamic fully, we do want to acknowledge that because of disability-related barriers girls with disabilities may be completely excluded from the formal education process. Indeed, in our work with People First, some stakeholders shared that they left school early because their needs were unmet.

While we review education as a life long process here, and include post-secondary education, it is also important to note that education is a key area in terms of impacts on youth and girls with disabilities. As such, while much of the analysis here may be applied to persons with disabilities across the education system,

"For those with intellectual disabilities, 22.5% of children have to go outside their community for schooling, and 30% report segregated schools and classes as their only option."

this is a particularly important issue with respect to youth and girls with disabilities, as these experiences are such a significant and foundational part of their lives. Indeed as we learned in both our stakeholder interviews and facilitated discussion through our partnership with People First, these early experiences often impact and shape individuals throughout their lives. As an example, more than one individual voiced concern that the exclusionary process engrained within many education settings with respect to disability leads to increased social isolation and lower levels of esteem and confidence which can limit opportunities long into adulthood.

In Canada, we know that education is not equally accessible as students with disabilities continue to lack accommodation, institutional support, funding and the infrastructure necessary to access the same levels of support as their non-disabled peers.[62] In their report on the challenges faced by persons with disabilities in Canadian schools, the Canadian Human Rights Commission (CHRC) identified 4 key barriers to education for persons with disabilities that include: a lack of accommodation and support, a lack of services and funding, ineffective dispute resolution mechanisms, and a lack of disability supports and education on First Nations reserves.[63] Examples of these barriers are outlined below.

5.1 Accommodation

There are still significant barriers related to accommodation at all levels of education and across all provinces in Canada. These include barriers that prevent students from attending classes of their choice and writing exams in inclusive environments, both of which have an impact in terms of a students' ability to achieve their full potential.[64] Accessibility in the classroom must be seen as a holistic endeavour which includes universal design to ensure the physical space itself can be accessed and is accommodating of various needs, appropriate and accessible signage, lecture and course material that is accessible (i.e. shared in ways that every student can access), and accessible technology that helps enable student success.[65]

5.2 Lack of Services & Funding

The availability of services and funding are key for students with disabilities. Yet, there remain significant pressures on school-based resources and there are notable delays for students with disabilities, including those with mental health and learning disabilities, as funding and access remain inadequate for these groups.[66] A lack of services and funding are a particularly impactful barrier as students with disabilities incur greater expenses than those without disabilities. While unique to each individual and their disability, these could include extra costs associated with tutoring, interpreters, readers and braillers, transportation, and note-takers.[67]

5.3 Ineffective Dispute Resolution

Unfortunately, for many students with disabilities ineffective mechanisms for dispute resolution mean many students with disabilities must rely on adversarial court systems to resolve disputes around accomodation.[68] While this is a specific barrier for the general population, students living in remote locations face significant barriers as this process often involved travel to access services, which means students with disabilities in remote, northern, fly-in, and First Nations reserves often see their needs here unmet.[69] Additionally, in one of our key informant interviews we were reminded of the importance of an intersectional lens as who is seen as worthy of services and who is framed as a threat is often shaped by factors like race. In terms of dispute resolution, there is also evidence that suggests students with disabilities and racialized students are disproportionately impacted by zero-tolerance disciplinary systems.[70] This is worth noting as these students are likely already tied up in adversarial systems related to their ability to participate in ways that likely make advocating for accomodation and/or fighting disputes around this nearly impossible.

5.4 Unmet Needs on First Nations Reserves

With respect to access to programs and services delivered on First Nations reserves, it has been alleged that funding is inequitable and discriminatory as compared to off-reserve funding, particularly where special education and disability supports are concerned.[71] In practical terms this means students with disabilities living on reserve do not have access to the same level of supports and services as their peers living off-reserve. Here it is important to note the federal government role in supporting on-reserve education. The government's recent action around enhancing First Nation education (kindergarten to grade 12) underscores this barrier as key results

of their consultation process included the identification of priority issues around both the need for increased funding, including for programs to support persons with disabilities, and increased support for students including students with disabilities. Of specific interest is the need to respond to First Nation children dealing with trauma, availability of mental health support, anti-bullying, and suicide prevention.[72]

"Students with disabilities living on reserve do not have access to the same level of supports and services as their peers living off-reserve."

Where geographic location is concerned, there is also evidence to suggest that in the Canadian context, children with disabilities in rural settings report more difficulty in accessing special education supports as compared to those in urban settings.[73] Where children with disabilities in Canada are concerned, it is important to note that we lack national tools to track the progress and experiences of children with disabilities and this is a significant gap that needs to be addressed, both generally, and through a gendered lens. What we do know however, underscores the need for more research exploring the experience of children with disabilities. For example for those with intellectual disabilities, 22.5% of children have to go outside their community for schooling, and 30% report segregated schools and classes as their only option.[74]

While there are clear gaps in the literature in terms of applying a gendered lens to the issue of education, it is clear that there are real gaps in research and programs with respect to the intersectional marginalization of girls with disabilities.[75] For children and youth, research indicates that racialized students are more likely than white students to receive punishment in schools.[76] This is a significant consideration as it speaks to yet another way that policies and programs fail students with disabilities through a lack of accommodation and disability awareness among

educators, and the ways that race can shape perceptions. Additionally, bullying and the exclusion of persons with disabilities in education settings continue to be experienced throughout the education system. The CHRC found that 1 in 4 persons with disabilities in Canada reported being bullied because of their disability, and 25% of persons with disabilities shared that they were avoided or excluded in educational setting because of their disability.[77] Of note here is the response we received from our facilitated discussion with members of People First of Canada, as the issue of being bullied in childhood elicited an intense response with many

of the 25 participants disclosing experiences they had never shared before. Through this discussion participants questioned CHRC stats and commented that based on their own experiences they found these to be low. Participants also shared regular experiences of "bullying" that reflected forms of verbal and physical abuse and shared that they didn't feel protected by adults in the education system. These results indicate that we to work to address the unique experiences of children, including girls, with disabilities within education settings as forms of bullying and abuse are disproportionate among this group.

"The CHRC found that 1 in 4 persons with disabilities in Canada reported being bullied because of their disability, and 25% of persons with disabilities shared that they were avoided or excluded in educational setting because of their disability."

While bullying and exclusion are reported as a part of the overall experience of those with disabilities, applying a gendered lens and looking specifically at the experience of girls with disabilities highlights unique needs here. While there is a lack of literature addressing children, victimization, bullying, and minority status,

Canadian research does indicate escalated incidents in middle years among children with disabilities, specifically, those with autism, which includes being the victim of pushing, punching, kicking and spitting.[78] Of note as well is how victimization may escalate because of intersecting identities. For example, in this research one young Tamil girl with autism was the target of bullies because of her abilities and perceived intelligence, as well as her physical appearance, language, and skin colour.[79] This may illustrate how girls with disabilities face additional victimization, and how girls who belong to more than one minority group may face bullying and victimization on multiple fronts. More critically, this raises important questions about the ability of our education systems to respond to the unique needs of those with intersecting identities, including girls with disabilities.

"In Canada, women with disabilities aged 25-54 are more likely (18.3%) to report having no degree, diploma, or certificate than women without disabilities (8.3%)."

Shifting more to post-secondary education, the impacts of the education system on women with disabilities are a bit more apparent. In terms of demographics, we know that university students with disabilities in Canada are more likely to be women, and less likely to identify as Indigenous than non-university students with disabilities.[80] In Canada, women with disabilities aged 25-54 are more likely (18.3%) to report having no degree, diploma, or certificate than women without disabilities (8.3%).[81] Adults with intellectual disabilities also remain 4 times as likely (53.6%) as those without disabilities to have not completed high school, and only 18.9% report completing post-secondary qualifications.[82]

Women with disabilities in Canada also report that they experience post-secondary education differently because of their disability. These experiences include half of women reporting that they took fewer courses, half of women reporting that it took longer for them to reach their existing level of education, and just over

46% report that their career choice was influenced by their disability.[83] The CHRC research also notes the following impacts which all remain higher for women with disabilities versus men: higher portion of part-time studies because of disability (38.2% of women with disabilities), a long-term interruption in studies because of disability (29.6% of women with disabilities), and having to take courses by correspondence (16.7% of women with disabilities).[84] Where intellectual disability is concerned, two thirds of adults report their condition resulted in taking fewer courses and it taking them longer to attain their level of education.[85] For those with episodic disabilities existing policies can create specific disadvantages including the reality that a reduced course load (necessary during periods of disability) can have significant financial implications as part-time studies often means one is not eligible for scholarships, other funding and placements that can have an impact on employment opportunities. One of our stakeholders shared how acquiring TBI shaped their post-secondary education journey:

> "It took a number of years to complete the coursework, but I was able to return to university to earn my second undergrad degree, then complete an MBA. I started out as being unable "to handle" more than one or two courses per semester; after a while I was constrained by lack of money to take more courses. I was on provincial disability assistance during that time." - research participant

For girls and women with disabilities, research indicates that access to and experiences within educational settings are unique. These experiences call for policies and programs that pay attention to gender and intersectionality, especially as education is a key determinant of health that is highly correlated with other positive life outcomes. This may indicate that the importance of education, including access to post-secondary education, is a critical need among persons with disabilities.[86]

6. Employment, Unemployment & Working Conditions

Employment is an important consideration as it provides income and identity, conversely, unemployment and/or poor working conditions can have a negative impact on individuals. Where employment, unemployment, underemployment, and working conditions are concerned, women with disabilities continue to face barriers and inequity.

Women with disabilities face well-documented barriers in terms of labour force participation. In general, women with disabilities are less likely to participate in the labour force with only 61.3% of women with disabilities between the ages of 25-54 participating and a 13.4% unemployment rate.[87] As with other measures, as the severity of one's disability increases labour market participation tends to decrease, as only 46.3% of women who report severe to very severe disabilities aged 25-54 participate in the labour force.[88] Additionally, among those who identify as trans, research from Ontario illustrates significant discrimination including 18% of respondents reporting that they were refused a job, 32% suspecting this is why they were turned down, and 17% having to decline a job offer because of the lack of trans-positive and safe work environments.[89]

Yet the presence of labour market participation is not the only measure of relevance with respect to women with disabilities. Indeed the kind of work and related working conditions, including wages matter as well. Women remain more likely than men to be employed in non-permanent positions that make them more vulnerable to layoffs and fluctuations in income.[90] As outlined in the general analysis of income, women with disabilities continue to earn less than women without disabilities.[91]

More than 2 in 5 women with disabilities in Canada report part-time employment,[92] which is significant as it impacts income and access to disability benefits like EI. Women with disabilities also report feeling disadvantaged in their employment because of their disability (44.5%), while 12.6% of women with disabilities share that they were refused a job in the last 5 years because of their disability.[93] For those with intellectual disabilities, 61.3% felt disadvantaged, 34.6% felt they had been refused a job because of their disability, 31.4% believed they had been denied a promotion because of their disability, and 28% felt they had been denied a job interview.[94] For those with episodic disabilities, the unstable and uncertain aspects of their disability can impact employment in unique ways. This includes the unpredictability of one's condition making it more difficult to get a job because of gaps in one's resume and it can make particular forms of work, like those with hard scheduling requirements, more difficult to navigate.

"Women with disabilities are less likely to participate in the labour force with only 61.3% of women with disabilities between the ages of 25-54 participating and a 13.4% unemployment rate among women with disabilities."

Women with disabilities are also more likely than men with disabilities to require workplace accommodation.[95] For those with intellectual disabilities 53.8% required accommodation, including 30.2% needing modified work hours, 27.5% require modified duties, and 16.9% require human support; only 39.6% reported that all their accommodation needs were met.[96] Where workplace accommodation is concerned, it is important to gauge employer perceptions about women with disabilities. There is a wealth of evidence in the literature that supports the significance of attitudinal barriers among employers

including evidence that perceptions of disability greatly impact one's ability to find and secure employment.[97] Additionally, it seems that for women with disabilities,

employment discrimination can take place because of both gender and disability status as women with disabilities continue to experience the lowest employment and earning levels, especially among those with multiple or intellectual disabilities.[98]

Where employment and disability is concerned, the type(s) of disability experienced also influence labour market experiences. For example, for those with episodic disabilities the nature of their disability and fluxuations between disability

"Women with disabilities also report feeling disadvantaged in their employment because of their disability (44.5%), while 12.6% of women with disabilities share that they were refused a job in the last 5 years because of their disability."

status and measures around employability and unemployability used to determine access to income support can act as a barrier.[99]

With respect to employment dynamics and the reality that women with disabilities continue to experience disproportionate barriers, it is increasingly important that efforts on this front examine gender discrimination that impacts women with disabilities more broadly in related areas like education, social services, and health.[100]

7. Livelihoods

In working through this research process we were keen to explore the invisible aspects of girls and women's contributions. Here, DAWN's research committee suggested that orienting this exploration through the lens of livelihoods may be a way to capture the often unseen and unrecorded contributions girls and women with disabilities make. Where the labour of girls and women with disabilities is concerned then, it is important to acknowledge the unpaid and informal labour that makes up one's daily life and contributes to one's family and community.

One thread that was strong in our interviews with stakeholders and our facilitated session with People First reflected the reality that for many women with disabilities unequal access to education often means a significant barrier to paid employment. More than one stakeholder shared that they feel those hiring are unwilling to value learning opportunities outside of formal education. This was of particular significance for women with intellectual disabilities who shared that while they could not find paid work, they were active volunteers who often needed to develop and utilize valuable skills that were seldom seen by employers as transferable. Women with intellectual disabilities shared that they had served on local and national boards, traveled to the UN to present on Indigenous issues, helped inform and facilitate learning sessions in high schools to address the use of the R-word, and been leaders locally in advocating for accessibility in their community. Yet, all of these women with disabilities also shared that they felt employers did not value these contributions as much as formal education. Of interest in these discussions as well was that until promoted and encouraged, many of the participants didn't themselves think of these contributions as significant. One of the things this may indicate is that there is a need to explore the livelihoods of women with disabilities in greater detail to shed light on this often invisible labour and build spaces where women with disabilities are empowered to claim and celebrate skills and

knowledge that fall outside paid employment.

Where disability is concerned unpaid labour is a significant aspect of lived experience. As an example, people with disabilities may find themselves locked out of traditional employment relationships because of barriers and discrimination which may leave them more vulnerable to unpaid and/or exploitive labour. Where gender is concerned, women with disabilities continue to contribute in significant ways that are often times ignored (care labour). In this section we aim to explore these often invisible forms of labour in ways that help illustrate the gendered nature of disability and unpaid work. This is important as those who work in exploitive sites (below minimum wage) and those who provide care labour are often understood by policy makers as non-working bodies yet their contributions are significant.

7.1 Exploitive Work

Exploitive forms of unpaid work, like sheltered workshops, have a deep history with respect to the experiences of persons with disabilities. Often framed as training or rehabilitation programs, sheltered workshops are segregated sites where people with disabilities work for less than the mandatory minimum wage. Their positioning as training situates them uniquely outside many existing labour laws and regulations, and in the Canadian context persons with intellectual disabilities are vulnerable to this form of unpaid labour. While the sheltered workshop model has declined in recent years, other segregated employment programming with exploitive compensation models have remained dominant where intellectual disability and employment programing are concerned.[101] For those with intellectual disabilities segregated programs and sheltered workshops remain a mainstay in day programming.[102] There is a noticeable lack of research where women, intellectual disability, and vocational qualifications are concerned.[103] Yet, there is evidence that people with intellectual disabilities, including women, would prefer

to work outside of these settings.[104] While gendered analyses are largely missing with respect to sheltered workshops, there are concerns that women and those who are younger have remained in sheltered workshops.[105] There is a clear need to explore the experiences of exploitive work through a gendered lens to better understand the dynamics of this form of unpaid work. Additionally, as sheltered work is phased out, there needs to be a better understanding of other how other exploitive models persist and the unique ways various populations remain vulnerable to exploitation.

While sheltered employment models occupy a significant space in research around exploitive work and disability, there is a need to apply both a disability and gendered lens to research and policy that looks at exploitive forms of labour. As an example, there has been increased interest in issues related to human trafficking and work, and while we know women and girls are the majority of victims,[106] there is a pressing need to apply a disability lens to this work. This is especially true as there are threads in the research that indicate disability is an important factor, including issues like addiction, mental health and intellectual disability as risk factors where trafficking is concerned,[107] and the documented relationship between disability and depression among seasonal and migrant agricultural workers (including their prevalence among women).[108] Clearly there is a need to apply both a gendered and disability lens to these issues, especially given the space these discussions are taking up in policy debates.

> *"While gendered analyses are largely missing with respect to sheltered workshops, there are concerns that women and those who are younger have remained in sheltered workshops."*

7.2 Caregiving

Caregiving is an important form of unpaid labour for many women with disabilities. Yet within the care literature, there is a tendency to carve out an identity for "caregivers" based on the presence of a family member with a disability, which has meant that within discussion around care that the needs of persons with disabilities are often seen as secondary to the needs of the caregiver.[109] This is problematic for a number of reasons, but most importantly because unpaid care labour is often conceptualized as something that non-disabled women carry out, and in this framing the care labour of women and girls with disabilities is rendered completely invisible. This is in part the result of foundational pieces in feminist research on care that separate the experiences of women with disabilities and women without disabilities.[110] While there is a wealth of literature addressing the needs of those who provide care and support for persons with disabilities, there is less space in the literature for exploration of the experiences of women with disabilities as caregivers. This is problematic as it not only erases these contributions, but also because being a caregiver impacts women with disabilities and their access to the social determinants of health. A lack of funding for a full range of independent living also means care labour continues to fall to women and negatively impacts their labour market participation.[111] While there is evidence that informal caregiving by persons with disabilities is common in Canada,[112] more analysis is required.

For women with disabilities who are mothers, caregiving likely includes unique aspects and

"In Canada, research indicates mothers with disabilities feel the need to present themselves as 'normal' to be more accepted and often fear their children will be taken away if they don't meet expectations."

barriers. In Canada, research indicates mothers with disabilities feel the need to present themselves as 'normal' to be more accepted and often fear their children will be taken away if they don't meet expectations.[113] Mothers with disabilities are also likely to experience additional stress and barriers due to their higher rates of precarious employment and lack of access to affordable child care services.[114]

"Mothers with disabilities are also likely to experience additional stress and barriers due to their higher rates of precarious employment and lack of access to affordable child care services."

Parents with intellectual disabilities, appear to generally be over-represented within child protection services.[115] In Canada, more than one in ten maltreatment investigation (in 2003) involved parents with a cognitive disability.[116] Interestingly enough, while the literature does not clearly link cognitive disability and child maltreatment, parents with these impairments are often not permitted to raise their children (research indicates 40% - 50% of children are permanently placed).[117]

In Canada, women with disabilities face challenges and scrutiny that women without disabilities do not face including being discouraged from parenting and at risk to lose custody, experiences that are exacerbated among women with disabilities who are also marginalized in other ways.[118] There is a need to explore this labour in ways that highlight the contributions of women with disabilities to counter stereotypes and stigma that continue to act as deterrents and barriers for mothers with disabilities.

8. Girl Children & Youth

There are serious gaps in our understanding of the issues facing children and youth with disabilities. In part, this may be a result of our reliance on adults (i.e. parents and guardians) to share and report on disability issues. As well, it must also be acknowledged that disability studies itself has tended to focus on adult experiences of disability. Conversely, within childhood studies, accounts of 'normal' development and 'normal' childhood experiences by many mainstream researchers have separated the needs of children from the social contexts that influence them.[119] This is particularly impactful for children and youth with disabilities as disability and childhood are still often understood through the lens of caregiving, which disempowers the unique voices, agency, and rights of children and youth. As a result, within much of the literature, children and youth are often relegated to either education and/or health discourses, yet children and youth with disabilities, in particular girls with disabilities, have unique experiences and needs.

While not specific to the Canadian context, there is research that indicates girls with disabilities have unique needs that require unique policy solutions. Indeed, girls with disabilities remain almost invisible in research, schools, and the community.[120] Some of the dynamics included in international research are:

- Globally, girls with disabilities remain the group least likely to have access to sexual and reproductive rights.[121]

- Girls with disabilities remain overlooked in recreation programing, both because of disability and gender.[122]

- While children with disabilities have been found to participate in a smaller range of recreation activities, girls with disabilities exprience this disparity at

the highest rates.[123]

- While it has been suggested that just as many girls as boys require special education services in the US, girls remain less likely to be identified and referred for these services.[124]

- Data out of the US suggests high-school aged persons with disabilities who date are at greater risk of dating violence, with girls with disabilities experiencing higher rates of poor mental health and substance use linked to these experiences of violence.[125]

- Girls with disabilities in Vietnam remain more disadvantaged than boys due to intersections between gender, disability, and social class, and are often disempowered even in schools.[126]

"Globally, girls with disabilities remain the group least likely to have access to sexual and reproductive rights."

Research addressing girls with disabilities is sparse[127] and, terms of recent national research in a Canadian context, there are clear gaps. However, we do know that children with disabilities in Canada are ethnically and racially diverse.[128] Yet, girls with disabilities face incredible marginalization as the result of norms and biases around both gender and disability.[129].

Where disability identification and supports are concerned, girls with disabilities may face additional barriers. For example, research around ADHD suggests that girls remain underidentified and underdiagnosed because of gender differences in the way ADHD may be exhibited.[130] Research also indicates that there is a need to further explore gender disparities in the diagnosis of learning disabilities as equal numbers of boys and girls experience difficulty with reading (one of

the most common indicators of a learning disability) which may indicate a large number of girls remain underserved and unsupported.[131] These two examples illustrate one of the major barriers girls with disabilities may face as differences in the way they present their disability and/or the way their behaviors are perceived can act as a barrier where disability identification is concerned. This may be of particular interest with respect to invisible disabilities as the gendered nature of the diagnostic process may exclude some girls with disabilities.

"Girls with disabilities remain overlooked in recreation programing, both because of disability and gender."

There is a pressing need to better understand girls with disabilities, particularly their experiences outside of education. Furthermore, as much of our understanding of youth and childhood are read through the lens of adult researchers, there is a need to engage girls with disabilities in ways that empower them and provide spaces for them to share their lived experiences.

9. Food Insecurity

Food insecurity, or the lack of access to quality food, is a serious determinant of health.[132] The proliferation of food banks and increasing number of Canadians relying on food banks point to serious issues where food security is concerned.[133] Food insecurity has important dynamics with respect to disability, as inadequate nutrition and dietary deficiencies are linked to an increase in chronic disease and persistent feelings of uncertainty which can impact health.[134] Additionally, some research indicates food insecurity can lead to a 1.5 to 3.5 greater likelihood where physical and mental health conditions are concerned.[135] For children, malnutrition early in life can impact psychological and physical development.[136] Available research including the Daily Food Bank's annual survey in Toronto (the largest and most comprehensive regional survey in Canada on food security[137]) reports that 62% of those accessing the food bank identified as having a disability or serious illness (a 10% increase from 2007), and those with disabilities and illness were far more likely to share not eating for an entire day versus those without disabilities and illness.[138] An intersectional lens is helpful in understanding the complexities associated with food insecurity, and while the literature doesn't always use a gendered lens, it is important to think about the ways women, especially women with disabilities, may be uniquely impacted. Previous research indicates food insecurity remains highest among low-income households, among those dependent on social assistance, Aboriginal people (specifically those living off-reserve), and single-parent households led by

"62% of those accessing the food bank identified as having a disability or serious illness (a 10% increase from 2007)."

women.[139] Age is also an important factor, as those 65 and over have increased their use of food banks by almost 27% over the last year.[140] While there is limited data on intellectual disability and food security, research out of the US suggests that young adults with intellectual disabilities face significantly higher rates of food insecurity as compared to their peers without disabilities.[141]

Food insecurity is a problem of particular significance for women with disabilities and is deeply rooted in other inequities that influence access to the social determinants of health. As research draws fairly clear links between financial security and food insecurity, there does appear to be a need for targeted income-based solutions.[142] Here, as with other areas, the need for comprehensive, targeted, gendered and holistic disability supports is apparent.

"Those 65 and over have increased their use of food banks by almost 27% over the last year."

10. Housing

In general, literature indicates that housing and homelessness are different issues for women, and that women experience a continuum that includes secure and precarious housing based on a number of key factors including the availability of affordable housing, employment, health and disability, safety, gender, culture etc.[143] Where disability and childhood are concerned, it is estimated that 12.2% of children with disabilities are in housing in need of major repair (compared to 7% of children without disabilities).[144]

As adults, women with disabilities continue to experience significant barriers in terms of accessing affordable, safe, and adequate housing.[145] In Canada, 46% of women who report having been homeless also have a disability.[146] For women with disabilities, housing, like other determinants of health, is not an isolated experience but is shaped by other factors including poverty, availability of support, location, and violence. Where housing and homelessness and the experience of women is concerned, an intersectional lens is necessary to fully understand the complexities of these experiences. In terms of women with disabilities living in Canada's north, there are unique dynamics which shape this experience. For example, resource projects and the related influx of workers in these areas dramatically push the cost of housing, which only exacerbates barriers for women with disabilities in terms of accessing accessible and affordable housing, which can lead to living in overcrowded and/or unsafe housing as well as increased risk of homelessness.[147] Additionally, our stakeholders shared that access to affordable and accessible housing differs in various communities. One women with a disability located in PEI noted that there is a need for more housing support that includes different types of housing. For this stakeholder, a lack of diversity in housing supports meant hospitals and long term care facilities were increasingly becoming housing options for relatively young women with disabilities. It is important to note the

risk of various forms of institutionalization for women with disabilities as many of the spaces where women with disabilities are housed are institutional in nature (group homes, hospitals, long terms care facilities etc.). Additionally, where women with disabilities are concerned we need to acknowledge that various forms of incarceration remain a reality for many. For example, it has been estimated that 40% of Ontario's population of incarcerated women have a history of TBI (sustained before they committed their first crime).[148]

Research and literature around homelessness has tended to focus specifically on various groups and/or identities and as such often miss the intersectional nature of the issue. For example, the experience of immigrant and refugee women around homelessness, particularly the complexities of these experiencinces, including the intersections of disability, trauma, mental health, intimate partner violence (IPV) etc. remain under-examined.[149] With respect to TBI and homelessness, one study estimates 42% of women who are homeless have TBI, and there are some indications that there is a causal relationship between TBI and homelessness.[150]

"In Canada, 46% of women who report having been homeless also have a disability."

Previous research in Ontario estimates that more than one of every two homeless people in Toronto report a health condition (55% of those experiencing homelessness).[151] While women in general are more likely than men to experience poverty, Aboriginal women with disabilities, older women, women of colour, and immigrant and refugee women are most affected by housing issues.[152] Among those who are homeless, LGBTQI2S youth remain overrepresented among this population[153] and among those who identify as trans, barriers to housing can be particularly difficult as many individuals end up homeless because of job and/or housing discrimination.[154] For those with intellectual disabilities, it is estimated that between 100,000 - 120,000 adults in Canada experience gaps with respect to housing.[155]

Here it is important to note that women often belong to one or more of these groups as well as the complex interplay between housing and health. For example, while women, including women with disabilities, are more prone to experiencing barriers to housing, this lack of access to stable housing can also influence health problems including higher risks of chronic disease, infectious disease, and premature death.[156] There are important links between housing and health that cannot be overlooked, including the reality that women facing housing issues are six times as likely as women who have adequate housing to commit suicide.[157] Furthermore, while access to healthcare is difficult for the homeless population in general, for women, these barriers are exacerbated as services are typically developed for men, meaning there are gaps with respect to the needs of women and children.[158]

"Among those who are homeless, LGBTQI2S youth remain overrepresented among this population and among those who identify as trans, barriers to housing can be particularly difficult as many individuals end up homeless because of job and/or housing discrimination."

With respect to homelessness, researchers have also identified "hidden homelessness" as an important aspect to consider. Unlike the population who live on the streets and/or access shelters, the "hidden homeless" have access to some form of accommodation (i.e. temporary accomodation with friends or family etc.).[159] Persons with disabilities are more likely to experience hidden homelessness, and those with mental health disabilities (21%) or learning disabilities (20%) are particularly vulnerable.[160]

Homelessness and housing needs have unique aspects for persons with disabilities, while those with physical disabilities may require accessibility features, someone with an intellectual disability may need a support workers to help them navigate tenancy issues, yet these supports may not be available.[161] With respect to intellectual disability, an estimated 13,200 adults aged 30 and older are living with their parents because they lack access to the resources and support necessary to live on their own, and an estimated 10,000 adults under aged 65 are in long-term care facilities and nursing homes because of a lack of supports and affordable housing.[162]

Homelessness is an important indicator and determinant of health for women and girls with disabilities as it both connects to and is influenced by other social determinants of health. While research in this area is often times limited to various groups, it is clear that an intersectional lens is needed and that the needs of women and girls with disabilities cannot fully be captured by only understanding them as members of only one group.

"With respect to intellectual disability, an estimated 13,200 adults aged 30 and older are living with their parents because they lack access to the resources and support necessary to live on their own."

11. Health Services & Well Being

In examining women with disabilities and health, we start from a place that recognizes that gender inequality remains prevalent in healthcare settings the world over.[163] In Canada, while women are more likely than men to have a disability,[164] health conditions that disproportionately impact women, like chronic fatigue syndrome, remain less understood than those associated with men, like spinal cord injury.[165] Aboriginal women experience disability at higher rates than Aboriginal men (22% and 14.6% respectively).[166] In terms of women with disabilities and their right to health care, women with disabilities continue to face discrimination in healthcare settings in ways that interfere with their health needs being adequately met.[167] These can include forms of pressure and neglect among healthcare providers including minimizing or ignoring reports of pain, not providing adequate time for communication needs, providing only limited treatment options, and pushing patients beyond their physical limits.[168] More than one stakeholder shared with us negative experiences they have had in a healthcare environment because they were a woman with a disability. For example, one stakeholder shared anecdotal evidence of a women with a disability in severe pain who was consistently told by healthcare practitioners to lose weight as a solution to her pain. While it turned out the woman had been living with an undiagnosed condition, those who she sought help from dismissed her lived experiences with this pain and instead focused on only one aspect of her body (her weight).

Additionally, women with disabilities often have unique interaction with healthcare systems, including the experience of receiving healthcare in ways that are often restricted to issues directly related to their disability.[169] Where healthcare is concerned an intersectional analysis is important as research suggests various

axes of inequality interact with each other and we need to be able to accommodate multiple intersections in an analysis.[170] There is evidence that disability itself may impact the kinds and amounts of barriers women with disabilities face.[171]

With respect to TBI, recent research is shedding light on the many ways a lack of a gendered lens is leaving women with TBI underserved. For example, while women athletes report higher numbers, greater severity, and longer duration in terms of recovery,[172] there are no women-specific guidelines in the medical community for protocols, guidelines, care plans, or education and resources.[173] As we will illustrate throughout this section, some women with disabilities face unique challenges and barriers that lead to increased levels of inequity where healthcare is concerned.

A life course analysis is useful in terms of evaluating the healthcare experiences of women with disabilities as needs shift throughout a woman's life. While these shifts are experienced differently in each individual and disability itself may impact how the aging process is experienced, there are age-related considerations that healthcare providers should include. For example, in adolescence, issues like developing a healthy body image, sexual identity and reproductive health may be priorities, while young and middle-aged women's needs may shift to fertility issues, abuse, and conditions like fatigue, heart disease, and osteoporosis.[174] As women with disabilities age, they experience many of the same conditions as the general population and thus protocols around bone density and mammograms may be more pressing.[175] However, the general experience of accessing healthcare for women with disabilities suggests that there needs remain unmet, through a series of structural and attitudinal barriers. This was reaffirmed in one of our stakeholder interviews by a woman with an intellectual disability who shared that healthcare was one of the spaces they felt remained inaccessible to them. For this stakeholder, the experience of being spoken over by doctors and not heard was common. Coupled with insufficient support for things like dental and eye care, they felt cost remained another significant healthcare barrier for women with disabilities.

11.1 Breast Screenings

One area of particular interest when examining the experience of women with disabilities and health care services is reflected in research and experiences around breast cancer. For example, where screening and breast cancer are concerned, women with disabilities remain less likely than their non-disabled counterparts to access cancer screening. [176] This is a particularly relevant issue as research indicates women with disabilities have higher breast cancer mortality rates.[177] Specific to the Canadian context, women with disabilities report a number of barriers with respect to cancer screenings that includes the complex and arduous process of arranging and attending appointments, normative assumptions about women's bodies, and accessing health care information.[178] These barriers can be exacerbated by unreliable accessible transportation (i.e. late and no-shows), as well as the need for an attendant to accompany an individual, which may fall outside of their duties and/or go beyond the allocation of attendant hours.[179] While there is the need for more research on this subject, it does appear that mammogram rates among Indigenous women are lower.[180] There are also disability-related needs including transportation to screenings, which call for the need to incorporate intersectionalities like disability, gender, age, and geographic location with respect to Indigenous health as it related to screenings

> *"Women with disabilities report a number of barriers with respect to cancer screenings that includes the complex and arduous process of arranging and attending appointments, normative assumptions about women's bodies, and accessing health care information."*

and mammograms.[181]

Barriers related to the physical accessibility of healthcare sites are also an important consideration. In one Canadian study, the majority of women with disabilities remained unaware of accessible facilities related to getting breast and vaginal exams.[182] Additionally, women with disabilities face physical barriers in the cancer screening process which include machines and scales that require specific positioning or standing, inaccessible exam tables, unmet communication needs, a lack of information in alternative formats, and inaccessible and unreliable information.[183] Research also indicates that women with disabilities are less likely to be recommended by physicians for screening, especially women with multiple disabilities and older women with disabilities.[184] There is evidence to suggest this is is also true for women with intellectual disabilities who have lower rates of breast and cervical cancer screening than women without disabilities.[185]

Assumptions about disability, and discomfort among healthcare providers around disability, are also important barriers women with disabilities still face. For example, in one recent study around healthcare provider perspectives related to women with disabilities with breast cancer, healthcare providers expressed uncertainty with respect to how to appropriately and respectfully communicate with women with disabilities.[186] These barriers illustrate that access to breast health for many women with disabilities remains uneven and there is a serious need to incorporate a disability lens when designing and delivering healthcare.

11.2 Sexual & Reproductive Health

Where sexual and reproductive rights are concerned, women with disabilities continue to face stigmatization and barriers. It is important to ground these barriers historically, as reproductive health has tended to exclude women with disabilities and policies have managed their bodies in unique and troubling ways. This legacy

is an important part of understanding the often contentious terrain for women with disabilities where reproductive rights are concerned. Included in this history is a legacy of surgical sterilization,[187] as Canada was influenced by the eugenics movement throughout the 20th century.[188]

The eugenics movement was particularly impactful for women with disabilities, and both Alberta and British Columbia had legislation enabling sterilization for those diagnosed as "mentally ill" and "deficient." [189] In Alberta, data from the Alberta Eugenics Board case files indicates that 1,154 women with disabilities were sterilized under eugenics practices, with close to 40% of these women being sterilized after 1955.[190] Unfortunately in the case of British Columbia, records of these practices have either been lost or destroyed.[191] While other provinces may not have had official sterilization laws, countless women with disabilities were likely sterilized as these procedures were often performed on young women with disabilities through parental consent.[192] This is an important historical legacy that certainly informs modern practices for many women with disabilities, particularly as parents may still yield power and control that can more broadly influence access to and decisions around reproductive health. Indeed in our research we spoke to one woman with a disability who shared that her parents had made reproductive health choices on her behalf, without her consent, and against her will. Sadly the power and influence many parents and guardians hold likely indicates that these unofficial forms of reproductive coercion persist in many ways.

It is also important to recognize the sexist, racist, and imperial bend of sterilization practices[193] as, in the Canadian context, these policies also disproportionately impacted Indigenous women. For Indigenous women, coercive sterilization was practiced through legislative frameworks and informal practices which targeted and/or failed to protect Indigenous women.[194] While the literature on this topic tends to treat women with disabilities and Indigenous women as separate categories, it is important to recognize women targeted through these practices could have identified in multiple ways.

Sterilization laws in Alberta were not repealed until 1972. In 1995, Leilani Muir, a women with an intellectual disability, successfully sued the Alberta government over the practice of forced sterilization. Muir who had been admitted to the Provincial Training School for Mental Defectives in 1955, had been sterilized at age 14.[195] Muir's advocacy led to an an official apology from the Alberta government and compensation to hundreds of others who had been the victims of sterilization.[196]

While the practice of sterilization looms large in the legacy of reproductive rights for women with disabilities in Canada, there are contemporary issues which continue to shape the experience of women and girls with disabilities in Canada. Women with disabilities continue to face a number of barriers accessing sexual and reproductive health.[197] The literature on this speaks to a number of barriers women with disabilities face which including limited contraception options, inaccessible equipment/facilities, and a lack of knowledge about disability from health care providers.[198] As a result of these barriers, women with disabilities are more prone to coercion, abortion, and loss of custody.[199] Other social determinants of health also shape how women experience and access reproductive health. For example, stigma, discrimination and poverty may all shape sexual confidence and self-esteem.[200]

In part many of these barriers are grounded in negative attitudes around sexual and reproductive rights for women with disabilities.[201] Indeed, service providers receive insufficient training where disability is concerned.[202] Experiences accessing sexual and reproductive

"Women with disabilities share that they have limited options in terms of contraceptives, as practitioners often appear surprised that they are sexually active and fail to ask about contraception and STIs."

health also vary among women with disabilities. Research indicates women with physical disabilities continue to face barriers with respect to maternity care including

barriers related to practitioners unwillingness to provide care, a lack of accessible equipment, lack of disability-specific knowledge and data, and systemic barriers like time limits.[203] Additionally, women with disabilities share that they have limited options in terms of contraceptives, as practitioners often appear surprised that they are sexually active and fail to ask about contraception and STIs.[204] For women with spinal cord injuries, a lack education among healthcare providers remains a key determinant and barrier with respect to accessing gynecological care.[205]

For those with intellectual disabilities, barriers may be unique, especially in adolescents as parents and guardians may shy away from the topic of sexual health and/or ignore it all together which leads to individuals having very little control over related decision-making, and there may also be a noticeable lack of sexual education that is adapted and accessible to this population.[206] Other barriers for girls and women with intellectual disabilities include: a lack of training and expertise among healthcare professionals, hesitancy among providers to address sexual health, a lack of knowledge rooted in limited opportunities for sexual education, disability related barriers, a high occurrence of sexual assault among this population, a lack of awareness and dialogue around human rights and sexual expression among this group, undertreatment where menstrual disorders are concerned, and continued systemic barriers.[207] These barriers can lead to negative outcomes for persons with intellectual disabilities including a lack of knowledge around sexual health and relationships that may increase risks associated with victimization and unwanted outcomes like unplanned pregnancy and STIs.[208]

While there are many barriers that prevent women and girls with disabilities from accessing sexual and reproductive rights, there are ways to increase access and equity which include: supporting self-advocacy so persons with disabilities become partners in their care, and the need to teach healthcare providers about disability to avoid ignorance and surprise that persons with disabilities are sexually active.[209]

In general, healthcare providers' perceptions about disability as well as their lack of knowledge around disability are important parts of the social context that shape the healthcare process.[210] The general and specific healthcare barriers outlined throughout this section speak to the very real impacts and consequences of these inequitable contexts and the need for disability-related training among healthcare professionals. Most importantly, there is a pressing need to involve women and girls with disabilities in the process of creating and delivering this important curriculum. Disparities among certain groups also suggest the need for specific and targeted policy and public health action to address these inequities.

Within the Canadian context, there is also need for more work around emerging issues and their impact on women and girls with disabilities. For example, there are clear tensions between the CRPD and Canada's Medical Assistance in Dying Act, as many have argued the act itself is in violation of Canada's obligations where disability and right to life are concerned.[211] There are real and pressing concerns about this Act and its impact given underfunded palliative and disability supports programs which may shape the decision making process. As our discussions around this research uncovered, there are also aspects to this issue, including pressure on women with disabilities to access assisted dying so they are not "burdens" for their families. Additionally, there are very real concerns that some girls and women with disabilities, because of the nature of their disability, may be more vulnerable. Many advocates fear that for women with disabilities, this Act fails to account for these real reasons many women with disabilities may seek out assisted dying, which include a lack of access to needed services and supports (suicide prevention, addictions treatment, trauma-informed services etc.) and because disability still remains stigmatized and undervalued.[212] Given the range and number of barriers that still exist with respect of women and girls with disabilities accessing healthcare, there are concerns that need to be addressed. Women with disabilities require access to compassionate, comprehensive, and evidence-based care throughout all stages of their lives,[213] and until that is a reality, we cannot expect that this population will not be further impacted through such policies.

12. Sexuality

For persons with disabilities, specifically women with disabilities, sexuality remains an issue that is trapped in prevalent misconceptions and myths that mean the sexuality of women with disabilities is often neglected.[214] While there is literature on the subject of sexuality and disability, the voices of persons with disabilities remain largely absent and as with other issues, people with disabilities are often presented as fetishized objects.[215] Even within disability studies, issues around sexuality, identity, and relationships often remain neglected. People with disabilities continue to be marginalized through systemic barriers that block access to knowledge and resources around sexuality and sexual behaviour.[216]

For persons with disabilities, healthy expressions of sexuality have tended to be viewed as deviant.[217] For girls with disabilities, parents play an important role where development and sexuality are concerned. Some research suggests that notions about dependence and inability have lead to situations in which mothers and daughters become interlinked in complex ways, which among other things, can lead to lead to increased protection.[218] This sense of 'oneness' has led to situations in which girls with disabilities face barriers in being viewed as independent sexual beings.[219] While this dynamic is in many ways reflective of aspects of the caregiving process, and the identities and roles it tends to shape for women and girls with disabilities, the influence of this dynamic on lived experience

"While people with disabilities are as vulnerable as the general population to things like HIV, they are often missing in prevention, care and treatment initiatives."

across a number of different life experiences, including sexuality, should not be lost. This is an important dynamic to consider as the involvement of parents in girls with disabilities lives can influence a range of experiences including how sexuality is expressed, how one developes sexualy, and reproductive health.

While people with disabilities are as vulnerable as the general population to things like HIV, they are often missing in prevention, care and treatment initiatives. One environmental scan that looked at the intersections between HIV/AIDS Service Organizations (ASOs) and Disability Service Organizations (DSOs) in the Greater Toronto Area found very few instances of accessible services identified within the HIV sector and within the disability sector, very few mentions were made of programs or services for people living with HIV.[220]

For LGBTQI2S persons with disabilities, heterosexism, ableism, and homophobia in health, social services, education, and disability services remain significant barriers, and persons with disabilities who are LGBTQI2S also continue to experience discrimination within the disability movement and ableism within the broader LGBTQI2S movement.[221] The literature also reveals a bias in terms of heteronormative practices which may further marginalize some women with disabilities.

Women with intellectual disabilities face significant barriers as their sexuality is often stereotyped, and they are often depicted as asexual and childlike which leads to denial of their needs.[222] Other barriers include: isolation which impacts access to social contexts where learning can take place, family control, a lack of role models, and internalized notions around ideal bodies that influence feelings around attractiveness and desirability.[223]

Furthermore, the literature on intellectual disability and sexuality is often limited to issues around sex education, vulnerability, consent and exploitation, with little attention to sensuality and pleasure.[224] In practice, gatekeeping remains a significant barrier within disability organizations and among parents in terms of supporting sexual expression among persons with intellectual disabilities.[225]

For women with intellectual disabilities there may also be barriers related to socialization, sexual expression, partner selection and notions about femininity and sexual restraint.[226] As many women with intellectual disabilities may be in situations where parents and support workers exercise more control in their decision making process, carving out healthy and confident sexual individual identity can be difficult. Recent research around the dynamic between support workers and adults with intellectual disabilities helps underscore these power dynamics as findings indicate support workers remain conflicted as they understand people with intellectual disabilities have the same rights and needs as others, yet also perceive adults with intellectual disabilities as having 'deficits' and frame sexuality as problematic.[227] There are clear gaps between policy and practice that continue control and infantilize women with intellectual disability in ways that deny them the agency to explore and define their own sexuality.

"For LGBTQI2S persons with disabilities, heterosexism, ableism, and homophobia in health, social services, education, and disability services remain significant barriers, and persons with disabilities who are LGBTQI2S also continue to experience discrimination within the disability movement and ableism within the broader LGBTQI2S movement. "

13. Gender Identity

There are real gaps in the literature connecting disability and transgender studies [228] and gender identity studies. One of the difficulties in examining experiences around gender identity among persons with disabilities is that existing research tends to overly pathologize this issue. Here there are similarities with respect to how trans experiences are framed using the medical model, a significant considerations in terms of the power granted to doctors in the lives of trans persons with disabilities.[229] The Ontario Human Rights Commision (OHRC) found that individuals expressed concerns with the inclusion of "gender identity disorder" in the Diagnostic and Statistical Manual of Mental Disorders as is assumes individuals who identify as trans have mental health issues.[230] Yet there is notable tension here with respect to trans and disability identity as while it is incorrect to assume a link between gender identity and the presence of disability, without disability status those who are trans can lack funding through provincial disability supports to things like hormones.[231] This is significant as for some aligning their outward and inward identities are important and transitioning may be necessary for some individual's health, safety, fulfillment, and psychological well-being.[232] Yet, many individuals share that with respect to accessing hormones and interaction with the mental health system and hospitalization, they face continued discrimination. This includes not being treated with dignity, not being allowed to transition genders, sexual harassment, and segregation from other patients.[233] These negative experience with service providers, coupled with a lack of transition services and limited financial capacity, leads many to seek informal solutions which include hormones from non-medical and or nonprescribed sources.[234]

14. Violence & Abuse

With respect to violence and abuse, research is clear in terms of its impact on women and girls with disabilities. While research specific to children and youth remains somewhat underdeveloped, the literature does indicate children with disabilities face unique risks in terms of violence and abuse. While lacking in a gender analysis, one recent US study found that children with disabilities were at an increased risk of victimization, and that there are serious gaps in terms of prevention and services geared to children with disabilities.[235] Recent Canadian data also seems to support the increased victimization of those under 15 (see below). When exploring violence against women with disabilities it is important to acknowledge that some forms of mistreatment do not fall within the the Criminal Code (i.e. forms of cultural and social devaluation etc.) yet existing research with women with intellectual disabilities indicates that these 'grey areas' are important aspects of lived experience.[236] Therefore, while official statistics around violence against women tell a powerful story, as with other areas impacting girls and women with disabilities, there are invisible details that existing research does not always consider.

For women with disabilities in Canada, the recently released *Violent Victimization of Women with Disabilities* provides the most up to date statistical analysis. Pertinent findings from this research include:[237]

- Women with disabilities are twice as likely as those who do not have a disability to be the victim of violent crimes, as well as twice as likely to have been victimized more than once in the last 12 months.

- 39% of self-reported violent crime (including sexual assault, robbery, and physical assault) involve a victim with a disability, 45% of these represent women with disabilities.

- Women with disabilities are twice as likely as women without disabilities to have been sexually assaulted in the last year.

- 23% of women with disabilities have been the victims of emotional, financial, physical, sexual violence, or abuse by former or current partners in the past 5 years.

- With respect to spousal abuse, 39% of women with disabilities have experienced spousal violence, 46% have been physically injured because of this violence, and 38% have feared for their lives.

- 38% of women with disabilities report physical or sexual assault before the age of 15, and 18% report sexual abuse by an adult before the age of 15.

- Women with a disability most often reported the perpetrator was a friend, acquaintance, or neighbour (44%) and 30% of incidents of victimization occurred in their home.

"Women with disabilities are twice as likely as those who do not have a disability to be the victim of violent crimes, as well as twice as likely to have been victimized more than once in the last 12 months. "

- In addition to high overall rates of abuse for women with disabilities, women with disabilities were more likely to report being the victim of multiple and separate incidents of violence in the last 12 months (36% of women with disabilities).

Sexual assault remains a heavily gendered crime as self-reported and police-reported data confirms a large majority of victims are women.[238] Women with disabilities living in marital or common law unions are reported as 40% more likely to experience violence,[239] while rates of intimate partner violence (IPV) are higher among women who report an activity limitation than those without.[240]

For women with disabilities, the risk of violence increases when they are racialized, younger, Indigenous, LGBTQI2S, migrant workers, immigrants, non-status migrants or living in rural areas.[241] While the statistics around violence against women with disabilities speaks to the gendered nature of this issue, and intersectional lens uncovers patterns that impact certain groups of women with disabilities in troubling ways:[242]

- 24% of women with cognitive disabilities (which include learning, intellectual and memory disabilities) and 26% of women with mental-health related disabilities report being sexually abused before the age of 15.

> *"Women with disabilities are twice as likely as women without disabilities to have been sexually assaulted in the last year."*

- Women with disabilities who experience violence as children are almost two times as likely as those who had not experienced physical abuse to be victimized in the last 12 months.

- For women with cognitive and mental health disabilities, rates of violent victimization are four times the rates of those who do not have a disability.

- In general, women with disabilities who identify as lesbian, gay or bisexual experience 2.3 times higher rates of violence than among heterosexual women with disabilities.

- For women with a cognitive disability who identify as lesbian, gay, or bisexual rates of violent victimization are well above those among heterosexual women with cognitive disabilities.

- Women who experience mental-health related disabilities and those with cognitive disabilities experience disproportionately high rates of sexual assault.

- Women with sensory disabilities experience 2.5 times higher levels of violent

victimization than women without a disability.

- Women who experience two or more types of disabilities also experience higher rates of victimization.

- Women with cognitive disabilities are more likely to be the victim on violence from a common-law partner, or current or former spouse (43%).

"For women with disabilities, the risk of violence increases when they are racialized, younger, Indigenous, LGBTQI2S, migrant workers, immigrants, non-status migrants or living in rural areas."

There are also important links between domestic violence and disability as it has been estimated as many as 276,000 women in Canada will experience TBI annually as the result of intimate partner violence.[243] Women with disabilities who are the victims of violent crimes are more likely to make use of victims' services.[244] With respect to IPV, 71% of women with disabilities report contacting or using formal support services following violence.[245] Yet, women with disabilities face unique barriers when accessing general services. For example, it has been noted that women with disabilities face more barriers in leaving abusive situations as both disability-related services and services for victims of abuse are not always able to respond to the needs of women with disabilities.[246] Access to supports and services can be particularly difficult for certain women and girls with disabilities. For example, one study exploring the experiences of violence among Muslim immigrant women and girls in Canada noted that one woman with a disability was ignored by both immigrant-focused and disability-focuses services as neither saw her as the type of client they were mandated to support.[247] Additionally, women with disabilities are five times more likely to report unsatisfactory services from police (than among women without disabilities).[248] Where the perpetrator is a caregiver, women with

disabilities face unique challenges as reporting abuse can jeopardize their access to needed care.[249] Caregiver abuse is an important aspect to consider with respect to violence against women with disabilities, as caregiver and/or IPV can include forms of abuse that are less apparent like threats of abandonment, emotional abuse, isolation, intimidation, withholding and/or misusing disability supports and equipment.[250] There are all unique aspects that impact women with disabilities and should be considered in broader analysis of this issue.

It is also important to note the correlation between violence and disability, as experiencing violence can have impacts on mental health, including higher rates of depression.[251] For example, one recent study found that women with intellectual disabilities (the majority being Indigenous) began from a "compromised position" that started with childhood trauma, which included experiences of geographic isolation, and other vulnerabilities that led to violence and abuse and conflict with the law.[252] Where violence and abuse are concerned, and with respect to disability, there are interrelated elements at play including violence as both the cause of disability and disability as a factor increasing the risk of victimization.[253] For these reasons, it remains critical to continue centering the diverse experiences and voices of women and girls with disabilities in discussions of violence and victimization. Additionally, there may be a need for risk-intervention programs geared to women that address gender-specific aspects of lived experience.[254]

"There are also important links between domestic violence and disability as it has been estimated as many as 276,000 women in Canada will experience TBI annually as the result of intimate partner violence."

15. Transportation

Access to accessible and affordable transportation is key where inclusion and participation are concerned. One-fifth (21.2%) of women with disabilities aged 15 and older regularly access public transit, and women with disabilities are more likely than men to use public transportation.[255] In terms of accessible and/or specialized transit, its usage among women with disabilities increases with the severity of one's disability (11.2% of women who report having a severe disability versus 6.1% of women who report a mild or moderate disability).[256] In terms of transportation-related workplace accommodations, smaller numbers of women with disability have access to accessible parking compared to men with disabilities (33.6% versus 64.3% respectively) and specialized transit (27.9% versus 54.5% respectively).[257]

Transportation is key in facilitating opportunities for social and economic inclusion and independence, and in Canada there are legal frameworks to ensure accommodation (to the point of undue hardship).[258] Yet in Canada transportation-related barriers remain persistent for women and girls with disabilities. While this report has woven transportation barriers throughout and where relevant, transportation itself remains an important consideration. One stakeholder underscored the importance of accessible transportation when they shared that in their community (Newfoundland) accessible transportation needs to be booked 24 hours in advance, which means this transportation in unavailable in

"One-fifth (21.2%) of women with disabilities aged 15 and older regularly access public transit, and women with disabilities are more likely than men to use public transportation."

the case of an emergency and/or when the need to travel comes up unexpectedly.

In Ontario, research indicates that a lack of access to information about transportation and travel coupled with limited financial assistance prevents women with disabilities from fully participating in social life.[259] Recent national data supports this as 46.1% of women who report either a severe or very severe disability report difficulty in using public and/or specialized transportation.[260] The most common difficulties for women with disabilities include: getting on or off a vehicle (51%), that a condition is aggravated by going out (47.6%), the overcrowding of transit (29.2%), difficulty getting to and/or locating public transit stops (28.1%).[261] Again, these increase alongside the severity of one's disability. For women with disabilities in Northern communities, transportation can be particularly difficult, as women may depend on taxis, yet availability can be impacted by better paying resources jobs.[262] For women with episodic disabilities it may be more difficult to qualify for accessible and/or specialized transportation which can have serious and negative impacts on things like employment.

"Recent national data supports this as 46.1% of women who report either a severe or very severe disability report difficulty in using public and/or specialized transportation."

Throughout this research and in speaking to stakeholders it is clear that transportation is one a key social determinant of health that often acts as a barrier in other areas of life (employment, health care, social inclusion etc.). As such, and given the reliance of women with disabilities on public forms of transportation, it is imperative that transportation is viewed by policy makers through a holistic and gendered lens.

16. Gaps Identified Through This Research

Throughout this research process we were able to identify several key gaps in the literature around women and girls with disabilities. Our engagement with stakeholders was key in identifying these gaps. Below we have outlined some of these key gaps:

Lack of a Gendered Lens in Disability Research //

Disability research largely presents disability as a monolithic experience. Yet as we see throughout this report, a gendered lens matters.

Girls with Disabilities //

There is an urgent need to explore the experiences of girls with disabilities, specifically to ground this exploration in the views of girls and/or reflections of women with disabilities on their childhoods.

Lack of Intersectionality //

Unsurprisingly there is a lack of intersectionality where disability research is concerned. This point was strongly reinforced through our stakeholder engagement. This is of particular concern as the results of our research confirm intersectionality matters, yet it is often not a consideration in policy and practice.

Lack of Research Grounded in Lived Experience //

In many areas where we explored, while there was literature on the topic, it was often not from the perspective of those with lived experience. This was particularly true of literature around childhood and intellectual disability which tend to be

filtered through the lens of non-disabled adults and guardians. Because of this, there are aspects to these issues that remain overlooked.

Invisible Disabilities //

A part of this research, and the partnerships that informed it, were specific to addressing the lack of certain experiences of disability within the literature. Yet as our report highlights, there is a pressing need for more analysis where these invisible and often undocumented aspects of disability are present.

Episodic and Chronic Disabilities //

More research needs to be conducted regarding the specific experiences of women living with episodic disabilities. Indeed there is insufficient writing around women and chronic illness, especially pieces that focus on the experiences of women with chronic illness.[263] Many conditions associated with episodic disability occur more often in women than men. For example, the sex ratio of multiple sclerosis for women in Canada has been gradually increasing over the last 50 years.[264]Arthritis and mental health issues also occur more commonly in women. Still there is very little research that looks at the experiences of women living with these specific episodic disabilities. One possible reason for this is that episodic disability is a relatively new way of thinking about disability and does not have a mature and widely accepted terminology associated with it. There is a great deal of overlap with chronic illness literature. There are also numerous different terms used to denote episodic disability including "episodic health condition" and "episodic illness". Although Statistics Canada does currently undertake the Canada Survey on Disability, it is not a longitudinal survey and there has only very recently been a marker introduced for 'episodic disability.' Consequently, it has been very hard to understand the overall numbers of people living with episodic disabilities.

Indigenous Issues //

There is a pressing need to better understand Indigenous experience of disability in Canada. As this is diverse, it is important that diversity among this population is included.

Life Course Analysis //

One's needs change over time, and thus there is a need to better understand how girls and women experience disability throughout the life course and what this may mean in terms of needed supports.

17. Recommendations for Next Steps

Throughout this report we have identified a number of issues and gaps that future work can address. Again, our engagement with stakeholders was crucial in helping to inform our recommendations and next steps. Here we would like to share some key recommendations we have identified:

1 Gender and disability must be applied to key policy work (human trafficking etc.) to ensure that girls and women with disabilities do not continue to remain invisible in these endeavors.

2 As applying a gender lens is an important aspect of disability-focused work moving forward, DAWN Canada is willing to act as a leader to help support the growth of this capacity among allied disability organizations.

3 There is a need to better engage communities of girls and women with disabilities who remain hard to reach and underrepresented. This includes women and girls in institutional settings, those who lack formal diagnosis, those who rely on non-verbal communication methods etc. To do this, DAWN (and other allied researchers) must move forward with non-traditional research frameworks that are more inclusive (arts-based methods, play, storytelling etc.). In part this calls on researchers to go to where girls and women with disabilities are and engage them in different spaces.

4 There is a need for research that goes beyond identifying barriers and creates opportunities to highlight capacities and contributions as well as to develop leadership among girls and women with disabilities (possibly through mentorship opportunities).
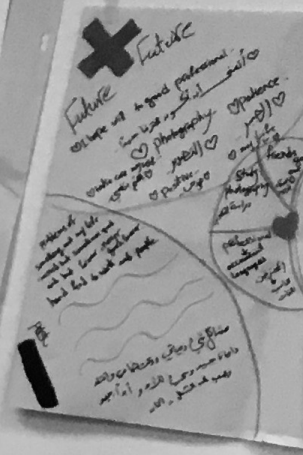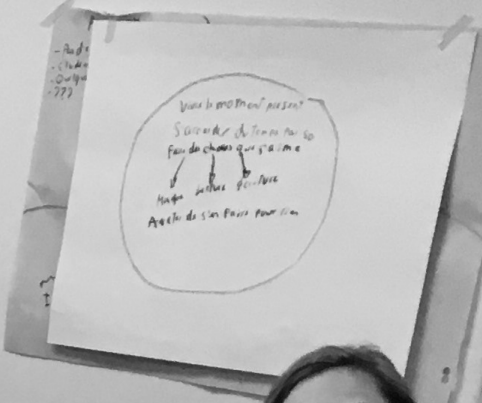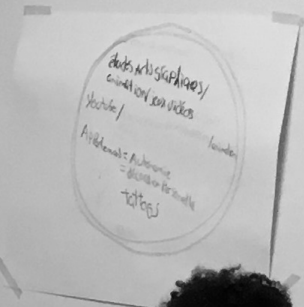
18. Strategic Openings

This research process uncovered a number of issues that inform what we are calling strategic openings. These are relationships, opportunities, and spaces in which gendered and intersectional work on girls and women with disabilities can and should be taking place. We see this piece as evolving as we move beyond this exploratory report and into greater engagement in this area. Below are some key strategic openings we have discovered:

1 One of the areas we covered in this report was the impact of resource development on women with disabilities. While we often apply an assessment lens to the environmental impacts of resource development, it is clear that women with disabilities are impacted in unique and important ways where resource development is concerned. Here then, it is necessary to apply a disability and gendered lens where major resource projects are happening across Canada to ensure their impacts on girls and women with disabilities are both understood and proactively addressed to ensure development does not exacerbate barriers for this group.

2 There are upcoming opportunities for engagement, including sharing our findings and connecting with strategic allies. This includes active participation in the upcoming "Women Deliver" conference around sexual and reproductive rights.

3

As accessibility legislation is adopted provincially, and we move closer to the roll-out of federal accessibility legislation, there needs to be a comparative analysis that examines the impact of legislation on girls and women with disabilities. For example, a gender-based disability analysis across provinces that have accessibility legislation versus provinces that do not, in order to understand the ways that legislation impacts the lived experience of girls and women with disabilities. These results could also practically inform accessibility legislation across Canada.

4

As a part of sharing of these results and facilitating new partnerships, DAWN can strategically identify academic and research allies and work with them to produce and share learning briefs that can be accessed by the public. This benefits researchers as it brings their results to a broader community-based audience and benefits DAWN as it can connect with and build partnerships as it moves forward on a broader research agenda.

5

There are a number of upcoming national and international forums with disability-focused panels and opportunities that DAWN Canada should participate in and share these results with.

6 There is existing work around girls with disabilities in Vietnam that is strongly connected to themes and issues DAWN is exploring. There is a need to further explore these connections as there may be opportunities to engage and learn from each others work.

7 DAWN has worked with several partners in this research process and this work has solidified the need to formalize aspects of these partnerships moving forward. This will help ensure DAWN can continue to conceptualize disability in ways that are inclusive of underrepresented and often invisible disabilities, while also increasing the capacity among partners to include gender-based analysis in their day-to-day work.

8 As a part of DAWN's commitment to moving forward with community-based and emancipatory research, DAWN will need to strengthen and formalize relationships with academic allies to help develop a specific research ethics process for certain projects.

9 As DAWN is committed to building and sharing a research database, there is a need to strategically partner with those in library sciences to best navigate how to collect, organize and share these resources with the broader community

10 As we move forward with research agendas that are intersectional there needs to be a parallel process to build community-based supports. For example, opportunities for peer-support groups by and for women with disabilities to ensure that research participants have opportunities beyond their engagement with researchers to access support and share lived experience. Here then, there is a need for strategic partnerships with existing disability groups that have the capacity for peer-support (yet may lack experience delivering disability-services through a gendered lens).

Appendix 1: Endnotes

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255   Burlock, A. (2017) Women with Disabilities. *Women in Canada: a Gender Based Statistical Report*. Statistics Canada. Available at: https://www.statcan.gc.ca/pub/89-503-x/2015001/ article/14695-eng.htm

256   Burlock, A. (2017) Women with Disabilities. *Women in Canada: a Gender Based Statistical Report*. Statistics Canada. Available at: https://www.statcan.gc.ca/pub/89-503-x/2015001/ article/14695-eng.htm

257   Burlock, A. (2017) Women with Disabilities. *Women in Canada: a Gender Based Statistical*

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258   Jacobs, L. A. (2017). The Universality of the Human Condition: Theorizing Transportation Inequality Claims by Persons with Disabilities in Canada.

259   Crooks, V. A. (2004). Income assistance (the ODSP) and disabled women in Ontario, Canada: Limited program information, restrictive incomes and the impacts upon socio-spatial life. *Disability Studies Quarterly*, *24*(3).

260   Burlock, A. (2017) Women with Disabilities. *Women in Canada: a Gender Based Statistical Report*. Statistics Canada. Available at: https://www.statcan.gc.ca/pub/89-503-x/2015001/article/14695-eng.htm

261   Burlock, A. (2017) Women with Disabilities. *Women in Canada: a Gender Based Statistical Report*. Statistics Canada. Available at: https://www.statcan.gc.ca/pub/89-503-x/2015001/article/14695-eng.htm

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Appendix 2: Bibliography

In addition to the resources outlined in this report, we wanted to include a larger bibliography with resources for those interested in these issue. We endeavour to find ways to grow, update and share these resources as we move forward in our work on intersectional and gendered analysis of disability.

On this note, we acknowledge the work of our research committee and extend our deep gratitude to Dr. Deborah Stienstra for her support and insight in creating this selective bibliography which includes key academic resources that reflect the research areas presented throughout this report.

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Appendix 3: Project & Methodology

A3.1 Project Objectives

The research framework and methodology were developed to best support the project's key objectives. These include:

1. Increasing knowledge and understanding of key issues facing women and girls with disabilities in Canada;

2. Bringing together strategic partners and experts who can inform this work.

A3.2 Project Needs & Community Grounding

As DAWN Canada's work is deeply grounded in the needs of women and girls with disabilities in Canada, and connected at a grassroots level to lived experience in this area, the organization was able to establish a need for this type of research. DAWN Canada also worked strategically with partners (People First of Canada, Realize, and the Acquired Brain Injury Research Lab) to help provide information and insight around areas already identified as gaps. We worked with our partners to help inform the final report and identify opportunities moving forward.

A3.3 Conducting a Literature Review

Our literature review focused on community documents and open source material including policy documents, government reports and statistics, unpublished literature and research, community-based information, some academic literature etc. A literature review was deemed appropriate for the scope of this work as it provided access to relevant information on this subject and a summary of these findings allowed for informed conclusions about this topic.[1] Using a literature review also informed the final research report, and provided the means necessary to identify existing gaps and inconsistencies, and inspire future research ideas.[2] While our focus was on community-based sources, and given the time constraints for this research (6 months), we worked to create a bibliography to supplement these sources. We are committed to adding to and expanding this as we move forward.

A3.4 Supplementing the Literature Review

As this is an area DAWN is well-versed in, and has already connected with stakeholders to gather feedback and insight about this project, we recognized that there were significant gaps with respect to our knowledge and understanding about women and girls with disabilities in Canada. We also recognized that existing literature on disability often lacks a gender analysis. To supplement our literature review we carried out key informant interviews with 10 stakeholders, collected written responses from an additional 5 stakeholders, and a facilitated a 4 hour session with 25 members from People First (a mixed-gender group with a

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1   Cronin, P., Ryan, F., & Coughlan, M. (2008). Undertaking a literature review: a step-by-step approach. *British journal of nursing*, *17*(1), 38-43.
2   Cronin, P., Ryan, F., & Coughlan, M. (2008). Undertaking a literature review: a step-by-step approach. *British journal of nursing*, *17*(1), 38-43.

majority of women). This research process confirmed gaps, steered the research process, and informed our next steps.

A3.5 Other Research Considerations

In developing this research DAWN acknowledged historic tensions and power imbalances between researchers and the disability community and sought approaches that were grounded in lived experience and conducted in inclusive and empowering ways. For example, the following key barriers where disability and research are concerned have been noted:

- A large body of existing knowledge about disability that is rooted in medical models and formal services rather than individual experiences;[3]

- A "knowledge for" rather than "knowledge with" relationship between researchers and the community;[4]

We sought engagement with the community that challenged problematic power dynamics through more participatory and emancipatory activities. Participatory research frameworks reflect a process in which the planning and execution of the research is done with individuals whose realities are being examined.[5] Where disability issues are concerned, this engagement allows participants opportunities to influence the research process, share their knowledge, skills, and contributions, and anchor the research in socially relevant questions and outcomes.[6] In practical ways, our research process was informed by participatory research in the following

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3   Braddock, D., & Parish, S. (2001). An Institutional History of Disability. In Albrecht, G., Seelman, K., & Bury, M. (Eds.) Handbook of Disability Studies. (pp. 11-68). London: Sage Publications.

4   Church, K. (1995). *Forbidden narratives: Critical autobiography as social science* (Vol. 2). Psychology Press.

5   Bergold, J., & Thomas, S. (2012). Participatory research methods: A methodological approach in motion. *Historical Social Research/Historische Sozialforschung*, 191-222.

6   Stack, E., & McDonald, K. E. (2014). Nothing About Us Without Us: Does Action Research in Developmental Disabilities Research Measure Up?. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(2), 83-91.

ways:

- Researching issues the community identified as a need;

- Focusing the research process in a way that tapped into the community for knowledge;

- A process with ongoing engagement between the researchers, DAWN Canada representatives and partners (including a majority of those who identify as being a woman with a disability) to ensure the project remained inclusive;

- Stakeholder interviews and written responses to ensure a balance between the literature and lived-experience;

- A commitment to accessibility and plain language for various research pieces. On this note, other accessible formats and tools will follow this larger report.

While participatory research provided the means to make the research process more inclusive, we are also mindful of its limitations, including the reality that while the research process may be more inclusive, opportunities for transformative change can be rare.[7] Including strands of emancipatory research helped us create a space to ask questions about exclusion while at the same time working to identify and challenge power relations that influence and uphold marginalization. Emancipatory research is also philosophically in-line with research which seeks to include an intersectional lens as we acknowledge that disability is not monolithic and that some women and girls with disabilities experience additional barriers because of their identity (race, LGBTQI2S, Indigenous etc.). Emancipatory paradigms are also grounded in notions of reciprocity, gain, and empowerment.[8] Within an emancipatory paradigm, we sought to identify, challenge, and dismantle power relations within the research process. In practical ways, this meant:

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7   Stack, E., & McDonald, K. E. (2014). Nothing About Us Without Us: Does Action Research in Developmental Disabilities Research Measure Up?. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(2), 83-91.

8   Oliver, M. (1997). *Doing Disability Research* [Online version]. Leeds: The Disability Press.

- A commitment to valuing lived-experience and community-based knowledge within the text;

- Identifying power imbalances and the need for intersectionality and naming these in the research;

- Creating spaces that empowered individuals with disabilities to lead and inform the research process (People First facilitated session).

- Producing real and tangible next steps grounded in community needs

- A collaborative process grounded in lived experience that continually engaged and responded to emerging issues and needs

- Ensuring the final results are accessible to persons with disabilities (plain language tools, bilingual, free access, alternate formats etc.). Again, many of these pieces will follow as stand-alone pieces and supplements to this larger report.

Appendix 4: Women & Girls with Intellectual Disabilities in Canada Expanded Report

DAWN Canada and People First of Canada have partnered to conduct a literature review and research around women and girls with intellectual disabilities in Canada. This research is part of a larger project around women and girls with disabilities in Canada that seeks to address the lack of a gendered and intersectional analysis. This partnership has been developed to look at women and girls with intellectual disabilities as the needs of this group is often ignored in research. This partnership and the resulting report are grounded in the reality that women and girls with intellectual disabilities in Canada face unique and specific barriers that require specific research, policy, and advocacy solutions.

This report is based on the results of a literature review, 5 key informant interviews with women with intellectual disabilities, and a 4 hour facilitated discussion with 25 members of People First at their most recent AGM (April 2018). This report is an exploratory first step that will help shape future work on women and girls with intellectual disabilities in Canada between DAWN Canada and People First.

We have organized our research and results using the categories below, to reflect key issues we wanted to explore. Where possible we applied an intersectional and gendered lens. In doing this research we were able to confirm that there is a real need for more research through an intersectional and gendered lens for persons with intellectual disabilities as these aspects are often ignored in the literature. The report will be organized into the following sections:

- **Social Exclusion**

- **Income and Income Security**

- **Education**

- **Employment, Unemployment & Working Conditions**

- **Unpaid Labour**

- **Housing**

- **Health Services**

- **Violence & Abuse**

- **Transportation**

A4.1 Social Exclusion

Social exclusion is a process that denies individuals the opportunity to participate in different aspects of Canadian life.[9] Social exclusion is experienced through four unique areas including: barriers to participation in civil affairs like laws and regulations, barriers to social goods like health care, exclusion from social and cultural opportunities, and economic exclusion.[10] The literature and our research confirm that women and girls with intellectual disabilities continue to be excluded is most aspects of Canadian life. For example, in Canada persons with intellectual disabilities are still institutionalized, including in large institutions, long-term care facilities, nursing homes, and other residential facilities.[11] While the literature in this report will support this, it is also important to note that social exclusion was a key theme in our interviews and facilitated discussion. For persons with intellectual disabilities, including women and girls, social exclusion is an important

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9   Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian facts*. York University, School of Health Policy and Management. Available at: http://thecanadianfacts.org/the_canadian_facts.pdf

10   Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian facts*. York University, School of Health Policy and Management. Available at: http://thecanadianfacts.org/the_canadian_facts.pdf

11   Canadian Association for Community Living (2010) Position Statement on Housing. Available at: http://www.cacl.ca/sites/default/files/CACL%20Policy%20Position%20Housing.pdf

and key barrier to real and meaningful inclusion that shapes all aspects of their lives. Throughout this report we will reflect on what social exclusion means for women and girls with intellectual disabilities.

A4.2 Income & Income Security

Income is one of the most important determinants of health as it shapes overall living conditions. Income security measures are designed to protect individuals as their lives shift.[12] For people with intellectual disability, income security includes Federal and Provincial disability programs.

The literature on income security and our interviews and focus group confirm that for women and girls with intellectual disabilities, these supports are often not enough. Poverty rates are one measure that indicates income level and income security remain a real barrier for those with disabilities. For persons with intellectual disabilities, rates of poverty are three times that of persons without disabilities, with these rates highest among persons with intellectual disabilities not living with a family member (75%).[13] This last point is important, as those with intellectual disabilities who seek greater autonomy from family members can be particularly vulnerable to poverty. If this is the case, we have to ask important and critical questions about the kinds of choices people with intellectual disabilities actually have when independence will put them at greater risk of poverty.

In Canada, 23% of those who report having a disability experience a low-income compared to 9% of those without a disability.[14] For adults with intellectual disabilities

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12   Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian facts*. York University, School of Health Policy and Management. Available at: http://thecanadianfacts.org/the_canadian_facts.pdf

13   Canadian Association for Community Living (2013) Assuring Income Security And Equality for Canadians with Intellectual Disabilities. Submission to The House of Commons Standing Committee on Finance. Available at: http://www.ourcommons.ca/Content/Committee/411/FINA/WebDoc/WD6079428/411_FINA_IIC_Briefs/CanadianAssociationforCommunityLivingE.pdf

14   Wall, K. (2017) Low income among persons with a disability in Canada. Statistics Canada. Available at: http://www.statcan.gc.ca/pub/75-006-x/2017001/article/54854-eng.pdf

71.8% are out of the labour force, 6.0% are unemployed, and there is only a 22.3% employment rate (the lowest of any type of disability).[15] While there is no breakdown available in terms of gender, the median income for working aged adults with intellectual disabilities was reported as only $10,800, with 71.9% of adults relying on government transfers as their greatest source of income.[16] While there is limited data on intellectual disability and food security, research out of the US suggests that young adults with intellectual disabilities face significantly higher rates of food insecurity as compared to their peers without disabilities.[17] These numbers tell a story that reflects that many persons with intellectual disabilities, even those receiving disability supports, do not have enough to live on comfortably and this lack of support influences the choices they make about their lives.

This was reinforced in our focus group as the group shared the following concerns about persons with intellectual disabilities:

- Disability support is not equal across the country and there are often different rules and guidelines in different provinces and territories.

- Income support can be frustrating for persons with intellectual disabilities who are also Indigenous.

- Clawbacks on any money a person earns make it difficult to move out of poverty and/or get a job.

- Qualification criteria can change frequently and this creates added complexities and barriers.

- Many support applications require a note from a doctor but many doctors

15   Bizier, C., Fawcett, G., Gilbert, S., & Marshall, C. (2015). *Developmental disabilities among Canadians aged 15 years and older, 2012*. Statistics Canada= Statistique Canada. Available at: http://www.statcan.gc.ca/pub/89-654-x/89-654-x2015003-eng.htm
16   Bizier, C., Fawcett, G., Gilbert, S., & Marshall, C. (2015). *Developmental disabilities among Canadians aged 15 years and older, 2012*. Statistics Canada= Statistique Canada. Available at: http://www.statcan.gc.ca/pub/89-654-x/89-654-x2015003-eng.htm
17   Brucker, D. L., & Nord, D. (2016). Food Insecurity Among Young Adults With Intellectual and Developmental Disabilities in the United States: Evidence From the National Health Interview Survey. *American journal on intellectual and developmental disabilities*, *121*(6), 520-532.

charge for these and for those living in poverty this can be a barrier.

- In some cases there is little to no support for those on income support for things like dental health, medication, eye care, and health related fees which creates added stress.

- Waitlists delay people getting help.

- People are forced to rely on food banks and community services to get the support they need.

- Many people feel they need to rely on advocates to help them get the support they need, but this can be a real problem if a person lacks support and/or is a self-advocate whose voice isn't being heard.

- Changes in governments impact disability supports, so many people feel that there supports are never guaranteed or permanent ("your life should not change every four years because of a new government").

A4.3 Education

In general there is a lack of research looking at disability and childhood in Canada, specifically research that is informed by those with lived experience (children and adults with disabilities). While we have tried to incorporate the experiences of children throughout this report, it is here under the education setting that participants were most likely to reflect on childhood experiences. As such, out of all the sections of this report, education will focus most heavily on childhood.

Education is seen as a key social determinant of health as there is a high correlation between education and other determinants of health like employment security and

income.[18] Women and girls with disabilities experience with education is thus a key factor to consider when examining existing barriers. Persons with intellectual disabilities face distinct barriers to education. This includes 22.5% of children with intellectual disabilities having to go outside their community for schooling, and 30% reporting segregated schools and classes as their only option.[19] A recent report by CACL[20], indicates that:

- 53% of parents feel their child with an intellectual disability does not receive necessary academic accommodations

- 67% of parents felt their children were excluded from curriculum appropriate to their learning

- 32% felt their children didn't have access to support staff as needed.

In one of our stakeholder interviews, a woman with an intellectual disability drew a link between these early forms of exclusion and the ongoing marginalization of women with intellectual disabilities well into adulthood. For this stakeholder, these early experiences are critical as they cut off individuals from natural networks and support systems that foster a strong sense of self, self-confidence, and the ability to be strong self-advocates later in life. They argued that for many women with intellectual disabilities, they never have the chance to develop their own voice. With education then, it is important to understand the foundational role these experiences play in shaping both the individual and their access to the resources and tools they may need to succeed later in life.

As a result of the many barriers those with intellectual disability face, adults with intellectual disabilities remain 4 times as likely (53.6%) as those without disabilities to have not completed high school, and only 18.9% report completing post-

18   Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian facts*. York University, School of Health Policy and Management. Available at: http://thecanadianfacts.org/the_canadian_facts.pdf
19   Canadian Association for Community Living (nd.) No Excuses. Available at: http://www.cacl.ca/action/campaigns/no-excuses
20   CACL (2018) If Inclusion Means Everyone Why Not Me? Available at: https://communitylivingontario.ca/wp-content/uploads/2018/05/If_Inclusion_Means_Everyone_Why_Not_Me_FINAL_s.pdf

secondary qualifications.[21] Where intellectual disability is concerned, ⅔ of adults report their condition resulted in taking fewer course and it taking them longer to attain their level of education.[22]

These, and other barriers were reinforced throughout our focus group and included concerns around the following:

- Segregated education classes remain a reality for many with intellectual disabilities.

- Other differences (including race, gender, sexuality etc.) made their education experiences more difficult and individuals often felt targeted because of their "differences."

- For many with intellectual disabilities accessibility and inclusion hinged on having strong family advocates. Yet this presents a real problem for those students that lack this support.

- Segregated and "special" programs led to increased exclusion and often meant barriers later in life as these individuals felt they were not given the chance to meet students without disabilities and build friendships and natural support systems.

- Participants often had to leave their communities (and in one case even their province) to access education.

For many of those with intellectual disabilities bullying, harassment, and abuse were significant parts of their educational experiences. How the education system is experienced is also a key concern for persons with intellectual disabilities. The CHRC found that 1 in 4 persons with disabilities in Canada reported being bullied

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21   Bizier, C., Fawcett, G., Gilbert, S., & Marshall, C. (2015). *Developmental disabilities among Canadians aged 15 years and older, 2012*. Statistics Canada= Statistique Canada. Available at: http://www.statcan.gc.ca/pub/89-654-x/89-654-x2015003-eng.htm

22   Bizier, C., Fawcett, G., Gilbert, S., & Marshall, C. (2015). *Developmental disabilities among Canadians aged 15 years and older, 2012*. Statistics Canada= Statistique Canada. Available at: http://www.statcan.gc.ca/pub/89-654-x/89-654-x2015003-eng.htm

because of their disability, and 25% of persons with disabilities shared that they were avoided or excluded in educational settings because of their disability.[23] At the People First focus group session, participants agreed that these numbers seemed low, as many shared that bullying was a predictable and painful part of their education experience. The most recent CACL research reports 64.9% of parents shared that their children experienced some form of bullying.[24] One of the most impactful experiences at the People First AGM centred on our discussion of education, specifically the reality of bullying for those with intellectual disabilities. This was an emotional process for participants who shared multiple stories of various forms of abuse at the hands of other children and adults in the school environment. Participants shared the following concerns specific to bullying in education settings:

- There is a stigma to being placed in "special" or "modified" programs that often makes students with intellectual disabilities bigger targets for bullies.

- Many individuals shared that throughout their formal education bullying was a constant experience and it made many feel they wanted to quit.

- Victims of bullying often respond with anger and/or lashing out, which led to them getting in even more trouble (and feeling even more frustrated and isolated).

- One participant shared that these negative experiences led them to think about suicide.

- Many participants shared that they were regularly called names, including the "R-word" that were hurtful.

- Participants also shared that while teachers were supposed to protect them,

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23   Canadian Human Rights Commission (nd.) Left Out: Challenges faced by persons with disabilities in Canada's schools. Avaialbile at: https://www.chrc-ccdp.gc.ca/sites/default/files/challenges_disabilities_schools_eng.pdf
24   CACL (2018) If Inclusion Means Everyone Why Not Me? Available at: https://communitylivingontario.ca/wp-content/uploads/2018/05/If_Inclusion_Means_Everyone_Why_Not_Me_FINAL_s.pdf

they did not feel safe or supported. In some case, participants felts adult staff took part in bullying as well (one participant in particular reflected on this as a part of their experience within the residential school system).

- For one individual who was gay, the bullying was directed at both their disability and sexual identity.

For participants, these dynamics resulted in decreased confidence and a sense that the system failed to protect them because their lives were not valued. What is clear is that this is a major issue that requires more exploration. As one participant noted, bullying requires an approach that recognizes the social relationships in schools including those who are bullied, those who bully, and other students who are part of these social situations.

The research clearly reflects significant barriers for children with learning disabilities. However, of note is the need for research to engage with children and adults with intellectual disabilities on these issues as there is a tendency for research to rely on parents, teachers, and other non-disabled adults to tell these stories. Our experience at the facilitated focus group illustrated the importance of giving persons with intellectual disabilities a space to share their stories. For many of these participants, things that they shared were not things they had previously shared with parents and caregivers, and also, at times, because of the sometimes complex nature of their relationships with their parents and guardians, participants expressed their wants and needs were significantly different than those their parents had articulated for them. There were also aspects of the focus group process that were empowering for individuals as they supported each other disclosing these often painful memories. This certainly speaks to the need for research to provide safe and supported spaces where individuals can explore their lived experiences.

A4.4 Employment, Unemployment and Working Conditions

Employment is a complex dynamic for persons with intellectual disabilities. Research here reflects the many barriers and disadvantages facing those with intellectual disabilities. Where paid employment is concerned, 61.3% of those with intellectual disabilities feel disadvantaged, as 34.6% felt they had been refused a job because of their disability, 31.4% believed they have been denied a promotion because of their disability, and 28% feel they had been denied a job interview because of their disability.[25] For those with intellectual disabilities then, there are several barriers that prevent them from even accessing paid employment. In our interviews with stakeholders, women with intellectual disabilities shared these frustrations as they noted they felt it was more difficult for them to access paid employment. Among their concerns was that they often lacked formal education (in large part because of the barriers covered in the last section) and that employers were unwilling to recognize the informal experiences and knowledge they had.

Participants in our focus groups noted that for those with intellectual disabilities there are many specific barriers that researchers and policy makers need to understand. These included:

- The reality that those with intellectual disabilities still receive sub-par wages (sheltered workshops).

- Persons with intellectual disabilities often have the skills necessary to work but are never given the chance to demonstrate these skills.

- When people with intellectual disabilities do find work they are often given the worst jobs (cleaning toilets etc.) and feel stuck in these jobs.

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25   Bizier, C., Fawcett, G., Gilbert, S., & Marshall, C. (2015). *Developmental disabilities among Canadians aged 15 years and older, 2012*. Statistics Canada= Statistique Canada. Available at: http://www.statcan.gc.ca/pub/89-654-x/89-654-x2015003-eng.htm

- Many participants felt that because of their intellectual disability they were more likely to be taken advantage of in the workplace.

- Some participants shared their frustration with what they perceived as a never ending string of "employment programs" that provide training but never lead to real jobs. They felt these skills were underutilized.

- Many felt that rules built into income support programs (clawbacks etc.) served as a disincentive to employment and another way people with disabilities are kept poor and disadvantaged in the workforce.

Once in the workplace, research indicates that 53.8% of those with intellectual disabilities required accommodation, including 30.2% needing modified work hours, 27.5% requiring modified duties, and 16.9% requiring human support; yet only 39.6% reported that all their accommodation needs were met.[26] Despite the attention researchers and policy makers have placed on employment, participants with intellectual disabilities (in the stakeholder interviews and focus group) shared that they continue to face a disproportionate number of barriers.

A4.5 Unpaid Labour

Unpaid labour is an important part of the economic contributions persons with intellectual disabilities make. This includes the work they do for below minimum wage (sheltered workshops), volunteer contributions, and caregiving labour.

Sheltered Workshops //

Exploitive forms of unpaid work, like sheltered workshops, have a deep history for persons with intellectual disabilities. Often framed as training or rehabilitation

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26   Bizier, C., Fawcett, G., Gilbert, S., & Marshall, C. (2015). *Developmental disabilities among Canadians aged 15 years and older, 2012*. Statistics Canada= Statistique Canada. Available at: http://www.statcan.gc.ca/pub/89-654-x/89-654-x2015003-eng.htm

programs, sheltered workshops are segregated sites where people with disabilities work for less than the mandatory minimum wage. Their positioning as training situates them outside of many existing labour laws and regulations, and in the Canadian context, persons with intellectual disabilities remain vulnerable to these forms of unpaid labour. While the sheltered workshop model has declined in recent years, other segregated employment programming with exploitive compensation models, have remained dominant where intellectual disability and employment programing are concerned.[27] For those with intellectual disabilities segregated programs and sheltered workshops remain a mainstay in day programming.[28]

While there is a noticeable lack of research where women, intellectual disability, and vocational qualifications are concerned,[29] there is evidence that people with intellectual disabilities, including women, would prefer to work outside of these settings.[30] While gendered analysis is largely missing with respect to sheltered workshops, there are concerns that women and those who are younger have remained in sheltered workshops.[31] There is a clear need to explore the experiences of exploitive work through a gendered lens to better understand the dynamics of this form of unpaid work. Additionally, as sheltered work is phased out, there needs to be a better understanding of other how other exploitive models persist and the unique ways various populations are vulnerable to their exploitation. While we did not have time to explore this topic in depth in either the interviews or focus group, there is clearly a need for more research here that is grounded in lived experience.

27   Canadian Association for Community Living (2011) achieving social and economic inclusion: from seg-regation to 'employment first. Law Reform and Public Policy Series. Available at: http://www.cacl.ca/sites/default/files/Achieving%20social%20and%20economic%20inclusion_0.pdf
28   Canadian Association for Community Living (2013) inclusion of Canadians with intellectual disabilities: a national report card. Available at: http://www.cacl.ca/sites/default/files/National%20Report%20Card%202013%20ENG%20Final.pdf
29   Fasching, H. (2014). Compulsory School Is Over and Now? Vocational Experiences of Women with Intellectual Disability. *Creative Education*, *5*(10), 743.
30   Canadian Association for Community Living (2011) achieving social and economic inclusion: from seg-regation to 'employment first. Law Reform and Public Policy Series. Available at: http://www.cacl.ca/sites/default/files/Achieving%20social%20and%20economic%20inclusion_0.pdf
31   May-Simera, C. (2018). Reconsidering Sheltered Workshops in Light of the United Nations Convention on the Rights of Persons with Disabilities (2006). *Laws*, *7*(1), 6.

Caregiving //

In our interviews and focus group it was apparent that people with intellectual disabilities are caregivers, yet they are often not recognized for these roles although they may care for family members, partners, friends, children and neighbors. The research in this area sheds light on some of the ways persons with intellectual disabilities as caregivers, specifically as parents, remain discriminated against. Parents with intellectual disabilities appear to be over-represented within child protection services.[32] In Canada, more than one in ten maltreatment investigation (in 2003) involved parents with a cognitive disability.[33] Interestingly enough, while the literature does not clearly link cognitive disability and child maltreatment, parents with these impairments are often not permitted to raise their children (research indicates 40% - 50% of children are permanently placed).[34] In our focus group session, one woman with an intellectual disability shared that although she had not previously disclosed this, she was the parent of a child who had been taken away. This was a deeply painful process for her and she shared how difficult it was for her to lack the support of her family where her parenting wishes were concerned. This story illustrated one of the many ways experiences are often unique for those with intellectual disabilities, as parents and guardians often wield disproportionate power in the decision making process and their assumed role as "caregiver" can often be disempowering to the individual themselves. There is clearly a need to engage with women with intellectual disabilities more thoroughly to explore their experiences and roles as parents and caregivers.

Volunteering //

One of the strongest themes that emerged was the role of those with intellectual disabilities as volunteers and leaders. While this was touched on in our focus

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32   Azar, S. T., Stevenson, M. T., & Johnson, D. R. (2012). Intellectual disabilities and neglectful parenting: Preliminary findings on the role of cognition in parenting risk. *Journal of mental health research in intellectual disabilities*, *5*(2), 94-129.
33   Westad, C., & McConnell, D. (2009). Caregiver Cognitive Impairment. *Child Abuse and Neglect (CIS-2003)*, 10. Available at: http://www.crom-wmrc.ca/fck_user_files/ChildWelfareProcessOutcomes(1).pdf
34   Westad, C., & McConnell, D. (2009). Caregiver Cognitive Impairment. *Child Abuse and Neglect (CIS-2003)*, 10. Available at: http://www.crom-wmrc.ca/fck_user_files/ChildWelfareProcessOutcomes(1).pdf

group, our stakeholder interviews provided important insight into these roles. Women with intellectual disabilities often shared that they had been advocates for many years. This included work locally and regionally on community issues (like housing and education) as well and national initiatives like the campaign to educate Canadian about the impact of the "R-word." There were also examples of women with intellectual disabilities representing Canada abroad on international disability rights issues. What was striking about these conversations was that many of the women did not freely offer these examples up, and needed some prompting to recognize these tremendous accomplishments. On more than one occasion, stakeholders shared frustration that employers failed to see their potential because of a lack of formal education, yet these same stakeholders served on volunteer Boards and committees and have been instrumental in shaping policy around intellectual disability in Canada. There is a pressing need to further explore these contributions to counter stereotypes about those with intellectual disabilities, as well as to provide spaces to celebrate the accomplishments of advocates and self-advocates with intellectual disabilities.

A4.6 Housing

With respect to intellectual disability, an estimated 13,200 adults aged 30 and older are living with their parents because they lack access to the resources and support necessary to live on their own, and an estimated 10,000 adults under age 65 are in long-term care facilities and nursing homes because of a lack of supports and affordable housing.[35] Housing was a key issue for both stakeholder and focus group participants as many reinforced that for those with intellectual disabilities, housing remains a critical area. In Canada, those with intellectual

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35   Meeting Canada's Obligations to Affordable Housing and Supports for People with Disabilities to Live Independently in the Community: Under Articles 19 and 28, Convention on the Rights of Persons with Disabilities (2017) Submission to UN Special Rapporteur on the Right to Housing for her next report to the UN General Assembly, 72nd Session. Available at: http://www.ohchr.org/Documents/Issues/Housing/Disabilities/CivilSociety/Canada-ARCHDisabilityLawCenter.pdf

disabilities still live in institutional settings (including institutions) and lack choice and autonomy where housing is concerned. In one of our stakeholder interviews, we were reminded that on issues like housing, researchers are likely missing important stories as individuals who have been placed in places like nursing homes are unlikely to be asked about their experiences and less likely to be connected to advocacy organizations.

Participants shared the following concerns:

- A lack of funding for the kinds of homes and housing arrangements individuals want to live in.

- A lack of choice (often because of inadequate funds) that leads to group homes and other residential settings as the only option.

- Asset limits that prevent individuals on disability supports from owning (or inheriting) a house which forces individual to rent or rely on agencies.

- Often times the way housing is supported for those with intellectual disabilities creates spaces (group homes etc.) that do not feel like a real home.

- While rent continues to increase, disability support payments have not kept pace.

- A lack of choice, and a lack of accessible and affordable housing has left many in unsafe housing arrangements.

- Often times those with intellectual disabilities are often relegated to wait lists and put where there is an open bed rather than where they choose who they live with and where they want to live. These are not person-centred approaches.

- Participants also made important links between housing and sites of incarceration, including institutions, and in one case a youth jail that had been converted into residential housing for those with intellectual disabilities.

Across the country it seems individuals lack the resources necessary for safe

and affordable housing. Furthermore, housing policies tend to rely on agencies and remain grounded in matching individuals with beds rather than exploring the housing choices and autonomy. These realities speak to the continued social exclusion of those with intellectual disabilities, and create potentially unsafe and disempowering housing realities.

A4.7 Health

Access to health services are an important social determinant of health, yet there are significant barriers which continue to prevent equitable access to health services, especially for women and girls with disabilities.

Sexual & Reproductive Health //

Where sexual and reproductive rights are concerned, women with disabilities continue to face stigmatization and barriers. Historically, reproductive health has excluded women with disabilities and policies have been introduced that managed their bodies in unique and troubling ways. Included in this history is a legacy of surgical sterilization,[36] as Canada was influenced by the eugenics movement throughout the 20th century.[37] The eugenics movement was particularly impactful for women with disabilities, and both Alberta and British Columbia had legislation enabling sterilization for those diagnosed as "mentally ill" and "deficient." [38] In Alberta, data from the Alberta Eugenics Board case files indicates 1,154 of women with disabilities were sterilized under eugenics practices, with close to 40% of these women being were sterilized after 1955.[39] Unfortunately in the case of British

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36   Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Developmental Disabilities Research Reviews*, *12*(1), 48-56.
37   Fabre, M., & Schreiber, E. The Coercive Sterilization of Indigenous Women in Canada: A Study of the Sexual Sterilization Act in Alberta and British Columbia. *BETWEEN ARTS AND SCIENCE*, 27.
38   Park, D. C., & Radford, J. P. (1998). From the case files: reconstructing a history of involuntary sterilisation. *Disability & Society*, *13*(3), 317-342.
39   Radford, J. P., & Park, D. C. (1995). The eugenic legacy. *Journal on Developmental Disabilities*, *4*(1), 73-84.

Columbia, records of these practices have either been lost or destroyed.[40] While other provinces may not have had official sterilization laws, countless women with disabilities were likely sterilized as these procedures were often performed on young women with disabilities through parental consent.[41] Sterilization laws in Alberta were not repealed until 1972. In 1995, Leilani Muir, a women with an intellectual disability, successfully sued the Alberta government over the practice of forced sterilization. Muir who had been admitted to the Provincial Training School for Mental Defectives in 1955, had been sterilized at age 14.[42] Muir's advocacy led to an official apology from the Alberta government and compensation to hundreds of others who had been the victims of sterilization.[43] This is an important historical legacy that certainly informs modern practices for many women with disabilities, particularly since their parents may still yield power and control that can more broadly influence their access to and decisions around their reproductive health. In our research one woman's parents made decisions for her about her reproductive health and even though she was an adult, doctors went along with their wishes (not hers).

Parental control is an important consideration where reproductive health is concerned as, especially in adolescents, parents and guardians may shy away from the topic of sexual health and/or ignore it all together, individuals may have very little control over related decision-making, and there may be a noticeable lack of sexual education that is adapted and accessible to this population.[44]

We also know women with intellectual disabilities face unique barriers where accessing sexual and reproductive health services are concerned. These barriers

40   Radford, J. P., & Park, D. C. (1995). The eugenic legacy. *Journal on Developmental Disabilities*, *4*(1), 73-84.
41   Radford, J. P., & Park, D. C. (1995). The eugenic legacy. *Journal on Developmental Disabilities*, *4*(1), 73-84.
42   Radford, J. P., & Park, D. C. (1995). The eugenic legacy. *Journal on Developmental Disabilities*, *4*(1), 73-84.
43   Eugenics Archives (nd.) Our Stories - Leilani Muir. Availbie at: http://eugenicsarchive.ca/discover/our-stories/leilani
44   Ramage, K. (2015) Sexual Health Education for Adolescents with Intellectual Disabilities. Saskatchewan Prevention Institute. Available at: http://skprevention.ca/wp-content/uploads/2017/01/7-527-Sexual-Health-Education-for-Adolescents-with-Intellectual-Disabilities.pdf

include: a lack of training and expertise among healthcare professionals, hesitancy among providers to address sexual health, a lack of knowledge rooted in limited opportunities for sexual education, disability related barriers, a high occurrence of sexual assault among this population, a lack of awareness and dialogue around human rights and sexual expression among this group, undertreatment where menstrual disorders are concerned, and continued systemic barriers.[45] These barriers can lead to negative outcomes for persons with intellectual disabilities including a lack of knowledge around sexual health and relationships that may increase risks associated with victimization and unwanted outcomes like unplanned pregnancy and STIs.[46]

While some of these issues were difficult for participants to navigate in group settings, they were covered in small group discussions and shared at the end of the session in writing. One example of this reflected a young woman with an intellectual disability (invisible) who lived in a group home and had been forced into a situation in which they had guardianship over her. She was not allowed to spend time with her boyfriend and had to "run away" for the day to have any alone or intimate time together as a couple. When she returned to the group home, she was forced to go to the doctor for a pelvic exam, morning after pill, and blood work.

General Health Care //

While stakeholders and focus group participants did not focus as much on reproductive health, they shared many general concerns about health care and persons with intellectual disabilities. These include:

- A tendency for doctors to talk to parents and caregivers rather than the individual.

- A feeling that doctors do not take concerns seriously and often dismiss complaints about pain (for example, telling a person to exercise more when

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45   Greenwood, N. W., & Wilkinson, J. (2013). Sexual and reproductive health care for women with intellectual disabilities: a primary care perspective. *International journal of family medicine*, *2013*.

46   Ramage, K. (2015) Sexual Health Education for Adolescents with Intellectual Disabilities. Saskatchewan Prevention Institute. Available at: http://skprevention.ca/wp-content/uploads/2017/01/7-527-Sexual-Health-Education-for-Adolescents-with-Intellectual-Disabilities.pdf

they share they have back pain).

- Not having a choice about medications and feeling forced to take certain ones.

- A lack of privacy if an aid, support worker or family member needs to accompany them to an appointment.

- Situations in which guardianship is forced on them and/or they do not feel they have the power to give consent.

- Parents and guardians often hold an individual's health card, which leads to a lack of privacy and need for consent to access health care professionals.

- Some participants share that they feared going to the doctor, even when sick, because they are scared that this will lead to them losing their rights and being placed in a psych ward. These fears reflect the reality that for many with intellectual disabilities, the threat of various forms of institutionalization looms large.

These examples illustrate how barriers to health care for persons with intellectual disabilities, including women, remain very real concerns and there is a need to push for shifts in attitudes about intellectual disability and rights in these settings.

A4.8 Violence & Abuse

In both our stakeholder interviews and among focus groups individuals shared that violence and abuse were a key concern for persons with intellectual disabilities, including women. Yet in our interviews while people confirmed that they "see a lot" of this and that it "happens behind closed doors", participants did not seem comfortable discussing this in the interviews. This was not surprising as the researcher was a stranger to them at this time. During the focus group, we decided not to cover this topic as our session on education was so distressing for many

participants when we discussed bullying and abuse in educational settings. Given this, there was agreement that while this is a discussion that needs to happen, a specific and supported space needs to be created to ensure participants remain comfortable and have the resources necessary if and when they disclose abuse. As such, this section will reflect only the research in this area.

Existing research indicates this is a significant issue for women and girls with intellectual disabilities as:

- 24% of women with cognitive disabilities (which include learning, intellectual and memory disabilities) and 26% of women with mental-health related disabilities report being sexually abused before the age of 15.[47]

- For women with cognitive and mental health disabilities, rates of violent victimization are four times the rates of those who do not have a disability.

- For women with a cognitive disability who identify as lesbian, gay, or bisexual rates of violent victimization are well above those among heterosexual women with cognitive disabilities.

- Women who experience mental-health related disabilities and those with cognitive disabilities also experience disproportionately high rates of sexual assault.

- Women with cognitive disabilities are more likely to be the victim of violence from a common-law partner, or current or former spouse (43%).

Given these realities, it is important that future research in this area engages women and girls with intellectual disabilities in ways that support their engagement in these conversations.

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47   Cotter, A. (2018) *Violence and Victimization of Women with Disabilities.* Statistics Canada. Available at: http://www.statcan.gc.ca/pub/85-002-x/2018001/article/54910-eng.pdf

A4.9 Transportation

Transportation was an issue participants in our stakeholder interviews and focus group felt passionate about. As they shared, transportation is often key to inclusion in all other areas of life. In one of our interviews, a woman with an intellectual disability shared that where she lived there were significant barriers to transportation and while she was comfortable asking others for support, she feared that many women with disabilities who are more marginalized will not be confident enough to ask for help with transportation. For our focus group participants, they noted that transportation options are different across the country and while major cities may have several public transportation options, in rural and isolated areas there may be little choice (not even cabs or shuttles). In one example, a participant shared that they had specialist appointments and needed to find someone to drive them to it because of a lack of transportation. In another example, a participant shared that they had been advised to move to a city if they wanted to access more transportation options. Additionally, it was noted that accessible transportation options can end early in the evening leaving individuals without the option to go out at night. In some communities, a lack of transportation options means children with disabilities have to leave school earlier than their peers because they have limited options for rides to and from school. For those with intellectual disabilities, a lack of plain language resources can mean navigating transportations systems is overly confusing and inaccessible. While much of this discussion focused on public transportation, participants also noted that a lack of accessibility in their communities limited options to travel by foot (accessible sidewalks etc.).

It is clear that social exclusion is made worse by a lack of accessible and affordable transportation across the country that impacts the ability of individuals to fully be a part of their community.

A4.10 Sexuality

Sexuality is an important area for many women with disabilities, and while participants only briefly touched on this, research in this area illustrates a number of barriers for girls and women with intellectual disabilities For example, women with intellectual disabilities face significant barriers as their sexuality is often stereotyped, and they are often depicted as asexual and childlike which leads to denial of their needs.[48] Other barriers include: isolation which impacts access to social contexts where learning can take place, family control, a lack of role models, and internalized notions about ideal bodies that influence feelings around attractiveness and desirability.[49]

Furthermore, the literature on intellectual disability and sexuality is often limited to issues around sex education, vulnerability, consent and exploitation, with little attention to sensuality and pleasure.[50] In practice, gatekeeping remains a significant barrier within disability organizations and among parents in terms of supporting sexual expression among persons with intellectual disabilities.[51] For women with intellectual disabilities there may also be barriers related to socialization, sexual expression, partner selection and notions about femininity and sexual restraint.[52] As many women with intellectual disabilities may be in situations where parents and support workers exercise more control in their decision making process, carving out a healthy and confident sexual individual identity can be difficult. Recent research around the dynamic between support workers and adults with intellectual disabilities helps underscore these power dynamics as findings indicate support

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48   Lin, L. P., Lin, P. Y., Hsu, S. W., Loh, C. H., Lin, J. D., Lai, C. I., ... & Lin, F. G. (2011). Caregiver aware-ness of reproductive health issues for women with intellectual disabilities. *BMC public health*, *11*(1), 59.
49   García, A. G., & Álvarez, C. D. (2014). Sexuality and functional diversity: an analysis from a gender perspective. *Procedia-Social and Behavioral Sciences*, *161*, 299-305.
50   Alexander, N., & Taylor Gomez, M. (2017). Pleasure, sex, prohibition, intellectual disability, and danger-ous ideas. *Reproductive health matters*, *25*(50), 114-120.
51   Alexander, N., & Taylor Gomez, M. (2017). Pleasure, sex, prohibition, intellectual disability, and danger-ous ideas. *Reproductive health matters*, *25*(50), 114-120.
52   Bernert, D. J., & Ogletree, R. J. (2013). Women with intellectual disabilities talk about their perceptions of sex. *Journal of Intellectual Disability Research*, *57*(3), 240-249.

workers remain conflicted as they understand people with intellectual disabilities have the same rights and needs as others, yet also perceive adults with intellectual disabilities as having 'deficits' and frame sexuality as problematic.[53] There are clear gaps between policy and practice that continue to control and infantilize women with intellectual disability in ways that deny them the agency to explore and define their own sexuality.

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53   Ćwirynkało, K., Byra, S., & Żyta, A. (2017). Sexuality of adults with intellectual disabilities as described by support staff workers. *Hrvatska Revija za Rehabilitacijska Istrazivanja*, *53*, 77-87.

Appendix 5: Episodic Disabilities Information by Wendy Porch from Realize

A5.1 Episodic Disability Defined

According to the Episodic Disabilities Employment Network: "Episodic disabilities are long-term conditions that are characterized by periods of good health interrupted by periods of illness or disability. These periods may vary in severity, length and predictability from one person to another. Some common examples of episodic disabilities include multiple sclerosis, arthritis, diabetes, HIV/AIDS, hepatitis C, chronic fatigue syndrome, migraines, chronic pain, some forms of cancer and mental illness. Unlike permanent disabilities, episodic disabilities are periodic — the episodes of illness come and go — but because they are also unpredictable, they can often be more difficult to manage with regard to employment."[54]

A5.2 Unique Needs

There is evidence that suggests those with episodic disabilities are a significant

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[54]   EDEN - What are "Episodic Disabilities"? http://www.edencanada.ca/en/faqsepisodicdisabilities

portion of the Canadian population. Furrie et al undertook an examination of the 2012 Canadian Survey on Disability data in order to better understand the population of people living with episodic disabilities in Canada. [55] The research team used both a list of episodic health conditions and a proxy for intermittent work capacity to develop a picture of the population of people with disabilities in Canada experiencing an episodic disability that results in intermittent work capacity. Applying this definition resulted in 1,882,490 individuals, or 82.4% of the adult population aged 18 to 64 years with disabilities in Canada, being classified as having an episodic disability. Reporting an episodic health condition increased as age increased. Among persons aged 18 to 29 years inclusive, 77.4% reported an episodic health condition. This increased to 81.4% among adults aged 30 to 44 years, 83.5% among persons aged 45 to 54 years and 83.7% among persons aged 55 to 64 years. Women were more likely than men to report episodic health conditions: "Consistent with the literature, both EPI populations include more females than males: 54.3% (EPI/WD) and 62.3% (EPI/No WD) versus 42.4% (No EPI/WD)."

55   Episodic Disabilities in Canada https://www.crwdp.ca/sites/default/files/Research%20and%20Publica-tions/episodic_disabilities_in_canada_-_october_4_-_final.pdf

A5.3 Social Exclusion

Social exclusion can be a particularly difficult barrier for those with episodic disabilities. Of note here is how stigma operates as a form of exclusion:

"Stigmatization is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination. Thus we apply the term stigma when elements of labeling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows them to unfold. With this brief explication of the stigma concept as background, we turn to a more detailed examination of each component we identified."[56]

The health conditions that can, in combination with the environment, result in episodic disabilities include some conditions that are highly stigmatized. For people living with mental health related disabilities and/or HIV the experience of stigma can be a very regular occurrence. Stigma is known to have an impact on the well-being of people living with HIV. [57] As well, women living with HIV face additional intersections of stigma, particularly if they are also members of an ethno-racial minority, are LGBTQI2S and/or are sex workers.[58] For women living with stigmatized episodic health conditions, social exclusion can be directly linked to social exclusion as individuals seek to avoid stigmatizing interactions through avoiding social situations.

56   Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual review of Sociology*, *27*(1), 363-385. Available at: http://www.heart-intl.net/HEART/Stigma/Comp/Conceptualingstigma.htm
57   Meta-analysis of health and demographic correlates of stigma towards people living with HIV.
58   https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3222645/#pmed.1001124-Logie1

A5.4 Disclosure

Given the stigma often associated with episodic disabilities, issues around disclosure can become particularly important. Most episodic disabilities are invisible. As a result, for women living with episodic disabilities, decisions about disclosure must be made on a day-to-day and person-to-person basis. In research related to women living with fibromyalgia, disclosure decisions are likened to "impromptu disclosure dances" where women must decide if and how much information to share depending on assessments made regarding the risks involved.[59]

Chronic pain is often associated with episodic disabilities and has been considered an episodic disability in its own right.[60] In one study looking at perceived pain behaviours and readiness to work, women "were perceived as being less ready to work than men, but not necessarily because they were perceived as having more intense pain than men (ie, even when accounting for observers' judgments of pain)."[61] P.847

How is unemployment among people with mental illness conceptualized within social policy? A case study of the Ontario Disability Support Program demonstrates that within social policy, unemployment amongst people living with mental illness is conceptualized as a lack of motivation rather than a complex problem rooted in systemic barriers. [62]

Disclosure of the need for accommodation is necessary to invoke access to workplace accommodations. However, disclosing a need for accommodations is especially difficult for people living with highly stigmatized episodic health

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59   Oldfield, M., MacEachen, E., Kirsh, B., & MacNeill, M. (2016). Impromptu everyday disclosure dances: how women with fibromyalgia respond to disclosure at work. Disability and Rehabilitation, 38(15), 1442 – 1453.
60   Episodic Disabilities in Canada https://www.crwdp.ca/sites/default/files/Research%20and%20Publications/episodic_disabilities_in_canada_-_october_4_-_final.pdf
61   Martel, M., Wideman, T., & Sullivan, M. (2012). Patients who display protective pain behaviours are viewed as less likable, less dependable, and less likely to return to work. PAIN, 153, 843 – 849
62   Gewurtz, R., Cott, C., Rush, B., & Kirsh, B. (2015). How is unemployment among people with mental illness conceptualized within social policy? A case study of the Ontario Disability Support Program. Work, 51, 121 – 133.

conditions like mental health conditions or HIV. In a Canadian population-based survey of 2219 working adults, a third or workers would not tell their managers if they experienced mental health problems. The most widely shared concern was that disclosing mental health problems would results in damage to their careers. [63]

A5.5 Income & Income Security

People living with episodic disabilities encounter barriers qualifying for provincial and national income security systems:

"According to some current definitions of disability, people are considered either fully disabled or able to work. However, some people living with episodic disabilities may be able and want to work part-time or during periods of good health, but remain on full disability benefits because there is no mechanism for partial disability benefits. In fact, the experience of many people living with disabilities is that these programs trap them in poverty by creating barriers to staying on the job or returning to work. For people living with episodic disabilities who have periods when their health permits them to work, this can be especially true."[64]

Additionally:

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63   Dewa, C. (2014). Worker attitudes towards mental health problems and disclosure. International Journal of Occupational and Environmental Medicine, 5(4), 175 – 186 accessed at http://www.theijoem.com/ijoem/index.php/ijoem/article/view/463/546
64   Navigating the Maze: Improving Coordination and Integration of Disability Income and Employment Policies and Programs for People living with HIV/AIDS - A Discussion Paper https://www.crwdp.ca/sites/default/files/Research%20and%20Publications/Enviornmental%20Scan/14.%20Navigating%20the%20Maze/Navigating%20the%20Maze.pdf

> "For those who navigate the peaks and valleys of episodic disability, the transition from welfare to work is not a linear route but an evolving process without finite resolution."[65]

Canada's income security system is thus a complex web of public programs that are uncoordinated and lack oversight.

A5.6 Employment

Employment is an important issue where episodic disabilities are concerned. Episodic disabilities are different from stable non-recurring disabilities in that they are characterised by uncertainty. Uncertainty impacts employment significantly. Women with episodic disabilities face specific employment related barriers that are related to an unpredictable and fluctuating capacity to work arising out of their episodic health conditions. Unpredictability of the condition makes it hard for women with episodic disabilities to get a job because of gaps in one's resume, it makes it stay at work as flares can occur at any time, resulting in intermittent work capacity. Women with episodic disabilities may gain employment but live in fear of a relapse. Intermittent work capacity is also difficult for employers and co-workers too and can be particularly hard in certain kinds of jobs – especially those with hard scheduling requirements or those that are customer-facing.

As Lysaught et al note in their paper on the impact of intermittent work capacity on employers:

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65   Vick, A. & Lightman, E. (2010). Barriers to employment among women with complex episodic disabilities. Journal of Disability Policy Studies, 21(2), 70 -80.

The unpredictability of IWC is particularly problematic and takes on several forms, including: rapid and unexpected disruptions in work performance; difficulty predicting the course of incapacity; unpredictability with regards to frequency of disruptions; unpredictability with respect to potential for decline in work function over time; and unpredictable terminations by employees in response to ongoing difficulties.[66]

Employers require ongoing supports in order to be able to understand episodic disabilities and accommodate workers appropriately including training , toolkits and access to resource networks.[67] As employees, women with episodic disabilities experience a number of significant challenges:

"Experientially, women with complex episodic disabilities live in two seemingly contradictory worlds: the world of the healthy (and sometimes employable) and the world of the ill (and sometimes unemployable). This fluid, in-between embodiment is a pivotal obstacle to preparing for, securing, and retaining work within an occupational milieu, echoing its own risks and instabilities." P. 77[68]

Women living with episodic disabilities are required to prove their disabilities in

66   Lysaght, R., Krupa, T., & Gregory, A. (2011). Employers' Perspectives on Intermittent Work Capacity – What Can Qualitative Research Tell Us? Retrieved from https://www.rehab.queensu.ca/source/EmployersPerspectivesExSum.pdf

67   Lysaght, R., Krupa, T., & Gregory, A. (2011). Employers' Perspectives on Intermittent Work Capacity – What Can Qualitative Research Tell Us? Retrieved from https://www.rehab.queensu.ca/source/EmployersPerspectivesExSum.pdf

68   Vick, A. & Lightman, E. (2010). Barriers to employment among women with complex episodic disabilities. Journal of Disability Policy Studies, 21(2), 70 -80.

order to be eligible for employment supports and/or income security programs. In Vick 2013[69] women with MS discuss adding additional layers of substantiating evidence to their requests for accommodation that women with visible physical disabilities are not required to do.

In *Living in the Skin that I am: An Organizational Autoethnography of an Adult Educator's Plight to Survive the Stigma of Invisible and Episodic disability in an Academy of Administrivia,*[70] Docherty-Skippen describes her "lived experiences while working in a university health-care setting as an adult educator with "invisible" and episodic health conditions." In her experiences, we see many of the difficulties faced by women with episodic disabilities in maintaining employment. Dockerty-Skippen is forced to prove that she has an episodic disability and is therefore entitled to accommodations: "I felt I had to defend myself for needing disability workplace accommodations. I felt like I had to "prove" to them that I was sick."p66

Although Docherty-Skippen eventually received accommodations for her episodic disability in her work within the academic field in Canada, she also experiences harsh criticism from both colleagues and managers regarding her needs and her disability:

"I went from high-functioning, capable, professional—able to take care of myself and my family—able to excel at my job—able to excel in university course work and professional development opportunities—to a plummet of despair and interruption." P 67

Eventually, Docherty-Skippen unable to continue working in a space with little

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69   Vick, A. (2013). The embodied experience of episodic disability among women with multiple sclerosis. Disability & Society, 28, 176-189

70   Docherty-Skippen, S. (2014). Living in the Skin that I am: An Organizational Autoethnography of an Adult Educator's Plight to Survive the Stigma of Invisible and Episodic disability in an Academy of Administrivia (Master's Thesis). Retrieved from http://dr.library.brocku.ca/bitstream/handle/10464/5742/Brock_Docherty-Skippen_Susan_2014.pdf;sequence=3

support, resigns from her position at the university.

For many women, the changing dynamic of their episodic health condition combined with insufficient support systems and hostility from managers and co-workers proves to be overwhelming at times, making maintaining employment extremely difficult. However, people with episodic disabilities can work, as long as the employer is able to see flexibility as an accommodation:

> "the key to employment for people with disabilities and intermittent work capacity is flexibility. For employers, this doesn't have to mean lowering expectations, but rather, being flexible about how the work is done, and developing accommodation arrangements that can adapt as needs change."[71]

A5.7 Education

There is not a great deal known about the specific educational experiences of young women living with episodic disabilities, however what is known is concerning. Realize has undertaken initial research examining the educational experiences of students living with episodic disabilities through conducting a literature review and through working in partnership with Dalhousie University to survey and conduct key informant interviews with students and staff at 5 post-secondary institutions in Canada. The research reveals a bias against students living with episodic disabilities, from other students who may exclude them due to negative perceptions of their ability and/or hostility related to accommodations they may have received. It also reports bias from staff and faculty who may or may

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71   Smith-Fowler, H. (2011). Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario? retrieved from: http://www.srdc.org/uploads/IntermittentWork_report_EN.pdf

not believe that the student has a need for accommodations and who suspect the student is trying to access an unfair advantage. Through the survey students with episodic disabilities reported concerns with accessing accommodations related to the need for medical documentation and access to specialists to substantiate their requests for accommodations. Long waiting times to access specialists meant that the needed information was not provided in time for accommodations to be in place in a timely manner. Students also reported difficulties accruing financial debt while simultaneously finding it very challenging to complete their course work while managing a chronic and unpredictable episodic health condition.

As one student noted:

> "I am accruing exponential and cumulative debt from not working, paying tuition, and medical expenses. And I am struggling with completing my program. Once I am better, I am behind in paid work and in school. I try to catch up with both, which often means pulling extra-long days, which also inevitably leads to a flare up. I can never get my head above water. My publications are nearly non-existent. I look like a failing grad student who is not able to finish despite my determination. I may not end up finishing my program."[72]

A scan of policies related to student supports indicates that students with episodic disabilities face particular financial disadvantages compared to students living with non-recurring disabilities. Tuition Fee Policies can be problematic. Many students with episodic disabilities have noted that during periods of disability, they have needed to take a reduced course load. This can add substantially to tuition fee costs, especially at institutions at which fees are assessed on a per-semester

72   Porch, W., Merritt, B., Versnel, B., Walsh, S. & Harrison, e (2016) Episodic Disabilities and Post-Secondary Education in Canada: A Pilot Study to Explore the Perspectives of Students and Disability Service Providers. https://www.cahr-acrv.ca/conference/archives/cahr-conference-2017/

basis, rather than a per-credit or per-course basis. At many post-secondary institutions, scholarships are reserved for students who are pursuing full-time studies. Many students with episodic disabilities find full-time status impossible to maintain due to the unpredictability of their health conditions. Student loans programs also fail to address the needs of students with episodic disabilities, as students who withdraw from courses unexpectedly will be considered to be overpaid for the time they actually attended.

"Overpayment status" limits the student's ability to access additional funds and/or resume their studies. If a student withdraws for health reasons, the student loan program may forgive the loan, but will not lend the student any additional funds until the loan is repaid. As well, Health Insurance benefits are primarily only available to students attending full-time, leaving out many students with episodic disabilities.

Preliminary research suggests students with episodic disabilities face attitudinal and structural barriers related to accessing post-secondary education. Additional work is required to further understand these barriers and raise awareness of episodic disabilities within the post-secondary education sector in Canada.

A5.8 Unpaid Labour

There is no research identified that examines the experiences of people living with episodic disabilities as caregivers, although, as many conditions that can result in episodic disabilities impact women more frequently than men, there is little doubt that women with episodic disabilities are assuming caregiving roles in their families.

As well, in those circumstances where women with episodic disabilities become ill and must seek assistance with maintaining caregiving duties at home, there must

be significant barriers encountered as in neither the childcare or eldercare sector is it possible to arrange for care services with little notice and for an unpredictable period of time.

A5.9 Sexual and Reproductive Health

People with disabilities are at least as vulnerable to HIV as the general population but are often missing from HIV prevention, care and treatment initiatives. An environmental scan that looked at the intersections between HIV/AIDS Service Organizations (ASOs) and Disability Service Organizations (DSOs) in the Greater Toronto Area found very few instances of accessible services identified within the HIV sector and within the disability sector, very few mentions were made of programs or services for people living with HIV. [73] A lack of accessible HIV services may, in fact, contribute to a greater vulnerability for people living with disabilities. This is very problematic within a UN policy context of UNAIDS' 90-90-90 Goals and the Sustainable Development Goals that call for the eradication of HIV by 2030.

A5.10 Transportation

Access to publicly funded accessible paratransit systems is difficult for people living with episodic disabilities. People with episodic disabilities fail to qualify for paratransit systems because they tend not to fit the definition of disability employed to determine eligibility. Lack of access to paratransit systems has a great impact on the ability of people living with episodic disabilities to access

73   Welsh, K., Porch, W., Murzin, K. (2017) Intersections of Access: HIV/AIDS Service Organizations & Disability Service Organizations (E) Toronto, ON. Conference poster. Canadian Association of HIV Researchers Conference. Montreal.

or maintain employment. Without the means to consistently get to work, work becomes impossible.

A5.11 Research Gaps

More research needs to be conducted regarding the specific experiences of women living with episodic disabilities. Many conditions associated with episodic disability occur more often in women than men. For example, the sex ratio of multiple sclerosis for women in Canada has been gradually increasing over the last 50 years.[74] Arthritis, and mental illness are also conditions that more commonly occur in women. Still there is very little research that looks at the experiences of women living with episodic disabilities specifically. One possible issue for this is that episodic disability is a relatively new way of thinking about disability and does not have a mature and widely accepted terminology associated with it. There is a great deal of overlap with chronic illness literature. There are also numerous different terms used to denote episodic disability including "episodic health condition" and "episodic illness". Although Statistics Canada does currently undertake the Canada Survey on Disability, it is not a longitudinal survey and there has only very recently been a marker introduced for 'episodic disability'. Consequently, it has been very hard to understand the overall numbers of people living with episodic disabilities.

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74   Sex ratio of multiple sclerosis in Canada: a longitudinal study
Orton S Herrera B Yee I Valdar W Ramagopalan S et. al.
The Lancet Neurology
2006 vol: 5 (11) pp: 932-936

Appendix 6: Extended Acquired Brain Injury Lab Report by Dr. Angela Colantonio

A6.1 About Report

Dr. Colantonio's research program examines women with Acquired Brain Injury (ABI) specifically Traumatic Brain Injury (TBI), the impact of sex/gender on outcomes, and innovative approaches to intervention. She carried out the first comprehensive study on long term outcomes after TBI among women, primarily focused on reproductive health; she was instrumental in developing an international, interdisciplinary task force addressing issues related to girls and women with an acquired brain injury which she currently co-chairs, and in asserting a stronger presence for research on girls and women with ABI.

Under her direction, the Acquired Brain Injury Research Lab at the University of Toronto has demonstrated innovative, global leadership in interdisciplinary research and knowledge exchange in brain injury, gender, assault, and its impact on marginalized women. Particularly, her research has drawn international attention to the relationship between traumatic brain injury and intimate partner violence (IPV), a previously underexplored area of women's health. She launched Canada's first national network of researchers and service providers supporting women survivors of TBI and IPV, including women with lived experience. This work

was funded by Women's College Hospital and the Canadian Institutes of Health Research, and gathered the first Canadian data on the intersection of TBI and IPV. Her team acquired subsequent funding from the Department of Justice Canada, to develop the first toolkit for front-line workers supporting women survivors of IPV with TBI. This is being developed with multiple community partners and women survivors.

Website: http://abiresearch.utoronto.ca

A6.2 Special Issue

In 2016, Dr. Colantonio's lab published a special issue on sex, gender and traumatic brain injury. Relevant articles are publicly available on our website and include:

Colantonio, A. (2016, February). Sex, gender and acquired brain injury: A commentary. *Archives of Physical Medicine & Rehabilitation, 97*(2 Suppl 1), S1-S4.

Saverino, C., Swaine, B., Jaglal, S., Lewko, J., Vernich, L., Voth, J., Calzavara, A., & **Colantonio, A.** (2016, February). Re-hospitalization after traumatic brain injury: A population based study. *Archives of Physical Medicine & Rehabilitation, 97*(2 Suppl 1), S19-S25.

Stergiou-Kita, M., §Mansfield, E., Sokoloff, S., & **Colantonio, A.** (2016, February). Gender influences on return to work after mild traumatic brain injury. *Archives of Physical Medicine & Rehabilitation, 97*(2 Suppl 1), S40-S45.

Toor, G. K., §Harris, J. E., Escobar, M., Yoshida, K., Velikonja, D., Rizoli, S., Cusimano, M., Cullen, N., Sokoloff, S., & **Colantonio, A.** (2016, February). Long-term health service outcomes among women with traumatic brain injury. *Archives of Physical Medicine & Rehabilitation, 97*(2 Suppl 1), S54-S63.

Haag, H., Coringal, M., Sokoloff, S., Yoshida, K., Kontos, P., & **Colantonio, A.** (2016, February). Being a woman with acquired brain injury: Challenges and implications for practice. *Archives*

of Physical Medicine & Rehabilitation, 27(2 Suppl 1), S64-S70.

Lindsay, S., Proulx, M., Maxwell, J., Hamdani, Y., Bayley, M., Macarthur, C., & **Colantonio, A.** (2016, February). Gender and transition from paediatric to adult care among youth with ABI: Experiences in a transition model. *Archives of Physical Medicine & Rehabilitation, 97*(2 Suppl 1).

A6.3 Girls & ABI Workshop Summary

§Harris, J. E., **Colantonio, A.**, Bushnik, T., Constantinidou, F., Dawson, D., Goldin-Lauretta, Y., Swayne, B., Warren, J. (2012, Feb). Advancing the health and quality of life of girls and women after traumatic brain injury: Workshop summary and recommendations. Brain Injury, 26 (2), 177-182.

A6.4 Videos & Podcast

Traumatic Brain Injury & Intimate Partner Violence. [Video]. End of project video created for Women's Xchange Challenge Grant. Avaliable at: http://abiresearch.utoronto.ca/research/batteredbraininjured/

Colantonio, A. (2016, February). Sex, gender and traumatic brain injury: A commentary. Supplementary Data [Podcast, 14:45 min]. Archives of Physical Medicine and Rehabilitation, 97(2 Suppl 1). https://www.archives-pmr.org/article/S0003-9993(15)01477-X/addons

A6.5 Media Resources

Dr. Colantonio has been interviewed about her work, and highlighted in the following publications:

Status of Women Canada. Applying GBA+ to Concussion Prevention and Treatment. English video: http://www.swc-cfc.gc.ca/med/multimedia/videos/index-en.html. French video: http://www.swc-cfc.gc.ca/med/multimedia/videos/index-fr.html

Five ways concussion is different in women. *Everyday Health*. **Dr. Colantonio** quoted. Available at: https://www.everydayhealth.com/neurology/ways-concussions-are-different-women-why/

Institute of Gender and Health, guidelines for CIHR sex and gender champions. (Co-author). Available at http://www.cihr-irsc.gc.ca/e/50652.html (2017/11)

3 Women [Radio program]. Toronto, ON: CIUT 89.5FM. **Dr. Colantonio** interviewed by Rev. Cheri DiNovo on women and brain injury.

Why does it seem like nobody cares about female concussion? *ESPN*. Available at: http://www.espn.com/espnw/sports/article/19775123/why-does-seem-cares-female-concussions. Also printed in *ESPN The Magazine's Body Issue, 2017*.

Researcher calls for more study on head injuries coming as a result of domestic abuse. *Telegraph-Journal*.

Abuse change women's brains – but exactly how isn't known. *CBC news, New Brunswick.* Featured interview with **Dr. Colantonio**. Available at: http://www.cbc.ca/news/canada/new-brunswick/women-brain-injury-1.4077333. (2017, April 20)

Wanted: Women's brains – to jump-start lagging research on female concussions. [Interviewed **Colantonio, A**] STATnews [Electronic Magazine] Available from https://www.statnews.com/2016/11/21/concussion-women-brains/. (2016, November 21).

Deziel, S. (2016, May 31). How medical research has failed women. *Chatelaine* [Electronic

Magazine]. http://www.chatelaine.com/health/women-medical-research-bias/

Interview: PINKconcussions Summit Faculty. Concussion and TBI differences in gender in civilians & soldiers. Available from http://www.pinkconcussions.com/speaker-interviews and https://www.youtube.com/watch?v=dJO0KHaFf0A (2016, April 3)

Toronto Rehab researcher examines sex and gender in brain injury. Special coverage of **Dr. Colantonio's** work in celebration of International Women's Day. Available from: http://www.uhn.ca/corporate/News/Pages/toronto_rehab_researcher_examines_sex_and_gen   der_in_brain_injury.aspx (2016, March 8).

Doctor's notes: Why we need to pay more attention to women's head injuries. Toronto Star,

Life/Health & Wellness column. Available from: http://www.thestar.com/life/health_wellness/2016/03/07/doctors-notes-why-we-need-to-pay-more-attention-to-womens-head-injuries.html. (2016, March 7).

Traumatic brain injury: does gender matter? Science fact or science fiction? A monthly series of the Institute of Gender and Health using research evidence to challenge popular myths and misconceptions about sex, gender and health. Available from http://www.cihr-irsc.gc.ca/e/49000.html. (January, 2015).

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