

IDEAL Community Consultations:

Intersectionality, episodic disability and access to health services, community supports and employment in Canada



realize
FOSTERING
POSITIVE CHANGE
FOR PEOPLE LIVING
WITH HIV AND OTHER
EPISODIC DISABILITIES

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Acronyms, Abbreviations and Definitions

2SLGBTQIA+	Two-Spirit, lesbian, gay, bisexual, transgender, queer, intersex, asexual and additional people who identify as part of sexual and gender diverse communities
ACAS	Asian Community AIDS Services
AODA	Accessibility for Ontarians with Disabilities Act
ASAAP	Alliance for South Asian AIDS Prevention
Ase	Ase Community Foundation for Black Canadians with Disabilities
CAAN	Communities, Alliances, And Networks
CMDCI	Canadian Multicultural Disability Centre Inc.
DAWN	DisAbled Women's Network of Canada
DEEN SS	Disability Empowerment Equity Network Support Services
DEI	Diversity, Equity and Inclusion
e.g.,	for example,
Episodic Disabilities	Episodic disabilities are chronic health conditions related to a variety of illnesses characterized by fluctuating periods and degrees of illness and wellness. These periods can be unpredictable in duration, types of symptoms and frequency of recurrence.
HR	Human Resources
IDEAL	Inclusion, Diversity, Equity and Accessibility Leading to Belonging
LET'S	Live Educate Transform Society
NEADS	National Educational Association of Disabled Students
ODSP	Ontario Disability Support Program
PaWC	Pride at Work Canada

Acknowledgements

The IDEAL project would not have been possible without the meaningful involvement of diverse people living with episodic disabilities, and community allies and partners. These contributors have been listed and acknowledged throughout the document.

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Suggested Citation: Palmer I, Egan M, Popiel M. (2024). IDEAL Community Consultations: Intersectionality, episodic disability and access to health services, community supports and employment in Canada: Executive Summary. IDEAL Community Consultation Team.

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IDEAL Executive Summary

INTRODUCTION

In Canada, barriers to employment and challenges to upward mobility in employment disproportionately affect people living with disabilities. The ability of government, employers and other sectors to effectively address historical workplace inequities is further complicated by entrenched ableism and notions such as the visibility of disability rendering one unemployable. Adequately confronting gaps in comprehension of the disparate experiences of people living with disabilities and their nuanced realities necessitates research helmed by the community itself. Access to employment for people living with episodic disabilities is also entwined with access to health services and other community-based services to ensure social determinants of health and health needs are being met in a timely manner to facilitate participation in the workforce.

There is a large gap in research on people living with episodic disabilities, and particularly in research conducted by people living with episodic disabilities. This report underscores the importance of research led by community and demonstrates the value of centring the voices and perspectives of those most affected. Having data informed and driven policies, procedures and initiatives will go a long way in ameliorating the outcomes of people living with episodic disabilities and increase their social capital, accelerating access to, and retention of employment within workplace cultures that support belonging, while providing each employee with the accommodations required to successfully fulfill the requirements of their position.

For people living with disability, feelings of oppression and stigmatization, both socially and systematically, are common experiences.

Ableism is the discrimination of and social prejudice against people living with disabilities (both permanent and episodic disabilities) based on the belief that typical abilities are superior. At its heart, ableism is rooted in the assumption that people living with disabilities require 'fixing' and defines people by their disability. Like racism and sexism, ableism



classifies entire groups of people as 'less than,' and includes harmful stereotypes, misconceptions, and generalizations of people living with disabilities. (Access Living, <https://bit.ly/3TbZEae>)

Intersectionality is the acknowledgement that everyone has their own unique experiences of discrimination and oppression, and we must consider everything and anything that can marginalise people. These identities or characteristics might include gender, race, class, sexual orientation, physical ability, and/or religious beliefs. (Womankind Worldwide, <https://bit.ly/3TxEzHB>) Every individual has their own experiences connected to the identities they belong to; for some individuals those identities bring positive experiences and empowerment, while for others, the social identities they carry each stigmatized and each bring their own forms of discrimination. For example, a white, cis, male, Christian, middle class, without disability or an Asian female that

identifies as queer, Buddhist, low income and is Deaf. The social and systemic experiences of these two disparate individuals would be quite different and for the intersectional individual, the weight of multiple forms of discrimination (racism, sexism, heteronormativity, faithism, classism and ableism) will be felt simultaneously but differently in different situations and spaces.

The impacts of ableism and intersectionality for many people can be significant, varied, and affect access to services and quality of employment experiences.

OVERVIEW

This document provides an overview and summary of community-led engagements hosted by 12 diverse, disability-serving organizations in partnership with **Realize** and the IDEAL (Inclusion, Diversity, Equity, Accessibility, Leading to belonging) Project. This project was funded by

Employment and Social Development Canada as a part of the EPisodic disabilities awareness and action Integrated into Canadian employment (EPIC) Project.

The primary goal of this initiative was to collaborate with a variety of national organizations serving people living with episodic disabilities to lead focused consultations within their respective communities to provide an intersectional examination into the living realities and various aspects of access barriers to health services, community-based organizations and employment for people living with episodic disabilities in the Canadian landscape. The participating organizations serve communities that provided unique intersectional considerations of gender, racial identity, faith community, health conditions, sexual identity, and age with disability.

Many people living with disabilities describe living with unpredictable cycles of wellness and illness, or other unpredictable effects. This has been defined as episodic disability. It is this unpredictability that can have significant impacts on social inclusion and workforce participation.

“Living with an episodic disorder is like riding a roller coaster you never bought a ticket for. Some days, you’re up and ready to conquer the world, and then suddenly, you’re plummeting into this abyss of fatigue and pain. It’s hard to explain to others because it’s not a linear thing.” (ASAAP Report)

“People don’t always understand that episodic disorders aren’t just about the physical symptoms. It’s the mental toll too. You start questioning your own abilities. Can I commit to that project? Will I be reliable? It’s this constant uncertainty that’s mentally draining.” (ASAAP Report)

Realize is the leading national, charitable, organization in Canada working to improve the health and well-being of people living with HIV and other episodic disabilities, across the lifespan, through integrated research, education, policy, and practice. In this capacity, **Realize** plays a central

role in mobilizing communities and other knowledge-holders to work together to lead initiatives that impact the health, social participation and quality of life of community members.

PURPOSE

This compilation of final reports will expand the collective knowledge and understanding of the issues that continue to impact the access to health services, community-based organizations and employment journey of people living in Canada who have distinct and diverse stigmatized identities and who are also living with episodic disabilities.

In addition, the IDEAL community-based focused engagements provided space for the voices, perspectives and expertise of people living with episodic disabilities who are most often pushed to the outer most regions of society and are rarely or not often enough given the opportunity to share and give voice to their truth, in their authenticity and to have those insights included in community-based inquiry that will then be shared more broadly.

The objectives of this initiative were:

1. To address the deficit of research on living with episodic disabilities through a disability-justice lens, led by people living with disabilities.
2. To examine the realities that diverse disability communities are navigating.
3. To better understand diversity in disability culture among subgroups such as youth, Muslims, 2SLGBTQIA+ folks and others.
4. To broaden perspectives on people living with episodic disabilities and work.
5. To examine access to and experience of health services and/or community-based organizations by diverse community members who are living with episodic disabilities.
6. To increase the capacity of employers to respond effectively to the challenges facing people living with episodic disabilities and provide appropriate accommodations.

PROJECT ACTIVITIES

Research Ethics Board approval was not sought to ensure the inclusion of diverse community members who may have concerns regarding colonial processes and to avoid ableist limitations of the current academic informed consent process. The findings from this work will directly inform the development of the project deliverables and the full reports are available publicly on the **Realize** website. This is an iterative, long-term initiative that builds progressively on previous work. Project participants were not identified beyond very basic self-reported demographic data collected by those conducting the consultations, and in the reports all quotes are attributed to anonymized participants only.

The IDEAL Project community-based inquiry took place between January and August 2023. Participating organizations communicated regularly with the **Realize** IDEAL Officer to receive initial guiding questions (Appendix A), final reporting framework (Appendix B), to monitor progress, and to troubleshoot emerging issues. Participating organizations received a small stipend for cost recovery of expenses incurred to participate in the project. Community member key informants (participants) were recruited by each organization through social media outreach and other channels (e.g., Eventbrite, flyers and direct outreach). Community member key informants received modest compensation for their time and participation.

Each organization determined their own outreach strategy, discussion questions above the baseline provided, screening procedures, accessibility needs, environment, and consultation process that worked best for their community. As the project lead and leader in the disability community, **Realize** deliberately structured the rollout of the community engagements to be as unstructured as possible with broad parameters allowing for the power to design the engagements resting in the hands of each partner agency acknowledging that the wisdom of what accommodation needs and best practices resides within each group and should neither be dictated from the outside or limited in possibility. A variety of modalities were therefore produced, offering choices and held space for maximum inclusion and maintenance of individual and collective dignity.

When leaders and experts from the disability community helm engagement, the ensuing interactions tend to be

rooted in care, consideration and intention to ensure that access, comfort, and meeting needs are the highest priority. Several reports named the use of an intersectional lens, the employ of a wide variety of techniques and technologies and in doing so modelled the ability to provide diverse and inclusive experiences that left no one behind or excluded anyone. An example of diverse approaches that met community needs and provided the intended result is the multiple methods used for consultation. These strategies included focus groups over the Zoom conferencing platform, facilitated in-person discussion, one-on-one interviews, on-line surveys, WhatsApp chats and workshops. Once consultations were complete, each agency then developed summary reports of their findings and submitted these reports to the **Realize** IDEAL Officer.

KEY FINDINGS AND DISCUSSION

Twelve community partner organizations participated in the project. Approximately 30 staff members participated in planning and conducting the consultation process. The partner organizations included advocacy groups, youth clinics, health clinics, community centres and a faith community. These organizations included:

1. Alliance for South Asian AIDS Prevention (ASAAP)
2. Ase Community Foundation for Black Canadians with Disabilities (Ase)
3. Asian Community AIDS Services (ACAS)
4. Canadian Multicultural Disability Centre Inc. (CMDCI)
5. CanAge
6. Communities, Alliances, And Networks (CAAN)
7. DisAbled Women's Network of Canada (DAWN)
8. Disability Empowerment Equity Network Support Services (DEEN SS) under their banner of Race and Disability Canada
9. Live Educate Transform Society (LET'S)
10. National Educational Association of Disabled Students (NEADS)
11. Pride at Work Canada (PaWC)
12. YouthCO

A total of 250 community members participated in 105 individual and group consultation activities organized by the participating organizations. Community participants were adults 18 years of age and older, who were living in Manitoba, Alberta, Ontario, Saskatchewan, Quebec and British Columbia. Participants self-identified as Indigenous Peoples, Black and other People of Colour, members of the 2SLGBTQIA+ community and members of the Muslim communities. Participants reported living with one or more of a wide range of visible and non-visible disabilities, including Long COVID. Other self-identifications include multiple additional identities including “mobility device user”, “CRIP”, “chronically ill”, “neurodiverse” and “MAD”. Participants also shared their current employment statuses including unemployed, employed part-time, full-time, casual (or gig-jobs), and entrepreneurs.

SUMMARY OF INSIGHTS

The five key themes to emerge from these consultations related to access to health services and/or community-based organizations, access to meaningful and sustainable employment, alternative methods of income support, the importance of an inclusive workplace culture, and impacts of social stigma on employment.

Among the many recommendations emerging from this work, addressing education, representation and creating culture are examples of ways to create inclusive environments for individuals living with episodic disabilities who may be most marginalized due to intersectionality and other factors. The recommendations will be discussed in the following section.

1. Access to Health Services and/or Community-Based Organizations

The reports identified that the level of accessibility and inclusion demonstrated by health services/community-based organizations is important to the choice of people living with episodic disabilities on whether to access services at a given organization. The reception from and attitude of service providers was noted across many reports as either a serious deterrent or an attraction to accessing services at a health service or community-based organization (vibes really matter) therefore, it is vital that steps be made to improve in this area.

“Inclusive décor that reflects the diversity of the community served was also identified as important to promoting inclusivity in community-based organizations.” (CAAN report)

Changes in staffing, inaccessible spaces and financial constraints to accessing services, supports, and programming was also repeated across engagements.

“A high turnover rate and lack of continuity (in staffing) required (participants) to start over because of internal shifts within the organization.” (NEADS report)

It was also acknowledged that health services and community-based organizations for diverse groups are severely underfunded, and this also creates barriers to providing services that would most benefit community members.

While some issues accessing health services and community-based organizations were common across reports such as the above-mentioned point, other barriers were more specific. For instance, seniors had particular concerns around engagement and participation access as highlighted in the quote below.



“Seniors with disabilities require one-on-one interaction for conversation” and should be shown “how the organization runs.” (CMDCl report)

As well technology, while barrier reducing for some, has adverse effects on access for other community members like our senior population - “especially when consistent and ongoing training is lacking” (CanAge report). This underscores the need for an intersectional lens on all aspects of programming, policies, and procedures to ensure that practices are tailored and responsive to individual needs. The need for more intersectional health services and community-based organizations where people can have their whole selves served in one location was repeated across reports.

Factors for improving access to services included improving ease of access (both physical space and administrative processes), considering location of programs (increasing virtual options), having paid opportunities (particularly for youth), access to life enhancing experiences, help with transportation, scheduling programming around religious observances (e.g., prayer times, fasting and diverse holidays), as well as on-going community engagement. These measures (and others detailed in the reports) could increase attendance and participation with health services and community-based organizations. In addition, it would be helpful if health services and community-based organizations ensured that staff were aware that many folks with disabilities are living with multiple conditions which can be any combination of visible, invisible, chronic, episodic, physical, mental, or cognitive. Participants

value spaces that embrace diversity, provide authentic, transparent services, as well as offering choices catering to different needs such as low sensory spaces or prayer rooms.

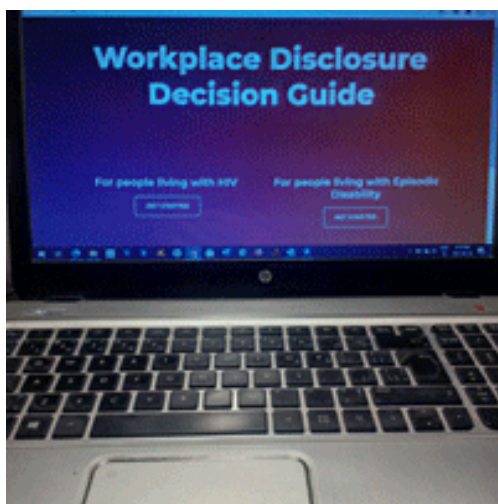
Of interest, consultation discussions within two organizations focused exclusively on access to health services demonstrating the unique needs between communities consulted. For example, this could suggest that employment is not a consideration or cannot be pursued while health concerns remain unaddressed or insufficiently supported and that these require mitigation before employment can be explored or even desired.

2. Access to Meaningful and Sustainable Employment

Being able to survive in the workplace is a very real concern for employees living with episodic disabilities. Adversity comes in many forms and can be formal, informal, intentional, or unintentional. Building an inclusive workplace requires inclusive procedures incorporated into everything from job postings and at all levels of the employee journey or experience. Every stage of the process of looking for employment was described as problematic across most reports from recruitment, to interviewing, onboarding, retention, and promotion.

Biases and assumptions rooted in ableism but connected to other oppressive systems (racism, homophobia, sexism, ageism, faithism) work together to prevent intersectional people with episodic disabilities from obtaining work and being successful in employment. For example, forms (to request accommodation) were highlighted as often being converted into tools “to surveil, avoid, and filter out marginalized communities (like Black, Queer, Trans)” (Ase report)

Embed intention toward meaningful methods to ensure



The Choice is Yours!

The Workplace Disclosure Decision Guide was written to help people living with HIV and people living with episodic disabilities make the decision to disclose or not disclose their health status in their workplace. Decisions about disclosure are personal and can be difficult to make. This guide can help you make the decision that's right for you.

<https://disclosureguide.realizecanada.org>



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equity is still not reliably incorporated into recruitment, retention, and promotion. Participants questioned the continued lack of creativity and innovation in supporting employees living with episodic disabilities.

“Many jobs demand secondary or post-secondary degrees thus creating a counterproductive cycle that restricts access to the workforce. People with disabilities should not have to jump through hoops or do their time to receive a promotion. Advancement should not depend on age, not having a disability, or be hierarchical in any way.”
(YouthCO report)

Across every report, ableism was noted by participants in various ways as upholding barriers and notions that disability marks an individual as needy, less than, incapable and unworthy. Reports described that systemically, the more intersections a person with an episodic disability carries, the more disadvantages related to all aspects of work they face. Experiences shared by community consultants provided evidence of increased exposure to discrimination, exclusion and violence in the form of ableism (microaggression, toxic positivity, minimalization).

“Because I’m Asian... I have to perform well!”
(ACAS report)

Challenges include inaccessible physical, cultural (or both) environments, limited flexible work options in traditional work that leads people with episodic disabilities into the gig economy/low-paying cash jobs which contribute to financial precarity and low rates of job sustainability.

“There is little valuation of the volunteer, independent and other work that people with episodic disability regularly participate in. A shift in that perspective is imperative to giving people with disabilities pathways into traditional workspaces.” (LET’S report)

Another barrier is the lack of recognition and support of entrepreneurs with episodic disabilities, the historical ways they contribute to society and willingness to support their independent efforts towards financial sustainability (LET’S report). It is of particular importance to note that while entrepreneurship could be a very viable income option for people living with episodic disabilities, there are very few supports or incentives, particularly the availability of bridge funding. Entrepreneurship and work in the gig economy are discussed in the LET’S report as not being supported by government funding and programming.

According to the reports, a lack of enforcement of workplace accommodations in relation to accessibility remains a widespread issue. The cumulative reports illustrate that the systems and procedures currently in place in most Canadian institutions are inconsistent and arbitrary in application, equity, and legal follow-through. There is little to no trust on the part of employees living with episodic disabilities in the upholding of rights, policies, or procedure as well as a lack of rigor in confronting discrimination.

It is still difficult for employees living with episodic disabilities to unveil episodic disability in the workplace, and so disclosure remains a consistent contentious issue across communities in the disability sector. Multiple reports specify tangible fears of revealing episodic disability to receive much-needed accommodations, supports, resources and/or adaptive equipment. Community participants reported experiencing negative impacts after disclosing episodic disability and/or requesting accommodations such as being viewed as incompetent, being booked for less shifts, barred from promotions, having work appropriated or attributed to co-workers who have not disclosed living with episodic disabilities, and being let go.

“The “critical role of managers as gatekeepers (alternatively) facilitating or limiting access to supports (benefits and resources) is an integral factor to the harmful experiences of individuals in the workplace.” (DAWN report)

Visible disabilities elicit assumptions of need, while invisible disabilities engender minimalization of symptoms and a much lower likelihood of accommodation. Accusations of



“faking it” to get-out of certain tasks. People living with invisible disabilities often battle invisible symptoms such as fatigue but have their challenges dismissed because they look “fine”.

Conversely, not disclosing forces employees living with episodic disabilities to employ stress-inducing tactics such as masking/code-switching, suppressing symptoms, working through pain, forcing themselves to fit into neurotypical modes of being/working, and even using vacation time in lieu of accessing medical time off. Intersectional marginalized folk, including employees living with episodic disabilities, tend to push their feelings aside and even downplay their emotions, the hurt of situations, and the harm endured out of necessity to not be further ostracized, to tough their way through situations out of both internalized and compounded (external) ableism.

“I felt that my employer was not interested in learning about my episodic disability and therefore did not feel I could speak to them about what I needed without jeopardizing my job.” (CanAge report)

It is important to note that inclusive workplace practices are recognized by employees “(I) felt well supported and received workplace accommodations for disability and faith.” (DEEN SS report)

Some low cost/no cost accommodations identified by participants that would enhance the experience of employment for employees living with episodic disabilities include:

- Frequent breaks /Naps
- Working sitting down
- Technology and ergonomic furniture such as sit-to-stand desks and dual monitors
- Prayer space/room
- Sensory considerations
- Eating during worktime (e.g., for managing Diabetes).
- Remote work and flexible core hours.

There is still a tendency to associate the word disability with something that needs to be fixed, hidden, or helped in a charity model way. Participants across engagements share frustration of not being viewed as assets or acknowledged for the skills they bring or the reciprocal benefits to accommodations.



“... the employer benefits when I can do my job well. Both my employer and I are working towards the same goal. It’s mutually beneficial. They are not doing me a favor...” (DEEN SS report)

For episodic disability to be more accepted, disability must be positioned in a positive light. A fundamental step would be validating the struggles of people living with episodic disabilities and taking tangible steps to improve their experiences.

“Design the position to be more accessible for someone with a disability, even when doing so would not change the deliverables or results of the job.” (PaWC report)

Valuing disability and employees living with episodic disabilities as a strength will go a long way in ensuring that people living with episodic disabilities are gainfully employed, can fulfil the expectations of their positions, and have opportunity for career advancement. Organizational leaders in positions of power can operate more visibly in solidarity with marginalized employees with episodic disabilities and stigmatized identities. Leadership can disrupt inequitable systems by promoting reciprocal communications. Taking action to make sure that workplaces are accessible at the front end and the back end is incredibly important to the positive experiences of intersectional employees living with episodic disabilities.

3. Issues Impacting Income Support

The social location of episodic disability is most often in poverty and deep poverty. This is due to the limited avenues for people living with episodic disabilities to enter the labour market as well as insufficient knowledge or the existence of beneficial pathways out of income supports

into independent financial stability. Participants reported feeling forced into low-paying cash jobs due to lack of opportunity in the traditional workforce and low income on government assistance. Participants shared regularly having precarious finances. Governments at all levels were identified as barriers by the inaccessibility of their support where funding application processes are primarily forms based. These forms tend to be complex and difficult, particularly for youth, post-secondary students, seniors, and adults with episodic disabilities on assisted living programs (such as ODSP). There were also concerns about “losing support” (ASAAP report) if individuals living on government assistance programs begin to work and then have a relapse, flareup or new onset of their condition as is common with the episodic nature of many disabilities. Fluid, flexible, and targeted supports and programs are required to meet the changing needs of individuals living with disabilities.

Each report highlights additional barriers for employees living with episodic disabilities, including a lack of support services that address intersectional needs, mental health services, and little opportunity for mentorship/skill development. To combat the economic disparities of the population living with episodic disabilities, there needs to be a more active, consistent and long-term commitment to diverse and scaffolded supports for sustaining the pursuit of independent and workforce-based livelihoods. Funding needs to support new and multipronged avenues (entrepreneurship, artists) and not continue to go towards only the same standard approaches that are leaving people behind.

4. Importance of an Inclusive Workplace Culture

Workplace culture was another significant theme that was consistent across all reports. Workspaces are microcosms of mainstream society and mirror its values and norms. The structure of ableism still tells people living with episodic disabilities that it is in their benefit to assimilate into the dominant culture and then to suppress, change or mask some part of themselves to be more palatable to the mainstream folk is the best way to be successful. This goes beyond episodic disability to race, faith, orientation, age and gender. Intersectional people often feel that they are not permitted to be their whole selves when some parts of their identity are stigmatized. So many people living with episodic disabilities are living constricted lives, holding in some part

of their identity, or trying to completely omit other traits, to conform to someone else’s picture of “ideal”.

“Being able to be yourself without judgment or denial of one’s living experience is critical in creating belonging.” (YouthCO report)

Employers have the responsibility to ensure that all employees including those with episodic disabilities, can bring their full selves to their work, which is imperative to ensuring that employees are able to perform to the best of their abilities. This includes being able to be open to all aspects of their identities and intersections. Insights throughout the cumulative reports confirm that the predominant view of episodic disability is still largely associated with whiteness, visibility, homosexual, Christian, older, and neurotypical. Stereotypes contribute to the exclusion and “othering” of employees living with episodic disabilities.

People living with episodic disabilities (particularly people that identify as trans, non-binary, female, a practitioner of a non-European faith, and those who are racialized) are often limited to the narrow perspectives of their managers, supervisors and co-workers despite demonstrated capacity. Conversely, Asians with disabilities struggle with stereotypes of the model minority and “living up to elevated performance expectations, as well as cultural stigmas of both disability and 2SLGBTQIA+ identity” (ACAS report). Either way, stereotypes are detrimental to the experience of employment for people with episodic disabilities. Many community participants report less experience of safety and belonging amongst colleagues. Negativity and exclusion come in the form of micro-aggressions, being perceived as “DEI hires”, not feeling respected and being stereotyped.

“People (have) preconceptions on mental illness; people told me they don’t believe it exists. People told me that...they think that you make it up for attention or stuff like that. Which is why I sometimes don’t feel comfortable talking about it.” (ASE report)

“People will say the most horrific Islamophobic and racist things thinking I am not Arab or Muslim...” (DEEN SS report)

Exclusion manifests in many forms including microaggressions, ignoring people because you don't know how to interact, taking credit for work, and being left out of private social gatherings. These reports indicate that many work environments are not places where people living with episodic disabilities feel seen, heard, respected, and validated. The weight of feeling constantly misunderstood and judged has a negative impact on connecting and trusting co-workers and senior management. It is important to remember that creating access is often not within the power of those experiencing marginalization.

“People assume my interests or assume what I want to do in my free time, and they don't invite me.” (Ase report)

The concept of belonging is clustered with others like inclusion, diversity, equity, accessibility, relationship, connection, acceptance, attachment. Naturally human beings tend to explore belonging along lines of commonality. To foster true inclusion of diverse people, we need to promote connecting on diversity.



5. Impacts of Social Stigma on Employment

Another major theme emerging from the research is that the stigmatization of people living with disabilities, whether visible or invisible, chronic or episodic, increases when gender, race, orientation, and faith are also factors. There are many sub-themes attached to social stigma such as, feelings of imposter syndrome and/or isolation based on age, social class, appearance, accent, and other factors. Different identities feel the pressure and sting of discrimination and pressures based on stereotypes. For instance, anti-Black racism and heteronormativity, while faithism, ageism and misogyny are still significant areas of concern as well as barriers to advancement and a sense of belonging.

“Anti-Black and ableist perceptions of Black people with episodic disabilities also lead to participants being excluded within the workplace, further exacerbating episodic disabilities and mental health conditions. This narrow view of disabilities often leads to Black people with episodic disabilities often being segregated and discriminated against, leading to fear of disclosing their episodic disabilities within an unsafe work environment.” (Ase report)

The collective investigations confirm a lack of flexibility across the labour market to respond effectively to the diverse and layered needs of intersectional employees living with episodic disabilities. Many participants described ableist remarks and attitudes as part of their everyday lives at work, make accessibility efforts redundant. All systems of oppression construct difference as less, as needy, as less deserving, and inherently distrustful. It is important to consider how different identities are constructed, what are the prevalent biases against Muslims, seniors, orientation, and other factors in relation to social interactions in the workplace.

“Multiple intersections can feel like coming out multiple times...” (ACAS report)

There remains an inequitable onus on people living with episodic disabilities to confront ableism and inaccessibility to demand change versus on society, employers and government to recognize the failures of systems, procedures and attitudes to meet the needs of people living with episodic disabilities and address those gaps. There are insufficient proactive measures in place that position episodic disability as attractive, as decision-makers and leaders.

“I wish workplaces would implement universal accessibility beyond disability...” (PaWC report)

Dismantling systems of supremacy is complicated and always requires multi-faceted approaches.

Recommendations:

Among the many recommendations emerging from this work, addressing education, representation and creating culture are examples of ways to create inclusive environments for individuals living with episodic disabilities who may be most marginalized due to intersectionality and other factors.

EDUCATION

Employers need to increase their awareness of the wealth of skill, capacity, creativity, and leadership existent in the disability community as well as the diversity of needs. Employers would also benefit from improving equitable practices that promote open and authentic channels to providing those supports and accommodations. On-going and diverse training is vital to the dismantling of onerous, stigmatizing and inconsistent application of legal policies such as the Accessibility for Ontarians with Disabilities Act (AODA). Professional development training in IDEAL will also counter the reluctance of leaders to confront all forms of discrimination and build acknowledgement of the fact that intersectional folk living with episodic disabilities face a plethora of barriers, and not just ableism.

Understanding that employees with complex needs are deserving of the same care, consideration, and value as other workers requires leadership to invest in increasing their capacity to support the diversity of their staff. In addition, being intentional about reducing incidences of gatekeeping, micromanagement, and other discriminatory

practices through mandatory skill building requirements and reliable accountability procedures will go a long way in creating a baseline standard for employment equity.

Employers must shape, nurture, develop, and recognize leadership in diverse employees. This can be done by being explicit about policies, ensuring revamped recruitment, making disclosure beneficial and providing accommodations and supports with regular review. Tackling injustice in the workplace will necessitate awareness, understanding and the use of an intersectional lens on everything. A core competency of leadership should be an ability and willingness to examine and challenge ableism, both systemically and attitudinally.

Moving away from traditional accommodation processes which tend to be administratively burdensome (e.g., multiple forms administered once, without check-in and accommodation updates or modifications) to ongoing constructive conversations and recognizing peer support leads to improved mental health and positive systemic change (DAWN report).

REPRESENTATION

To improve representation of intersectional people living with episodic disabilities beyond entry level positions, there must be intentional recruitment of these historically equity-denied individuals. Equitable access to positions of leadership and influence is integral for cross-disability, diverse employees with episodic disabilities. It serves as a visible representation of senior-level professionals of capacity and skill. The ability to move from frontline, entry-level or mid-management positions to senior and executive levels has been hampered by ableist attitudes and norms. Having more representation on staff, especially at senior and executive levels with diversity in culture, gender, faith, orientation, age, race, and episodic disability is important for broader perspective, creativity, knowledge building, and inspiration.

In considering episodic disability and the need to challenge the persistence of the dominant narrative, there needs to be more support of disability-led and disability centred projects which position people living with disabilities in leadership, in power and which will contribute to the building, visibility and amplification of the social capital of people living with disabilities.

CREATING CULTURE

The work of inclusion must be collective yet built into each individual as well. Inclusive policies and procedures embedded at every level will support the maintenance of equitable cultures. Also, important cultural figures such as “aunties” and “matriarchs” make environments more welcoming (Ase Presentation, November 2023). The integral presence of “accomplices” -being centred in action rather than through traditionally inactive “allyship”, aids the transition to the creation and maintenance of supportive workplace environments (NEADS report). Facilitating introductions and inclusion into groups within organizations is also very helpful to increase inclusion. Smaller identity-specific groups are also helpful, for example, women only peer support and opportunities to be supported and offer support to other employees living with disabilities (DAWN report). A sense of authentic belonging and acceptance is integral to a workplace environment that is positive and is one of the most conducive aspects to ensuring that employees living with episodic disabilities thrive in the workplace. Another consideration is flexible work options such as job sharing (ACAS report), remote, and part-time work, flex hours, increased mental health accommodations, and targeted support services.

Limitations and lessons learned

Limited funding had an impact on the scope of this work, however additional funding will be sought to address this issue. For example, funding was not available to provide communication support services for those who identify as deaf or hard of hearing or individuals living with intellectual or communication disabilities, and consultations were held in English only. We were also unable to fully include those living in remote and/or northern communities and those living in Eastern provinces. Future work will also target the inclusion of community members living in rural communities and other provinces. Funding also impacted the number of consultation sessions and the number of community members that could be invited to participate. Future work will also explore job roles and sectors (e.g., HR, DEI, healthcare). Technical challenges included digital literacy challenges (e.g., using Zoom) and access to computers, phones, and internet services. In some cases, on-line bots interfered with online registration for engagement events. Despite these challenges, participating organizations

noted a significant increase in staff awareness and capacity building to create supportive environments for diverse people living with episodic disabilities and other barriers to health services/community-based organizations and employment. All participating organizations have committed to continuing collaboration on this important work. Community participants were invited to a two-day symposium in November 2023 where highlights of the consultations were presented by the participating organizations. The event provided the opportunity for community participants to hear about the outcomes of their own consultations as well as hear from others. In this way, living experts with episodic disabilities were recognized, respected, and remained connected to the work that they had contributed to. Following this event, a subsequent gathering of the partner agencies was held to further foster connection and community amongst the diverse disability-serving organizations.

In addition, these consultations will inform the development of accredited training for individuals and organizations that prepare them to include, support, accommodate, and work with people living with episodic disabilities.

CONCLUSIONS AND NEXT STEPS

There are nuances to the episodic disability experience that are not generally considered or understood. Service providers, employers, and government need to consider the disparate realities of people living with episodic disabilities; their diverse identities, complex medical concerns, requirements and displays, as well as the ebb and flow of many diseases and conditions. Employees living with episodic disabilities are deserving of the same care, consideration, and value as other workers. The following 12 reports provide valuable insights into finding optimal solutions for diverse employees living with episodic disabilities, creating environments and systems that work for all employees and changing perspectives of these workers as enriching rather than deficits.

It is important to note that many of the partner organizations reported that community participants asked for more space to have the same type of discussions, and spoke of the necessity and value of peer mentorship, peer support and the building of community among individuals with shared identities and experiences being of high value.

It is imperative to fund the closure of the gaps in disability-led research to increase the use of disability informed and data-influenced policies, procedures and initiatives.

Partner's Reports

1. Alliance for South Asian AIDS Prevention
2. Ase Community Foundation for Black Canadians with Disabilities (Ase)
3. Asian Community AIDS Services (ACAS)
4. Canadian Multicultural Disability Centre Inc. (CMDCI)
5. CanAge
6. Communities, Alliances, And Networks (CAAN)
7. DisAbled Women's Network of Canada (DAWN)
8. Disability Empowerment Equity Network Support Services (DEEN SS)
9. Live Educate Transform Society (LET'S)
10. National Educational Association of Disabled Students (NEADS)
11. Pride at Work Canada (PaWC)
12. YouthCO

Appendix A

These example questions related to access to health services. Organizations developed additional questions related to experiences with community-based organizations and employment.

Focus Group Questions (Inclusion, Diversity, Equity and Accessibility Leading to Belonging [IDEAL])

1. **Who in your community serves you well?**
 - a. Disability/2SLGBTQ+ organization
 - b. Community organization
2. **What services are missing or what services do you need that organizations aren't able to provide?**
 - a. What support would be most welcomed?
3. **If you need support, what organizations do you rely on for support?**
4. **How do you find/have you found support organizations? (Prompt: Is it community driven, word of mouth, do they go outside of community because of stigma/ shame or othering?)**
5. **What is your preferred means of interacting?**
 - a. are in person services most ideal (Prompt: local to you, in your community)
 - b. are virtual services/ online etc., more accessible (Prompt: more private, secure, safe)
6. **If you're in a new community space, what makes you feel welcome and comfortable?**
7. **What can an organization do to increase your comfort? (Prompt: consider the people, approach, and the built environment)**
8. **What makes you feel that your needs, wants, and choices are respected/valued? (Prompt: Think about actions, words, and attitudes)**
9. **What prevents you from approaching/using services at an organization?**
 - a. Physical space
 - b. Who is running the support service
 - c. Accessibility issues (physical/emotional/other limitations)
 - d. Cost to attend
 - e. Other

Appendix B

Final Report Guiding Framework

In your final report please include the following headings:

Overview Of Agency and Target Community

Objectives Of Community Engagement

Approach to, Scope of Community Engagement

Limitations To Community Engagement

Summary Of Insights

Recommendations For Moving Forward

Overview:

On (date), (name of organization) hosted a/a series of (focus groups, interviews, etc) in (region).

Community engagement was executed by (description of agency).

This document provides an overview and summary of the community engaged focus group(s), demographics of participants, limitations, summary of results and highlights of most prominent ideas.

Agency Framing and Scope

(Name of agency) is focused on (who do you serve, what do you do) in (region).

After community engaged focus group(s) held on (date), led by (agency name), we collected feedback from living experts on their experiences with episodic disabilities and agencies.

Approach to, and scope of, Community Engagement

*(describe how you planned and executed your focus groups. Included recruitment strategies, description of structure of focus group – one-to-one interviews, facilitated discussions, demographics of participants, time, etc.) feel free to share presentation slides and/or discussion questions.

Limitations Surrounding Community Engagement

(Describe any limitations, barriers or additional considerations that came up. Eg technology, certain challenges particular to your community)

Summary Of Insights

(Use headings such as Systemic Barriers, Social , day-to-day, etc to help organize results)

Recommendations For Moving Forward

Please highlight any important recommendations.