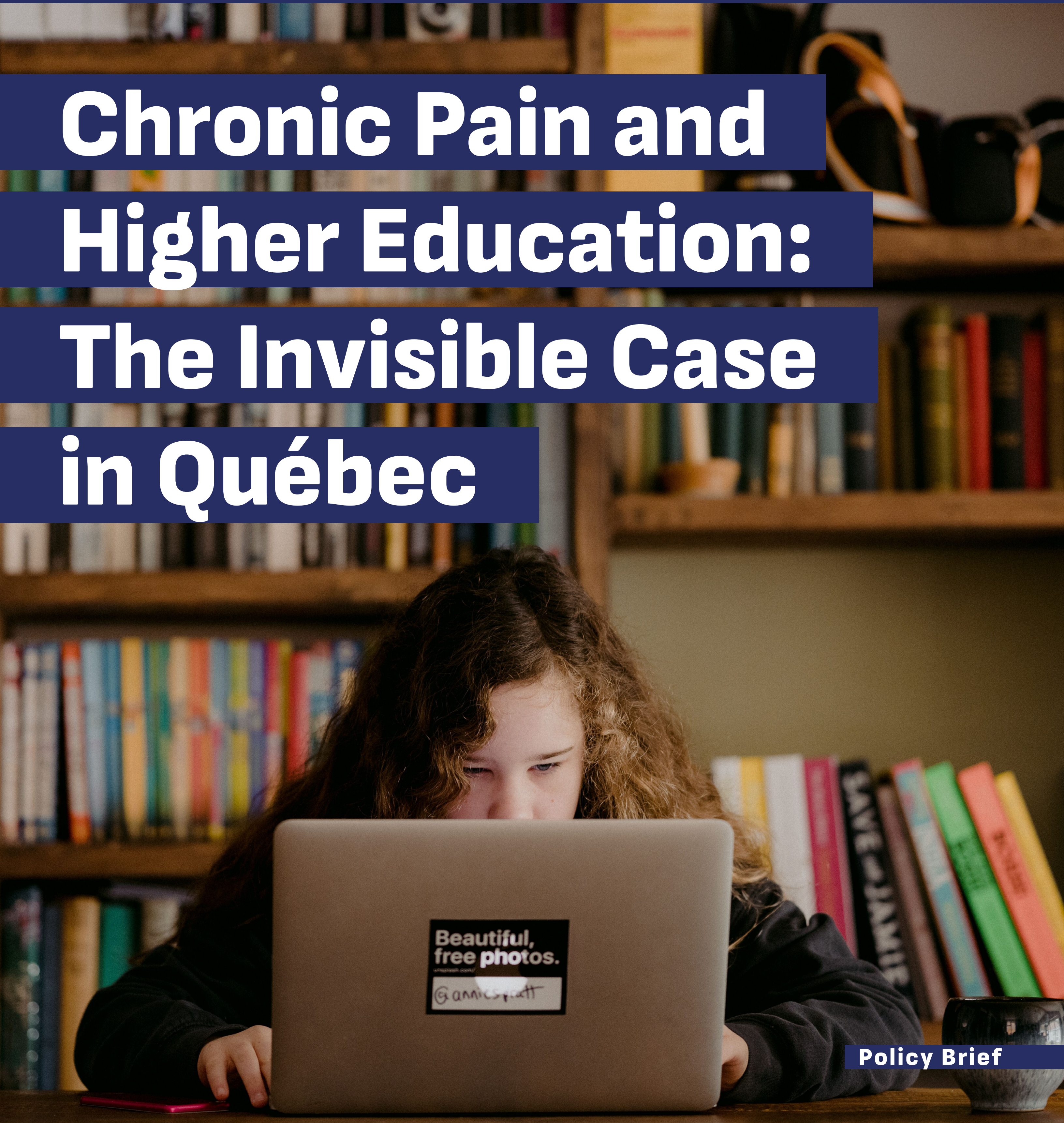
Y4Y Québec

# Chronic Pain and Higher Education: The Invisible Case in Québec



Policy Brief

Y4Y Québec

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## CONTEXT

Pain is often understood in terms of its obvious sources, such as broken bones. Too few, however, are familiar with the concept of chronic pain, and the ways in which it affects the day-to-day lives of those who suffer from it. Chronic pain affects roughly 11-38% of all children and adolescents, making it a very common disability, and about 20% of those living with chronic pain have it persist into adulthood (Ocay, 2022). Roughly 10% of adolescents and young adults (AYAs) transition to adult pain care between 16 and 25 years of age (Kudrina et al., 2022). These youth may also experience functional disability, higher rates of school absenteeism, poor sleep quality, and mental health problems. Furthermore, those that suffer from chronic pain often cannot pause their education to recover because recovery is not necessarily an attainable goal. It is crucial to support these students and young adults as much as possible as they are already disadvantaged by inadequate access to the healthcare they need.

The Canadian Association of Pediatric Health Centers' (CAPHC) guideline recommends that all young patients with chronic conditions be registered with a community-based primary care provider (PCP) (Kudrina et al., 2022). Unfortunately, few have access to PCPs or doctors, and worse still, apart from authorising prescription drugs, these professionals are often not trained to manage patients with chronic pain (Rowe, 2023).

> "The need for accommodations in educational environments, pressure to obtain formal documentation, struggles to accomplish the same work as their peers, and desire to have additional opportunities for pain-related visits (drop-off hours, telephone calls with a pivot nurse, online communication portal with team) underscored today's fast-paced and highly competitive environment outside of the clinical setting that puts AYAs in a significant disadvantage socially but also medically" (Kudrina et al., 2022).

## HOW DOES THIS AFFECT QUÉBEC'S ENGLISH-SPEAKING STUDENTS?

Students with chronic pain will often find themselves at a disadvantage in comparison to their peers. In this section, we will address the following issues faced by students with chronic pain conditions at English university institutions in Québec: reduced Campus Health hours, confronting not being believed, poor public transport options, and the boom of online courses. One of our interviewees, a previous member of Adaptech, referred to the useful illustrative concept of a "disability tax." This implies that everything an abled body person can accomplish becomes more taxing for a disabled student, whether it be physical (taking an uber to an exam rather than public transport to avoid the pain of walking), social (being unable to network), or other.

Reduced university Campus Health hours have hampered services for students with chronic pain. Because of enduring Covid-19 precautions, most university Campus Health services are now available only Monday to Friday from 9AM to 5PM. According to a Concordia University student quoted in their student paper, The Link: "I feel like my health and wellbeing aren't taken seriously because I'm young and healthy. I might be healthy but it doesn't mean I shouldn't be able to access care to prevent future issues" (Darey, 2021).

Adolescents and young adults are frequently dismissed when they report their experience of chronic pain. Too often, they are simply not believed to be telling the truth about their health. Even with proper documentation, some teachers will refuse to give accommodations based on their belief as to which disabilities "count." A testimony from a nonbinary, queer student of colour at a Montréal-based university stated: "I've had trouble getting extensions because of episodic pain related to disability. I had to defend myself and argue with the teacher until she pulled out the course outline with disability resource info on it. She then told me what my disability and comorbidity with other learning disabilities statistically looks like, instead of listening to my lived experience. I did not get an extension (I was asking for only 2 or 3 days)" (Tshuma & Hadley, 2020). There are many reasons a teacher could react like this. It could be due to the teacher being unable to put themselves in the student's position. Perhaps the student only approached them later during the semester. However, due to situations like this, it may be hard for students to come forward to disclose their need for accommodations.

The public transit systems on many campuses, furthermore, are often physically inaccessible to students with pain conditions. In the context of chronic pain, there is often a problem with mobility. While Concordia, McGill and Bishop's each have a shuttle bus for students with disabilities,they require medical documentation outlining one's impaired mobility (McVean, 2017). Unfortunately, not everyone can have access to such documentation, especially if one's doctor does not consider one "disabled enough" to require the documentation. Physical items such as chairs can also aggravate chronic pain (Tshuma & Hadley, 2020).

In an unexpected twist, the Covid pandemic has helped students with chronic pain by introducing remote classes to the mainstream. One of our interviewees corroborated this reality, telling us it was enlightening to experience Covid-19 as it put people in a situation that most folks with chronic pain are familiar with, such as not being able to leave the house for in-person classes. A participant of *L'Association québécoise pour l'équité et l'inclusion au postsecondaire*'s Zoom consultation summary report stated: "It's interesting to notice how things have BECOME more accessible for some of us with chronic health conditions or certain disabilities (flareups, can't leave the house at times, etc.). We used to get told that we couldn't meet learning objectives that way; now that everyone needs to meet their learning objectives that way, there's more creativity and more opening for people to figure out how to do that" (2020).

A non-exhaustive list of types of disabilities with chronic pain and chronic pain flareups:

- Multiple sclerosis
- Crohn's
- Arthritis
- Fibromyalgia
- Complex Regional Pain syndrome
- Autoimmune disorders such as Lupus

And others.

These are a handful of the many conditions one could be going through, and which an observer would not be aware of.

## SERVICES OFFERED BY CONCORDIA, MCGILL, AND BISHOP'S UNIVERSITY

We sought to document Concordia, McGill, and Bishop's University's current level of assistance for students with chronic pain.

**Concordia University:** There are currently 8 advisors in Concordia's Accessibility Centre for 3349 registered disabled students in 2020-2021 (Contact us - Concordia University, n.d.). This is roughly 418 students per advisor. This statistic, however, does not account for those who are not registered due to insufficient documentation, either from lack of access to a doctor or not being considered severe enough to require accommodations.

**McGill University:** In 2017, there were roughly 10 employees working at the Office for Students with Disabilities & Tutorial Services (currently known as Student Accessibility and Achievement) for 2000 students registered with accommodations (McVean, 2017). The Office currently has roughly 7 advisors for an unknown registered number of students with accommodations (Student Accessibility & Achievement, 2023).

**Bishop's University:** Bishop's' website states that there are 4 core members on the Student Accessibility team for an unknown number of registered students (Bishop's University, 2023).

These three universities are making a great effort to integrate what is called Universal Design Learning (UDL). UDL is described as "a framework to improve and optimise teaching and learning for all people based on scientific insights into how humans learn" (CAST, 2018). These projects, including workshops to educate faculty staff, are developed by the universities' Accessibility and Equity Centres so as to create a welcoming environment for students with disabilities.

Apart from UDL, however, the three aforementioned universities made it clear in conversation how difficult it is to provide support, as this is something that arises on an as-needed basis. Chronic pain is multi-faceted and students' needs will be very different, even, in some cases, for those with the same diagnosis. Some will be episodic, some chronic. The process depends on the student and must be highly interactive between the student and the student accommodation staff. The support that universities at this stage can provide requires proper, specific documentation.

In 2022, a student collective from Montréal's Concordia University created a group called "Disabled Spoonies and Friends" for those that suffer from a variety of disabilities, including chronic pain. The group is open to anyone in the Montréal region regardless of age, educational or professional background. Gabriella Dery from Disabled Spoonies and Friends said: "We are trying to fill in the gaps where the Access Centre has really let us down and is unable to provide the services that we all need" (Integlia, 2023).

Bishop's University also created a club for disabled and neurodivergent students called the Disabled And Neurodivergent Students club (DANS). DANS was founded by Pénélope Fortin, stating she wants "people to feel like they belong at [Bishop's University]" (The Campus, 2022). Pénélope, furthermore, singled out that there are currently no scholarships for disabled students (The Campus, 2022).

## ADVICE AND EXTERNAL RESOURCES

In the interim, the best way to support oneself as a youth living with chronic pain is to clearly communicate your needs to your doctor, advisors, and teachers as early as possible. Since doctors and advisors can be overwhelmed with other clients, it is important to try and contact them as soon as possible. The most current and standardised accommodations for chronic pain include extended time on exams, note-takers, and extensions on assignments (should the professor agree it is appropriate). Some accommodations can be made, but always by request. These can include, for example, priority in accessing course registration for making your schedule. Discussions with one's professor may help to evaluate if the assignments are manageable, and also to assess whether asynchronous learning is an option. There are also technologies available such as speech-to-text or read-a-loud that can be of assistance. Some educational organisations have even looked into robots to allow students to participate remotely.

Here are certain organisations to consider when preparing either yourself or someone with chronic pain for college education.

| Organisation | Contact | Website |
|---|---|---|
| **AQEIPS** – Quebec Association for Equity and Inclusion in Post-Secondary Education | **Telephone:** 514-499-9451<br>**Toll-Free:** 1-866-959-9451<br>**Email:** info@aqeips.qc.ca | AQEIPS<br>Facebook |
| **NEADS** – National Educational Association of Disabled Students | **Telephone:** 613-380-8065<br>**Toll-Free:** 1-877-670-1256<br>**Fax:** 613-369-4391<br>**Email:** info@neads.ca | NEADS |
| **Gouvernement du Québec** – Support services for college students | N/A | Getting started at college for students with disabilities |
| **AHEAD** – Association on Higher Education And Disability | **Telephone:** 704.947.7779<br>**Fax:** 704.948.7779 | Association on Higher Education And Disability |

| | | |
|---|---|---|
| **AQICESH** - Association québécoise interuniversitaire des conseillers aux étudiants en situation de handicap | **Email:** aqicesh@gmail.com | AQICESH |
| **DO-IT** - Disabilities, Opportunities, Internetworking, and Technology | **Telephone:** 98195-4842<br>**Toll-Free:** 888-972-DOIT (3648)<br>**Fax:** 206-221-4171<br>**Email:** doit@uw.edu | DO-IT |
| **Swivl** - The Automation Platform for Self Storage | **Telephone:** 1-888-837-6209 | Swivl |

## RECOMMENDATIONS

Y4Y Québec recommends:

- Increase access to services such as workshops and bootcamps for students with chronic pain to educate them on the tools available to them;
- Introduce scholarships for disabled students that suffer with chronic pain;
- Improve physical accessibility protocols for those with mobility issues, i.e. revising protocols to access the university's shuttle bus, etc.;
- Increase provincial funding for nonprofit and academic studies on Chronic Pain;
- Increase provincial funding for initiatives to help those suffering with chronic pain or scientific initiatives such as the Quebec Pain Research Network;
- Boost funding for educational institutions from the provincial government so that they can provide better infrastructure in their education buildings in the context of Universal Design Learning (UDL).

# IMPORTANT NOTICE

The author and Y4Y Québec respect the wishes of the contributors to this report, and have maintained their anonymity. The views shared herein do not necessarily reflect the views of the educational institutions studied, nor do they reflect the views of Y4Y's funders or partners.

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