

destigmatizing
disability

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NATIVE WOMEN'S ASSOCIATION OF CANADA MAGAZINE

DESTIGMATIZING DISABILITY



Why are so many Indigenous people afflicted with disability? Support for disability is a human right. Legacies of colonialism make Indigenous parents feel...
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KCI-NIWESQ

THE GREAT SPIRIT OF THE FEMALE SIDE OF LIFE OF ALL THINGS
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Welcome to the 25th edition of Kci-Niwesq, the magazine of the Native Women's Association of Canada (NWAC).

In these pages, we explore the intersection of Indigeneity and disability, and the impact that physical and mental disabilities can have on First Nations, Inuit, and Métis women, girls, Two-Spirit, transgender, and gender-diverse people.

Rheanna Robinson, a Métis professor with multiple sclerosis, tells us about her fears of being shamed and stereotyped. Dr. Robinson also talks about her acceptance of the physical changes that have accompanied the progression of her disease—acceptance that came from consulting with First Nations Elders and others, and her discovery that most Indigenous languages have no all-encompassing word for disability.

We hear from experts that the rates of disability are significantly higher among Indigenous Peoples than they are among the overall Canadian population. Neil Belanger, Chief Executive Officer of Indigenous Disability Canada and the B.C. Aboriginal Network on Disability Society, talks about the factors that contribute to this disparity, including Indigenous fears of receiving racist treatment from health care professionals. And Erynne Sjoblom, a senior policy advisor with the First Nations Health and Social Secretariat in Manitoba, tells us the root causes of the high rates of disabilities are similar to those driving other health inequities affecting Indigenous Peoples in Canada: cultural genocide, historical trauma, and ongoing colonization.

Symbia Barnaby, a Haida nurse who promotes health equity through an Indigenous lens, especially when it comes to people with disabilities, recounts the difficulties of getting help for five of her children who have neurodevelopmental disabilities. And she tells us about the difficult ordeal her family endured when the children were removed from her home because there were no supports available in her remote British Columbia community.

Members of the Canadian Pain Task Force talk about why pain is the most commonly cited disability among Indigenous Peoples. Jaris Swidrovich, an assistant professor in the Leslie Dan Faculty of Pharmacy at the University of Toronto, says pain, as it is understood by First Nations, Métis, and Inuit, is not just physical but also emotional and spiritual.

We hear from Ena Chadha, Chair of Ontario's Human Rights Legal Support Centre, who points out that disability is the most commonly cited ground in human rights complaints, even though people are protected from discrimination on the basis of disability at the provincial, federal, and international levels.

And finally, you will read about Judi Johnny, a member of Gwa'sala-'Nakwaxda'xw First Nation, who fought tenaciously from her wheelchair for the rights of disabled people. Ms. Johnny founded a feminist disability collective in Whitehorse called Women With Wings to support the leadership of Indigenous women with disabilities.

So, thank you once again for opening the pages that follow. Thank you for reading the 25th edition of Kci-Niwesq. Please drop us a line and let us know what you think at reception@nwac.ca.

Miigwetch.

Carol McBride



CAROL MCBRIDE / President
NWAC

DESTIGMATIZING DISABILITY

Disability is a spectrum, and all human beings will experience some form of it in their lifetimes. But disproportionately more Indigenous people than non-Indigenous people identify as living with disability. And, although support for debilitating conditions is a human right, many First Nations, Inuit, and Metis say there are societal obstacles that prevent them from accessing the assistance that could help them lead normal, happy, and productive lives.

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PUTTING DISABILITY FRONT AND CENTRE

The epidemic of disability among the Indigenous people of Canada

The rates of disability are significantly higher among Indigenous people than they are among the overall Canadians population. The factors contributing to that disparity include Indigenous fears of receiving racist treatment from health-care professionals. That is compiled onto other health inequities affecting Indigenous peoples in Canada: cultural genocide, historical trauma, and ongoing colonization.

Lack of supports for disability ranks high on the list of obstacles preventing Indigenous Peoples in Canada from enjoying happy, fulfilling lives.

The rates of life-altering disabilities are far greater for First Nations, Inuit, and Métis than across the general population. And, regardless of the type of disability, society can create substantial barriers that present significant impediments to those who want to have equal opportunity to participate in their communities and to the country at large.

“In terms of what we know, which isn’t a lot, the rates of exceptionalities, of disabilities, are higher for Indigenous Peoples across the gamut,” says Erynne Sjoblom, a senior policy advisor with the First Nations Health and Social Secretariat in Manitoba, who helped research and co-author a report last year called Supporting the Gifts of First Nations Adults Living with Exceptionalities.

“Whether we spoke to people who had psychiatric, neurological, or chronic illness-related (disabilities), or psychologically related (disabilities),” says Ms. Sjoblom, “from the limited data that is available out there, the rates are higher.”

There are few sources to indicate the full extent of disabilities among Indigenous Peoples in Canada. The Aboriginal Peoples Survey conducted in 2017 by Statistics Canada, which looks at First Nations people living off reserve, Inuit, and Métis, found that 32.7 per cent of off-reserve First Nations people aged 25 to 54 live with a disability, and First Nations women were more likely to have a disability than First Nations men (39.3 per cent versus 24.5 per cent.)

Although the survey looked at off-reserve First Nations people, experts say disability rates for on-reserve First Nations people, which have not been consistently measured, are expected to be just as high, or higher.

Other Statistics Canada surveys, meanwhile, have found that, for all Canadians (non-Indigenous and Indigenous combined) between the ages of 25 and 64, the rate of disability is about 24 per cent.

Despite a lack of research in this area, Ms. Sjoblom says the root causes of the high rates of disabilities are probably the same as those driving other health inequities

Putting Disability
Front and Centre



PHOTO:
ERYNNE SJOBLOM

Photo Credit:
Marsha Simmons

“Often, supports focus on trying to relieve the deficit instead of embracing people’s gifts and including them in community—including them in these activities that they want to be involved in. People have gifts and they want to be part of community life.

We should really support that.”

~ Eryne Sjoblom

affecting Indigenous Peoples in Canada: cultural genocide, historical trauma, and ongoing colonization. She notes that these issues are made worse by a lack of services and supports to Indigenous peoples with exceptionalities in their community of choice. Ms. Sjoblom highlights that participants in this study preferred to use the term exceptionalities over disabilities to take the focus off deficit and instead celebrate the unique gifts that Indigenous Peoples with diverse abilities bring.

Neil Belanger, Chief Executive Officer of Indigenous Disability Canada and the B.C. Aboriginal Network on Disability Society, says there are many reasons for the disparity between Indigenous and non-Indigenous people when it comes to rates of disability.

One is diet. It is often difficult to obtain fresh, healthy food on remote reserves, and the costs can be prohibitive. “That leads people to buy things that are less nutritious—what we consider junk food,” says Mr. Belanger. And that “leads to higher incidences of diabetes, which then gives you chronic disease and health problems, which could include amputations and all those things.”

In addition, he says, people living in Indigenous communities who participate

in traditional activities are more prone to injuries. “Whether you’re out berry picking, or you’re looking for medicines, or you’re using skidoos or other methods of transportation, sometimes you get hurt that way, too,” says Mr. Belanger.

Of course, poverty is a major factor in disability, he says, and poverty across the spectrum in Canada for Indigenous Peoples is high. “All those things that help a person stay healthy and maintain their health are often compromised because they don’t have access to them due to the poverty,” says Mr. Belanger.

Then there is the racism within health care systems that makes it less likely that Indigenous Peoples will seek treatment for disabilities. “It might be true or it might be perceived,” he says, “but the end result is that if you’re not accessing necessary health services that will help maintain your health, then your health deteriorates and you become disabled.”

Mr. Belanger also points out that there are few mental-health services offered in remote Indigenous communities. “So people continue to suffer. They start going into adverse behaviours (like substance abuse) that can lead to having a disability,” he says. “Or they turn somewhere to escape the historic effects of residential schools. All

those things combine to make a bleak picture for many, which can directly result in disabilities.”

Mr. Belanger says there are many things that should be done to change this inequality, but none of them are a cure-all.

For instance, he says, in 2019, the Government of Canada introduced the Accessible Canada Act, which mandated accessibility within the federally regulated entities, including First Nations. But First Nations were exempted until 2026.

Accessibility within First Nations correlates to wellness, isolation, and disability, says Mr. Belanger. “If you’re in a community that doesn’t have any roads and you use a wheelchair, if you’re in a community that doesn’t have any sidewalks or anything like that, if you can’t get into your community centre, you become isolated ... and isolation impacts your mental health.”

There are so many other priorities for First Nations—things like safe drinking water, transportation issues, lack of programs and services, high suicide rates—that accessibility for disabled people gets overlooked “because they’re dealing with all these other crises,” says Mr. Belanger. “We have to put disability

at the forefront within our communities.”

The report by Ms. Sjoblom and her team focused on the experiences of First Nations people living with disabilities in Manitoba, but its findings are likely applicable across the country. It concludes that there are inadequate resources, supports, and services in the community of choice for Indigenous people who have exceptionalities, and there has been a failure to deliver those supports and services in a culturally safe fashion. It makes 32 important recommendations on how to tackle the problem.

Ms. Sjoblom says many of the community-based programs for Indigenous persons living with disabilities in Manitoba are so overstretched that they can’t move beyond the day-to-day job of providing of acute care. There is no time to do holistic prevention or health promotion and, she says, the caseloads for federally funded on-reserve programs are enormous.

“They have a hard time recruiting staff in communities,” says Ms. Sjoblom, “so, often there are positions that go unfilled for many months. The tribal councils try to fill in when they can sometimes, but they’re dealing with people’s immediate needs and are struggling to do that.”

But change is happening, even if it is on a small scale. Ms. Sjoblom points to the Adults with Intellectual Development Exceptionalities (AIDE) Program on Pinaymootang First Nation that was built, from the ground up, by local First Nations experts using the recommendations in her study. “It is the first of its kind

and we are hoping to see it expanded,” she says.

Ms. Sjoblom says access to community, culture, and land-based activities are among the aspects of life that the Indigenous persons with disabilities interviewed in her study said they missed the most.

“They’re being limited not by their disability, but because there aren’t the supports to enable their participation in daily life and community,” she says. “So often, supports focus on trying to relieve the deficit instead of embracing people’s gifts and including them in community—including them in these activities that they want to be involved in. People have gifts and they want to be part of community life. We should really support that.”



PHOTO:
NEIL BELANGER

Chief Executive Officer
of Indigenous Disability
Canada

“We have to put disability at the forefront within our communities.”

~ Neil Belanger



PHOTO:
ENA CHADHA

Photo Credit:
William Osler Health System Foundation

PATCHWORK TREATMENT AND THE INVISIBLE MAJORITY

Support for disability is a human right ... in law

Ena Chadha says it's dangerous to be disabled and Indigenous in Canada because disabled Indigenous people are routinely report being dismissed and disrespected in health services and although they make complaints at human rights tribunals across the country, few of those cases have gone far to deliver justice.

Ena Chadha says it is dangerous to be disabled and Indigenous in Canada. When Indigeneity intersects with health issues, she says, Indigenous Peoples are subjected to compounding mistreatment.

Ms. Chadha, Chair of Ontario's Human Rights Legal Support Centre, also points out that disability is the most commonly cited ground in human rights complaints, even though people are protected from discrimination on the basis of disability at the provincial, federal, and international levels.

Disabled people are entitled to freedom from discrimination "as a fundamental human right in civil society," Ms. Chadha, a human-rights lawyer, investigator, and educator, said in a recent interview.

"Disability is, in fact, entrenched in our Canadian Constitution and provincial human rights statutes," she says. "Disability is a fundamental protected social and civil rights ground. Globally, it's included in various United Nations declarations," including the Convention on the Rights of People with Disabilities, which was ratified by Canada in 2010.

The Native Women's Association of Canada agrees. In an explanatory work on accessibility, the organization says "Indigenous persons with disabilities have the right to full and effective participation in all aspects of life. Realization of this right requires accessibility in terms of physical environments, transportation, information and communications, and access to other facilities and services in urban, rural, and remote areas."

"If we're not making sustainable changes to how we support communities, then it's just this patchwork. That's why we're in this dysfunctional cycle."

~ Ena Chadha

In 2020, Joyce Echequan, a 37-year-old Atikamekw woman, recorded herself being subjected to racist taunts by health care staff before she died at the Centre Hospitalier de Lanaudière in Saint-Charles-Borromée, Quebec.

Two months later, Ms. Chadha wrote an editorial that was posted to the website nationalnewswatch.com entitled "Why It's Dangerous to be Disabled and Indigenous in Canada." In it, she said disabled people in Canada routinely report being dismissed and disrespected in health services and that, although Indigenous persons have made complaints at human rights tribunals across the country about discriminatory treatment, few of those cases have gone far to deliver justice.

In discussing the discrimination experienced by disabled people, Ms. Chadha points out that almost every human being will, at some point, experience a disability, whether it is diminished sight, hearing, mobility, or some other form of physical or mental concern. "It's a universal experience at different times of our being."

That is one reason that disability accounts for the largest proportion of human rights complaints.

"It's really important to recognize that the most recent

Statistics Canada reporting indicates that women with disabilities constitute 30 per cent of our population," says Ms. Chadha. "We're an invisible majority. We're an invisible critical mass of people that politicians ignore."

On top of that, disability intersects with other human characteristics protected by human rights legislation, she says, including age, gender, race, religion, ethnic origin, sexual orientation, and genetic characteristics.

"We're talking about disability crossing all of the categories," says Ms. Chadha. "And especially from an Indigenous perspective, it's that confluence of really active pernicious stereotypes that plays out in forms of rampant discrimination and harassment."

Even though discrimination against disabled people is widely accepted to be a human rights violation, respondents, like employers and government, are quick to invoke exemptions, says Ms. Chadha.

"We don't say everyone is free of racial discrimination except in situations of A, B, and C," she says. But, when it comes to disabilities, inequality is often overlooked when costs to governments, service providers, landlords, employers, and others is

deemed to be too great to demand enforcement.

That is an issue that is especially problematic in remote and rural areas where there is a lack of mental health supports, says Ms. Chadha. "We know as entire Indigenous communities suffer from intergenerational trauma because of historical colonialism and violence against Indigenous Peoples. And, if we aren't taking proactive steps, and our government isn't providing those services, and we expect people to leave their communities and to fly five hours away to get a mental health support, we're just exacerbating the situation."

Yes, there is sometimes a price to be paid equality but, says Ms. Chadha, if you believe in the universal nature of disability, you will realize that accessibility benefits everyone. "You, as a tenant, may not need it today. But when your aging parent moves in with you or when you experience a workplace accident," she says, you might start to think "maybe we should have universally accessible housing along with affordable housing."

Many things must change to end the infringements of the human rights of disabled people, says Ms. Chadha.

First, she says, there must be an acceptance that disability is not

exceptional or extraordinary. "We're all dealing with it. And if we accept the universality of disability, then we're starting the discussion from a different place."

Second, says Ms. Chadha, health care should be more proactive and less reactive. "We really must look at the systemic issues of health care," she says. "Why are racialized women experiencing more maternal fatalities in birthing? Why does that happen disproportionately to our Black and Indigenous communities?"

And third, there must be healing within the Indigenous communities. "If we're not making sustainable changes to how we support communities, then it's just this patchwork," says Ms. Chadha. "And that's why we're in this dysfunctional cycle."

"Disability crosses all of the categories. From an Indigenous perspective, it's that confluence of really active pernicious stereotypes that plays out in forms of rampant discrimination and harassment."

~ Neil Belanger

“Diversity, need, traits, uniqueness, and differences that we all have are framed within the context of a community. They are held within a system that recognizes that vast scope of inter-relationships and interdependence between us all.”

~ Sandra Yellowhorse

NO SUCH WORD AS DISABILITY

Most Indigenous languages have no word for disability – because it focuses on exclusion

Through her research, Rheanna Robinson learned from Elders and other Indigenous people that she needed to start looking at her own Multiple Sclerosis in a different way – that Indigenous communities value inclusion over exclusion and that, in most Indigenous languages, there is no one all-encompassing word for disability.

It took Rheanna Robinson many years to publicly acknowledge that she lives with multiple sclerosis (MS). She didn't know how to deal with the shame and the stereotypes that can be associated with living with a disability.

Today, however, much of Dr. Robinson's research at the University of Northern British Columbia is focused on Indigenous perspectives of disability—academic inquiry framed by Indigenous worldviews of physical and mental differences. Through that learning, she has pushed herself to speak openly about her MS and to advocate for others who are categorized as disabled.

“What my research tells me is that for many Indigenous languages, there isn't a word for disability,” says Dr. Robinson, a member of the Manitoba Métis Federation. “There isn't a singular and deficit-oriented term that is attributed to somebody with varying ableist circumstances.”

There are Indigenous words to describe various physical and mental limitations. “Trouble walking, or having a sore back, or having vision loss, or hearing loss—there are words in Indigenous languages that do account for those things,” says Dr. Robinson. “But disability, as a colonial and socially constructed term that is often positioned in a deficit-oriented framework does not exist.”

PHOTO: RHEANNA ROBINSON



Sandra Yellowhorse, a cultural disability consultant and member of Diné (Navajo) Nation who works at the University of Auckland in New Zealand, says her people have a word k'é, which many Diné People have loosely translated to mean positive relationships or relationships oriented towards harmonious.

"K'é is the foundation in all our ancestral stories about disabled people," writes Dr. Yellowhorse in an essay that is posted on the Disability Visibility Project website. "Although people and communities in our stories are described as disabled and/or impaired, Diné stories are not solely about the ways they are disabled or impaired. They are not focused on what caused one's disability or impairment, or how disability is defined

(because these descriptors change across stories). Rather, the stories about our disabled relations are about k'é—specifically, its unique way of caretaking all our relations—both human and non-human."

Within this, says Dr. Yellowhorse, there is an understanding of diversity, need, traits, uniqueness, and differences that we all have. "Yet, those are all framed within the context of a community. They are held within a system that recognizes that vast scope of inter-relationships and interdependence between us all. Therefore, disability is a relational and collective concept."

Dr. Robinson was diagnosed with relapsing/remitting MS in January 1997 when she was 19 years old. For many years,

its symptoms, which include degenerating balance, walking, movement, vision, and speech, would come and go to varying degrees, but she was able keep her condition mostly hidden.

"To avoid any association with a disability identity, due to the ever-present shame and stigma that can accompany living with disability, I didn't talk about my MS," says Dr. Robinson. "I kept my health condition very private."

Now, in her late 40s, she has transitioned into a secondary progressive form of MS. The disease is in a period of continual advancement, and there is no intermittent recovery from its impacts. Alongside its evolution, she has become much more open about her circumstances. And, about five years ago, Dr. Robinson began to incorporate disability advocacy into her research.

It was a choice she made, in part, because although she knew Indigenous Peoples live with higher rates of disability than non-Indigenous Canadians, Indigenous literature and scholarship related to disability experiences are "woefully under-represented, and I feel it really is part of my life's work to mobilize disability-related conversations in a respectful and collaborative way."

Her new area of study opened the door to a different way of thinking about her own situation, and about disability in general.

"As I was trying to manage a new identity experience, I was advised by Elders and people in the community that I really needed to start looking at my disability differently," says Dr. Robinson. "I really needed to look back and consider how



Indigenous Peoples traditionally included conceptualizations of disability within community and that traditional teachings are contrary to the Western and socially constructed views of disability."

In the Western world, she says, disability is very much an individualized imposition. The policies and programs created to address it are primarily based on the medical and social models of disability. Indigenous values are not well represented here.

For Indigenous Peoples, it is about how personal characteristics and physical attributes complement community and relationships with each other, with the land, with their culture, and with the world entirely.

The Elders, Chiefs, and Matriarchs she consulted as part of her academic research, particularly with Nisga'a Nation, told her that equity and inclusion are inherent attributes of their laws and their traditional customs. To have a singular term, like disability, that would set somebody apart from the community, would run contrary to traditional Indigenous perspectives, which embody the spirit of all members of their Nation.

The Elders also explained that all people are welcomed into this world as a gift from the Creator. Everyone brings important individual and varying characteristics that make them part of the diverse population



of people who must work together, form communities, and relate to one another.

In addition, in the Western world, disability is encased in layers of fear, says Dr. Robinson. People are often scared to talk about disability, she says, and they're scared they could become disabled.

"Until we can move past the point of being ashamed of talking about our limitations and our differences, we are going to be in a continual and perpetual state of having those dichotomies of difference," says Dr. Robinson. "And this is necessary to acknowledge."

The discussion must start with the fact that disability discrimination is "absolutely harmful and profound for those of us living with disability," she says.

Dr. Robinson recognizes that, "internalized ableism has impacted me profoundly. It's going to be a long part of my journey to work through that." As she moves forward, she says she is grateful to find invaluable spaces where Indigenous knowledges have much to offer the world "in the context of disability and beyond."

"For many Indigenous languages, there isn't a word for disability. There isn't a singular and deficit-orientated term that is attributed to somebody with varying ableist circumstances. 'Disability' as a colonial and socially constructed term that is often positioned in a deficit-orientated framework, does not exist."

~ Rheanna Robinson

JUDI JOHNNY, THE WOMAN WITH WINGS

Judi Johnny was a slight woman with a soft voice who fought tenaciously and fearlessly for the rights of disabled people. She founded a feminist disability collective in Whitehorse called Women With Wings to support the leadership of Indigenous women with disabilities – a group eventually had to give up for lack of support and resources.

Judi Johnny was a slight woman with a soft voice who fought tenaciously and fearlessly for the rights of disabled people. Ms. Johnny, a member of Gwa'sala-'Nakwaxda'xw First Nation, near Port Alberni, B.C., died in February 2015 in Whitehorse, where she had lived for many years. She was 65.

Ms. Johnny was a proud feminist, a residential school survivor, and a lifelong advocate for those who lived with disabilities. She herself had post-polio syndrome, cerebral palsy, and arthritis, and had used a wheelchair since she was 40.

But her disabilities were part of her life from an early age. Even though they afflicted her physically, they were the reason she was confined to a mental hospital when she was young.

"As a child, just the thought, the idea that I wasn't even human, because of my disability and my race and my gender ... helped me in a sense. Well, it didn't 'help' me. But that's where I got the oomph to fight," Ms. Johnny said in a 1995 recorded interview posted on the Madness Canada website.

In 1991, Ms. Johnny founded a feminist disability collective in Whitehorse called Women With Wings to support the leadership of Indigenous women with disabilities (the group eventually had to give up for lack of support and resources). She was also a member of the board of directors of DAWN (the Disabled Women's Network of Canada) starting in 1992, and then again in 2010 after stepping away for a number of years.

THE TOUGH
RESIDENTIAL-SCHOOL
SURVIVOR WHO FOUGHT
FOR INDIGENOUS
WOMEN WITH
DISABILITIES

PHOTO:
JUDI JOHNNY

Photo Credit:
Whitehorse Star

“There will be Women With Wings again in the Yukon. We made that promise to Judi a long time ago and we still plan to keep it.”

~ Bonnie Brayton

DAWN Canada’s website says she advocated for the full inclusion of people with disabilities in her community until her last breath. It says she was adamant that she and all her friends should have access to restaurants, stores, and public spaces, that she was passionate about obtaining improvements to transportation for people with disabilities, and that she loved beautiful things and beautiful people.

“She was easily underestimated, but she shouldn’t have been,” says Bonnie Brayton, DAWN’s Chief Executive Officer. “The reality is, she was kind and thoughtful. And the way she used humour a lot of the time to make people see situations was one of her gifts.”

Ms. Johnny told Madness Canada that psychiatric patients protected her when she was confined to the asylum. She said she knew she had been institutionalized because she was not the right colour or gender, and it was a convenient place to “stash” her.

That injustice fuelled her determination as an adult to fight for justice and equality for disabled people.

“Right now,” she said in her 40s, “it’s a time to deal with those kinds of issues, so that I can carry on with life and be stronger, more politically active, than what I am now. I

feel that it’s a comfortable time of my life to acknowledge that and say ‘okay this has happened to me, and this is why I am the way I am now.’ I don’t care if you accept me any better or any worse, but this is where I am now. And I have nothing to lose.”

Ms. Johnny did the university coursework required to obtain a social work degree but, because of her disability, she could not secure the social work field placement required to obtain her credentials.

“When she went back to the Yukon and started Women With Wings, Judi told me it was really her way of taking what she felt in her belly that she needed to do in terms of change and trying to move that forward,” says Ms. Brayton.

Ms. Johnny said in a recorded interview with the Yukon Women’s Directorate that Women With Wings did not turn out to be as political as she would have liked, but it was a place for women with disabilities to meet and to “chill out” and to not worry about what other people thought of them.

“In those days, it was only white women who were involved (in the feminist movement) ... the feminist meaning wasn’t the same in every culture. So, I had to fight a Caucasian point of view and say, ‘we are a feminist, we have

a different culture, we have a different value system,’” she said in that interview. “It was kind of exciting to see that these women could protest a government. That, in itself, was liberating.”

According to Ms. Brayton, when she started as Executive Director of DAWN Canada in 2007, Ms. Johnny was a bit of a legend, even though she was no longer on the organization’s board.

Ms. Brayton says she was sitting at her desk in 2010 when the phone rang. “And this very sweet voice says ‘hello.’ And I said, ‘hello.’ And she goes ‘it’s Judi Johnny’ ... ‘I’ve been away for a long time. DAWN wasn’t doing very well. But you seem to be doing better now. So, I want to come back because I have work to finish with you.’”

She rejoined the DAWN board and resumed her contribution to its work for disabled women until her death in 2015.

Former Whitehorse mayor Dan Curtis told the Whitehorse Star after Ms. Johnny died that he often heard from her when she felt there was something that needed to be improved. “Judi was a strong advocate in many ways,” said Mr. Curtis. “She will be sorely missed.”

Denise Leschart, who drove the Handy Bus for Whitehorse Transit, told the Whitehorse Star that Ms. Johnny never gave up fighting for better public transportation for people with disabilities. Ms.

Leschart also remembered Ms. Johnny’s smile and her friendly conversation.

Ms. Brayton said Ms. Johnny “was very clear about what people’s rights were, and she would assert that to all the drivers for other people or anyone who needed to be reminded.”

On one of her last rides, says Ms. Brayton, “Judi told me that she was incorrectly strapped into the bus’s wheelchair harness and, by the time the ride ended, she was in distress. She ended up with pneumonia and then soon after she died.”

DAWN Canada has appointed Evelyn Huntjens to serve as Director of Indigenous Initiatives to honour Ms. Johnny’s memory and amplify the voices of Indigenous women living with disabilities. “There will be Women With Wings again in the Yukon.” Says Ms. Brayton. “We made that promise to Judi a long time ago and we still plan to keep it.”



“As a child, just the thought, the idea that I wasn’t even human, because of my disability and my race and my gender ... helped me in a sense. That’s where I got the oomph to fight.”

~ Judi Johnny

“PAIN, AS UNDERSTOOD BY FIRST NATIONS, MÉTIS, AND INUIT, IS NOT JUST PHYSICAL. WE ALSO INCLUDE EMOTIONAL AND SPIRITUAL PAIN IN THAT DEFINITION.”

~ JARIS SWIDROVICH



PHOTO: Jaris Swidrovich

THE DUAL STIGMA OF BEING INDIGENOUS AND IN PAIN

Pain is the most common type of disability cited by Indigenous people. The Canadian Pain Task Force says that may be because Indigenous articulate physical pain as being secondary to emotional pain, and they face multiple obstacles making it less likely that they will receive access to effective care

Pain is an insidious disability. It is not visible to others, but it gnaws at the body and the mind of those who suffer. And, in Canada, it is a disability that disproportionately afflicts Indigenous Peoples.

After surveying First Nations, Inuit, and Métis across the country through online questionnaires, workshops, talking circles, and written submissions, the Canadian Pain Task Force found that Indigenous Peoples conceptualize and experience pain differently than non-Indigenous people. They articulate physical pain as being secondary to emotional pain, says a report by the task force. They also face multiple obstacles, which makes it less likely that they will receive access to effective care.

According to the disability screening questions included in the 2017 Aboriginal Peoples Survey conducted by Statistics Canada, roughly one in five Métis and First Nations people living off reserve had a pain-related disability—a much higher rate than experienced by the Canadian population at large. And, among all Indigenous groups, pain was the most prevalent type of disability.

“We know from research and literature, but also I know from my own lived experiences—chatting with friends, family, and from some of the cross-country tours I did as part of the Canadian Pain Task Force, and learning from Indigenous folks—that pain, as understood by First Nations, Métis, and Inuit, is not just physical. We also include emotional and spiritual pain in that definition,” says Jaris Swidrovich, a task force member who is an assistant professor in the Leslie Dan Faculty of Pharmacy at the University of Toronto, as well as a Two-Spirit Saulteaux and Ukrainian member of Yellow Quill First Nation.

“There’s a very strong relationship between histories of trauma and especially early childhood adverse experiences, and experiences of systemic marginalization that can predispose people to chronic pain.”

~ Maria Hudspith



“Sometimes, when it’s a binary question of ‘do you experience pain,’ many of us (Indigenous people) would say ‘yes’, because it applies to all of those areas in our understanding of it,” says Dr. Swidrovich.

In addition, he says, most Indigenous Peoples in Canada, no matter who they are or where they live, have been subjected to colonial violence, whether it is current, past, or inter-generational. “Lots of that colonial violence is met with pain, like the loss of a loved one, or the loss of your language, or loss of ceremony.”

One of the most disturbing findings of the task force, says Dr. Swidrovich, is that so many Indigenous people who have sought help for chronic pain talk about being brushed off or even treated with disdain by health care providers. It was “to the point where many of them described making a decision to no longer try to access care because they’re rejected or because of whatever other stigma or racism is there.”

Last year, a Haida Elder named Penny Kerrigan was medivacked to Terrace, B.C., from the Haida Gwaii community of Old Masset

because she had been in severe pain for three days and a doctor in Old Masset had determined that she needed a CT scan.

By the time she arrived in Terrace, the morphine had worn off, but the staff at Mills Memorial Hospital ignored the paramedic who said she needed more painkiller. “In fact, they put me in a dirty room and ignored me for an hour,” says Ms. Kerrigan. When the doctor came in to see her, he asked what she was there for. “I said I came to get a CT scan and to see a surgeon, and he said: ‘I will decide whether or not you get a CT scan,’” she says.

Ms. Kerrigan was given the scan after multiple incidents of what she describes as racist behaviour on the part of hospital staff. “Then the head nurse came in and she told me I could go. I said: ‘What are you talking about?’ And she said: ‘Well, you need to leave.’ And I said: ‘Well, what am I gonna do?’ And she looked at my little carry-on suitcase and said: “Well, didn’t you have plans?”

Ms. Kerrigan was told to call a taxi and was given some regular-strength Tylenol. She went to a local hotel.

Still in immense pain, she wrote a Facebook post about her ordeal. They she talked

“BEING INDIGENOUS IS ONE THING AND BEING A WOMAN IS ANOTHER.”

~ Jaris Swidrovich

to her daughters and other people in her community, including Indigenous rights advocate Gladys Radyk. They called authorities at the hospital to complain and they urged her to return for treatment.

“They were outraged, and the hospital was scrambling,” says Ms. Kerrigan. She went back to the emergency ward only after being assured that she would be treated with dignity and respect.

Another doctor—who Ms. Kerrigan had asked to see at the outset but was told he no longer worked at the hospital—took another look at her scan and saw that she had appendicitis. She was quickly operated on.

The case is now before the Human Rights Tribunal.

Ms. Kerrigan has worked a consultant and an executive director and as a liaison officer for the National Inquiry into Missing and Murdered Indigenous Women. She believes her case would have been handled differently if the hospital staff had known her background, but she says an Indigenous person should not have to show their credentials to get respectful treatment.

“All I could think about was the Elders in my community who get dismissed (when seeking medical care) because the (hospital staff) feel like they’re drug seeking,” says Ms. Kerrigan. “I’ve heard it over and over again.”

Dr. Swidrovich says stories of pain being dismissed are far too common among Indigenous Peoples, and especially among Indigenous women.

One recent long-term study, he says, looked at many people who had been admitted to hospital for hip or knee surgery. It found that female patients were prescribed fewer pain medications and

in smaller doses compared to men who underwent the exact same procedures. “So, being Indigenous is one thing and being a woman is another.”

And pain treatment standards decline even further, says Dr. Swidrovich, when other intersecting identities are added to the mix, including HIV status, substance use disorders, and experiencing homelessness.



PHOTO: / Maria Hudspith



PHOTO: Penny Kerrigan

“For many Indigenous People who have pain, the experience of trauma, racism, and discrimination in the health care system drives them away from care instead of to seeking care.”

~ Maria Hudspith

“It was really quite disappointing,” he says. “I’ll never forget one of the (Indigenous) participants who said, ‘I’ve just made the decision to give up, I’m not going to access care anymore, and I’ll just die at home.’ And that was the end of her story. And I was just like, ‘Oh, my goodness.’”

Maria Hudspith, a co-chair of the Canadian Pain Task Force and Executive Director of Pain BC, says there are multiple reasons why the incidence of disabling pain is greater among Indigenous Peoples.

First, says Ms. Hudspith, painful chronic illnesses of all sorts, including arthritis and diabetes, disproportionately impact Indigenous Peoples, who also experience higher rates of injuries. And there is a high correlation between pain and trauma.

If someone has an acute injury to a shoulder, for instance, that is a “hardware problem,” says Ms. Hudspith, employing a computer analogy. “Our health system historically, for many populations, but often not for Indigenous populations, has been pretty good at treating the hardware part of health.”

But when pain becomes chronic, the brain and the nervous system are often involved, she says. And that is a “software problem,” which presents far greater challenges to the Western medical system.

“It’s often not visible to health professionals, although if you put somebody who has chronic pain in a functional MRI, their brain is often lit up like a Christmas tree in these parts that we know process pain,” says Ms. Hudspith. Those parts overlap with the parts of the brain that process emotions. “So there’s a very strong relationship between histories of trauma and especially early childhood adverse experiences, and experiences of systemic marginalization

that can predispose people to chronic pain.”

Indigenous Peoples in Canada experience disproportionate levels of trauma, both as children and as adults.

Western approaches to treatment are insufficient, says Ms. Hudspith. Chronic pain is a bio-psycho-social-spiritual phenomenon and requires a bio-psycho-social-spiritual approach to treatment. “But often, there isn’t that interconnection with traditional medicines and land or culture-based approaches,” she says. “And we know from so many conversations with Indigenous Peoples that those have a huge impact.”

Pain BC collaborates with Elders, Knowledge Keepers, and health care providers to run programs of pain self-management in their local communities. In addition to providing education about the science of pain, they integrate Indigenous knowledge and worldviews.

Accessing treatment for pain through Western medical systems can be challenging for Indigenous Peoples, says Ms. Hudspith. “For many Indigenous People who have pain, the experience of trauma, racism, and discrimination in the health care system drives them away from care instead of to seeking care.”

Indigenous Peoples are not treated seriously, she says. They’re told that their pain is in their heads, or that they are malingering, or that they are trying to get out or work, or that they are trying to get prescribed drugs they do not need. “All of those systemic biases are at play,” says Ms. Hudspith. “Indigenous Peoples are often invalidated and stigmatized, and Indigenous people with pain are bearing the additional burden of living with an invalidated stigmatized condition.”

THE RIGHT TO CARE, THE RIGHT NOT TO LIVE IN FEAR



No wonder Indigenous moms and dads are scared: When the same government ministries that provide support for disabilities are responsible for child apprehensions.

Symbia Barnaby says, a nurse of Haida and Mi'Kmaq ancestry who promoted health equity through an Indigenous lens, says are often reluctant to tell government authorities that their child appears to have learning disabilities or other special needs, and that fear is rooted in the colonial history of removing Indigenous children from their homes.

Symbia Barnaby knows how difficult it is to get support for children with special needs, and she understands why Indigenous parents are often fearful to ask for help.

Ms. Barnaby lives on the traditional unceded lands of the Coast Ts'msyen People in Northwestern British Columbia. She had her children—five of whom require some sort of neurodevelopmental support—removed from her care for five months in 2015. She asked for help before they were taken from her but was told there was no one who could provide appropriate respite care.

Today, she is desperately trying to obtain an autism assessment for her 15-year-old daughter. The waitlists at the public clinics in Prince George, a nine-hour drive away, are two years long. And, although there are private clinics in Vancouver that can see her within the month, the government patient-travel program for Indigenous Peoples will not cover the cost of the travel unless the assessment takes place at the nearest public clinic.

"My child will turn 16 this year," Ms. Barnaby, whose Haida name is Guu Gaa Jung, said in a recent interview. "If we wait the two years to go through the public system, we will miss the window of opportunity for autism funding and treatment because she will age out of provincially funded services."

Ms. Barnaby, who is of Haida and Mi'Kmaq ancestry, is a nurse who works alongside Elders and other helpers as they do traditional ceremonies and make traditional medicines. She also runs her own coaching and consulting business called Healing Nation Coaching and Consulting. She promotes health equity through an Indigenous lens, especially when it comes to people with disabilities.

"I speak from personal experience. It wasn't until I had my kids (returned to me) after they were taken back in 2015, and after what I've gone through since then, that I can turn around and help other people by saying what needs to be done differently," says Ms. Barnaby. "I've worked within the health care system and I am telling you, they're failing Indigenous families. We have the right to support, we have the right to school, we have the right to an education. And we are not being supported properly."

First Nations parents, she says, are often reluctant to tell government authorities that their child appears to have learning disabilities or other special needs. That fear is rooted

“Many First Nations communities are very remote, very northern, very rural. They just don’t have supports and services. Often the families are broken apart.”

~ Evelyn Huntjens

in the colonial history of removing Indigenous children from their homes.

Many Indigenous families in British Columbia do not understand that the provincial Ministry of Children and Family Services has different branches, and the branch that assists children with disabilities is not the same branch that takes children into protective custody, she says. “This is part of what leads to the fear and apprehension of coming forward for support or for services.”

“I have an older brother who was taken through the Sixties Scoop. My mom was as well. We have a long line of being removed from our families throughout many generations. So, it’s something that I know and understand. I eat, breathe, sleep this,” says Ms. Barnaby.

When Ms. Barnaby was pregnant with her sixth child in 2013, her obstetrician told her she was at high risk of complications. She and her husband, who was working full time to support the family, worried about what would happen if she were medivacked out of the community. So, they contacted a social worker and asked for respite care for children with special needs.

“We need educated relief care. We need somebody who was going to know how to take care of these kids who’s not going to abuse them, someone who’s going to know how to handle them,” says Ms. Barnaby. “The

social worker here in town said: ‘I’m sorry, that doesn’t exist in our community.’”

The only option offered to her was a voluntary care agreement that would allow her children to be put in foster care if she had to leave the area for treatment.

The social worker told her the agreement would allow her to get her children back at any time, but it would give her some relief. “And I was like ‘no, this is like one step in the door of taking my kids away from me,’” says Ms. Barnaby. But she didn’t know what else to do, so she reluctantly signed the forms.

A short time later, she was, in fact, medivacked out of the community as a result of the pregnancy, and kids went to stay with her parents in Kelowna through the voluntary care agreement.

She returned a week later. But Ms. Barnaby was on bed rest. And, even after the baby was born, the family began to crumble under the mounting stress from close relatives dying, from injuries, and from navigating the fractured system in place for children with support needs.

Two years later, there was an incident of violence and her husband had to leave the home as a result of a ‘no contact’ order.

“Then I was taking care of kiddos on my own,” says Ms. Barnaby. “I went to them (the

social workers) after the assault happened and said I need emergency respite. I need funding or I need somebody to be able to come in and help me ... I just need another adult in the house who could periodically look after my kids so I could sleep and rest.”

She was so exhausted and emotionally drained that her husband, after a brief telephone call with her, worried she would seriously harm herself. He called the RCMP and an ambulance.

“They came and they removed me from the house,” she says. “And then I was seen at the hospital by the social worker in the morning. And she’s like, ‘well, you know, after what happened last night, we have to take your kids away.’ She gave no space and time for me to explain what happened. Nothing. She had already done the paperwork.”

It took five months of fighting with bureaucracy and delayed court dates for Ms. Barnaby to get her children back. The family was separated over Christmas.

In the meantime, she was told that if she tried to reconcile with her husband and get back with her kids, “they would keep my kids from me permanently because that would show that I wasn’t making safe and sound choices,” she says. “So, I had to step away.”

That experience demonstrates that the threat of having



children apprehended is very real for Indigenous families, she says. “In no way, shape, or form was I being dangerous with my kids and in no way, shape, or form being hurtful or harmful,” says Ms. Barnaby.

Over the past nine years, as she has dealt with the autism, ADD, and ADHD needs of her children, and she has learned much about navigating the system and its various barriers. Today, she does workshops around inclusive education, Indigenous perspectives, gifts with disabilities, the social construct of disability, and the things that can be done to keep Indigenous kids supported in their own communities.

“I’ve worked within the health care system and I am telling you, they’re failing Indigenous families. We have the right to support, we have the right to school, we have the right to an education. And we are not being supported properly.”

~ Symbia Barnaby

The Western world looks at disabilities as a deficit, says Ms. Barnaby. “The name attention deficit disorder (ADD) literally has the word deficit built right into it. They’re looking at ‘how do you not fit into the general population’ and ‘how are you not able to work in an industrial setting.’ That’s the old concept.”

Ms. Barnaby said that to the best of her knowledge, there isn’t a word specifically for disability in Indigenous communities. “There are words that describe gifts that people may have, or attributes that they might have, but not the word disabled.”

That said, Indigenous people with disabilities do need assistance, especially as children.

PHOTO: EVELYN HUNTJENS



The distance to services is a huge barrier, says Ms. Barnaby. "If you are a single mom with four kids, and you're on a reserve and you have to leave (for medical reasons) and the closest place is a nine- or 10-hour drive away, what's happening with the rest of your children? What kind of care are they going to be under?"

There are also financial barriers, she says, both in terms of the cost of the services and in accessing them.

"And the other piece is the broken historical relationships with Indigenous Peoples and these education, health, social justice, and social welfare systems," says Ms. Barnaby. The colonial governments have "broken trust through that education system, and they've also broken trust by these children passing away.

Upward of 10,000 children died in residential schools." There was also the Sixties Scoop, the Millennial Scoop, the inadequate Indian Hospitals, and multiple other colonial systems and institutions that have failed Indigenous Peoples, she says.

Evelyn Huntjens, a member of Xeni Gwet'in First Nation in B.C., is Director of Indigenous Initiatives at DAWN Canada, an organization created to end the poverty, isolation, discrimination, and violence experienced by women with disabilities.

"Many First Nations communities are very remote, very northern, very rural. They just don't have supports and services," says Ms. Huntjens. That means many people living with disabilities must relocate from their homes

just to get access to services, she says.

"Often the families are broken apart," says Ms. Huntjens. "They're moving to an urban centre where they don't have that cultural link, that community link. And it magnifies the isolation and the poverty, losing that connection with your community."

DAWN, she says, is looking at ways that supports can be provided organically through local networks, and ways to provide training and mentoring to individuals in remote communities to create resources where none currently exist.

Ms. Huntjens echoes Ms. Barnaby's observation that Indigenous parents are often reluctant to seek support from government agencies for their disabled children.

In British Columbia, she says, it is the Ministry of Children and Family Development that is responsible for providing services to children with disabilities. That is the same ministry responsible for placing children in foster care.

"So, how are you going to get a First Nations family to say 'oh, here, let me admit my child has a disability, but you're the one that will take my child away from me,'" she asks. "Within the communities there's this big fear that their children are going to be taken away from them if the government has any reason to do so."

In Ms. Barnaby's case, she says many different people missed the mark when it came to building trust with her and her family, and with understanding her culture and the impacts that colonization has had on her decision-making.



Support for Indigenous people with disabilities should not be tied to an official diagnosis, she says. And those providing support "should have cultural competency, cultural safety, cultural humility. Core cultural aspects need to be included in order for people to be able to carry out culturally competent care. That's not present at all," says Ms. Barnaby. "Our people, our children, have the human right to these services and to not be discriminated against on the basis of their race or their abilities."

"Our people, our children, have the human right to these services and to not be discriminated against on the basis of their race or their abilities."

- Symbia Barnaby

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KCI-NIWESQ

is the magazine of the Native Women's Association of Canada (NWAC). Its objective is to highlight the work of the organization and to tell the stories of the Indigenous women of Canada.

NWAC, which was founded in 1974, is a national Indigenous organization representing First Nations (on and off reserve, with status and without), Métis, and Inuit women, girls, and gender-diverse people in Canada. Its goal is to enhance, promote, and foster the social, economic, cultural, and political well-being of Indigenous women within their respective communities and Canadian society.

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