

Discussion Paper

Episodic Disabilities and Post-Secondary Education

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Realize works to improve the daily lives of people living with HIV and other episodic disabilities. Since 1998, we have been a leader and a catalyst for improved access to rehabilitation services, including mental health services, for people living and aging with HIV and other episodic disabilities.

People with HIV and other episodic disabilities can face significant challenges to living well and living fully. We focus on understanding these challenges and how rehabilitation – including care, treatment and support – can manage them.

We believe that people living with HIV and other episodic disabilities can be better supported as they live and age. Rehabilitation is the most powerful and direct tool by which to enable positive changes for people.

Realize is membership-based, with individual and organizational members across the country having a say in the organization's direction. In addition we have a national constituency of people we reach annually through our courses, and think tanks of 3400, who apply their learnings working within a wide range of community-based organizations, professional associations, care centres, clinics, and research groups.

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Introduction

In 2018, **Realize** received funding from the Government of Ontario to develop training to raise awareness of episodic disabilities within the post-secondary sector in Ontario. This discussion paper was written to summarize work-to-date and inform an Ontario Summit held on October 3, 2018. The project is entitled “**Fostering Inclusion and Environments of Support for Students with Episodic Disabilities (FINESSED)**”.

Increasing Needs

As the numbers of students seeking accommodations for invisible and/or episodic disabilities increase, we must consider how to raise awareness within the post-secondary sector. This discussion paper outlines issues identified in previous research and reports results from a scan undertaken for this project related to the educational experiences of students living with episodic disabilities in post-secondary education. This discussion paper is not to be considered an exhaustive list of issues. It is instead to be considered a jumping off point for future discussions aimed at better understanding the range of issues encountered by these students, as well as the ways in which the current system can support or impair student accomplishments.

Episodic Disabilities in a Post-Secondary Education Context

In 2015-2016 **Realize** conducted an extensive literature review related to students with episodic disabilities, a survey of Disability Services Staff and students with disabilities, and key Informant Interviews with Faculty/Instructors. The following issues were identified through this work:

Little is known about Students with Episodic Disabilities

The Episodic Disability Network defines episodic disability like this: “Episodic disabilities are long-term conditions that are characterized by periods of good health interrupted by periods of illness or disability. These periods may vary in severity, length and predictability from one person to another.” **Realize** has worked with cross-disability partners on issues related to episodic disability since the early 2000’s. Episodic Disability is a relatively new concept. Many of the conditions associated with episodic disabilities are health conditions that have been known as chronic illnesses. This complicates efforts to find appropriate data in academic and grey literature.

As well, while there is some data related to the prevalence of episodic disability-associated conditions among Canadian youth, there is no equivalent data on to the prevalence of episodic disability-associated conditions among Canadian post-secondary students.

We know very little about students with episodic disabilities. We don't know how many students in Ontario live with episodic disabilities.

Estimated Prevalence of Episodic Disability in the Canadian Population

Table 1 provides some estimated data about the numbers of people with episodic disabilities but does not specify the numbers of students with episodic disabilities (Harrison, 2015).

Table 1: Estimated Prevalence of Episodic Disability-Associated Conditions in the Canadian Population

Condition	Number of Persons	Prevalence (%)	Age Range	Year
Arthritis	14,436 ^E	0.7 ^E	12-19	2011-2012
	197,707	2.9	20-34	
Asthma	356,249	11.0	12-19	2011-2012
	650,157	9.4	20-34	
Bipolar Disorder			15 to 24	2012
Lifetime	177,597	4.0		
12-mo	109,967	2.5		
Diabetes	15,492 ^E	0.5 ^E	12-19	2011-2012
	59,603	0.9	20-34	
Epilepsy	128,581	0.4	All Ages	2010-2011
Hepatitis C	138,600	0.5	14-79	2007-2011
HIV	78,511 ¹	--	All Ages	1985-2013
/AIDS	23,111 ²	--		1979-2013
Major depression			15 to 24	2012
Lifetime	474,311	10.7		
12-mo	315,928	7.1		
Migraine	604,000	8.1	12 to 29	2010/2011
Mood disorders			15 to 24	2012
Lifetime	565,175	12.8		
12-mo	362,604	8.2		
Multiple sclerosis	93,535	0.3	All Ages	2010-2011
Pain or discomfort by severity, moderate or severe	128,813	4.0	12-19	2011-2012
	546,235	7.9	20-34	
Schizophrenia	63,568 ^E	1.4 ^E	15 to 24	2012

^E Data with a coefficient of variation (CV) from 16.6% to 33.3% are identified as follows: (E) use with caution.

¹ A cumulative total of 78,511 HIV cases have been reported to Public Health Agency of Canada (PHAC) since HIV reporting began in Canada in 1985

² From 1979 to December 31, 2013, a cumulative total of 23,111 AIDS cases have been reported to PHAC.

Bias against Invisible and Episodic Disability

The literature review undertaken in 2015 identified bias against students with episodic disabilities that included Internalized stigma, as well as bias from:

- Other students
- Faculty

- Disability services staff

Students with episodic disabilities avoid disclosing their disabilities to other students as they are concerned their classmates hold negative attitudes towards people with disabilities. Students with disabilities also worry that their accommodations will be viewed by their classmates as unfair. Students with episodic disabilities say they have been even excluded from group work because classmates think they may be unreliable.

The literature review revealed evidence of academic faculty regarding common accommodations for episodic disabilities – like flexible deadlines, scheduling and attendance – as threatening to standards of “academic integrity.” Accommodations for students with episodic disabilities were often viewed as “unfair” to students who did not receive accommodations, and some faculty believed students to be faking their conditions or exaggerating symptoms.

Finally, the literature suggests that disability services staff may also lack knowledge about episodic disabilities. Harrison and Wolforth’s study of university and college disability service offices across Canada found that 10% of staff believed that between 10% and 25% of students were lying about their impairments or exaggerating their symptoms in order to gain an advantage (2012).

Eligibility for Accommodations among Students with Episodic Disabilities is Problematic

Access to accommodations in the post-secondary sector is strictly limited and extensive documentation from health care professionals is usually required. When flares are infrequent and/or unpredictable, as is inherently the case for people living with episodic disabilities, requirements for documentation to be provided before being able to access accommodations means that students can go months without needed supports which can have a significant impact on their academic success.

In the literature, some post-secondary institutions propose that students with episodic health conditions should primarily be considered under regulations allowing for accommodations on the basis of medical or personal crises, instead of under the policies and procedures that exist for students with ‘permanent’ disabilities.

Students with Episodic Disabilities may pay significantly more for their education as a result of per-semester fee structures.

Financial Issues are Common for Students with Episodic Disabilities

Several significant financial issues for post-secondary students with episodic disabilities appear in the literature.

Many students with episodic disabilities have needed at times to take a reduced course load. In institutions where fees are organized according to a pay per-semester structure, this adds substantially to the overall cost of their education. Students who are forced to quit their courses due to a symptom flare-up taking place after withdrawal deadlines may not be able to get a refund of tuition fees. Sometimes partial refunds are available to students withdrawing for medical reasons, but not always. Students in some institutions are also able to appeal decisions related to refunds when they are withdrawing from courses for medical reasons.

Students with episodic disabilities who are in receipt of provincial student loans may also find themselves in an “overpayment” situation in the event that they withdraw from school. “Overpayment” status can mean that they are ineligible for any additional loans. Overpayment status can also mean that a student is unable to register again until they address the outstanding balance.

At many universities, the scholarships that are available are mainly intended to support full-time students. Students attending part-time have very few scholarship opportunities available to them. Health insurance, an important support for students living with episodic disabilities, is usually only available to students who are attending “full-time”. The unintended consequence is that when students with episodic disabilities are ill and most need supports is ironically when they may also have to reduce their course load and inadvertently make themselves ineligible for student health insurance and related programs.

Student Survey 2016

Our 2016 Student Survey results are limited in that the number of respondents was not high; however several significant issues were highlighted by respondents. Up to one third of student respondents reported never having asked for accommodations because they didn’t “feel comfortable”. The accommodations respondents reported they would most benefit from were:

- Open course scheduling
- Generous course extensions
- Open assignment deadlines

- Flexible re-scheduling of final exams... or an offering of courses that do not have rigidly scheduled final exams
- Self-paced self-learning content/courses
- Online or video delivered courses
- Ability to challenge an exam when caught up

Other issues related to accommodations included difficulties associated with the need to supply specialist documentation in order to access accommodations. The unpredictability of their health conditions combined with the fact that health specialists frequently have long waiting lists results in students missing significant periods of their academic year without accommodations, waiting for access to specialists.

“The one specialist has a 3 month wait list, so if the medical issue crops up, I then need to wait 3 months until I can see the specialist and get them to fill out the paper work the disability service needs, 3 months being way too late for disability services to do anything, this is a major problem with having a condition that is episodic.”

– Student Survey Respondent

Even when able to secure accommodations, students experienced barriers. Several students also reported issues related to professors refusing to acknowledge their need for accommodation. Finally, students acknowledged experiencing additional financial burdens from their non-disabled peers. As one student wrote:

“Due to making up time from being sick, I don't have time to work part time while attending university. So far having been episodically sick and this impacting my education, I will probably end up paying around 25 - 30 thousand dollars more then if I had never gotten sick mainly due to retaking courses, and an additional year of living expenses while not being able to work. I also will be starting my career a year or two late.”

When asked about non-academic accommodations most responses specifically listed a quiet place to rest on campus as being the most helpful. Students reported wanting a private place on campus where they could release stress and rest as the non-academic accommodation that would have the most positive impact on their learning.

Disability Services Staff Survey 2016

Staff surveyed felt confident that they are knowledgeable about episodic disabilities with 80% responding yes to the question “In your opinion, are the staff members at the accommodation / disability services office knowledgeable about the needs of students living with episodic disabilities?” Staff identified several challenges, however, including that they do not receive enough information from health practitioners about student’s disabilities in order to make informed decisions about what “an appropriate post-secondary experience should look like for them”. Information that isn’t provided in a timely fashion is also problematic. They also indicated that some institutional procedures are particularly difficult for students with episodic disabilities including “no refunds for ill grades”. As well, they indicated that the rigid academic term was problematic as many students could complete their courses if they could exceed the end of term.

One staff person indicated that accommodations typically are not implemented after the fact and that students with episodic disabilities frequently present to disability services when they are already in crises. In this case a lack of provision of retroactive accommodations is problematic.

They also said that some faculty attitudes are problematic in regards to students with episodic disabilities. One respondent indicated that members of faculty seem to feel that if students cannot be at 100% they should take the term off, and that these attitudes are most prevalent related to students with mental health diagnoses versus physical diagnoses like MS or Crohn’s and Colitis.

Finally, one staff respondent reported that advisors within the disability services sector also have questions regarding the student’s responsibility to ‘manage their illness’ as it relates to their need for accommodations.

...Each advisor has their own interpretation of "student responsibility" in the accommodation process. If a student has been diagnosed a long time with a condition that is known to have flare-ups, then the expectation by some advisors is that the student should plan ahead to the best of their ability {...}. Other advisors will consistently advocate for the student regardless of whether or not the student has demonstrated that they have made their best efforts to manage disability related symptoms. Holding students with episodic disabilities accountable seems to be a very grey area.”

-Staff Survey Respondent

Faculty Key Informant Interviews 2016

A number of key informant interviews were undertaken with faculty. It was found that almost all interviewees struggled to identify “episodic disability”. Once a definition was provided, many interview participants were able to identify times when they had worked with students who had episodic conditions, however, they had never received any training on episodic disability. To the best of their knowledge, their institutions did not have a standardized definition of “episodic disability” that any interviewees had ever encountered. Interviewees also expressed a lack of knowledge regarding appropriate accommodations. Some interview participants spoke of students who did not understand their condition as a disability and relied on professors to navigate the situation of accommodation on case-by-case basis. Several faculty interviewees spoke of a tension between academic integrity and student accommodations; concerns over wanting to support students but, also wanting to make sure things were fair were expressed.

FINESSED Project Scan 2018

Methodology

Understanding where the post-secondary education sector is currently at in terms of relevant policies and procedures related to supporting students with episodic disabilities is integral to the development of training on the issue of episodic disabilities. In order to address this question, a scan was undertaken by **Realize** that examined the provision of services to students living with episodic disabilities based on policies and documentation available on the websites of all universities and 3 colleges in Ontario.

Institution websites were reviewed for evidence related to the following questions:

- Do universities and colleges have disability related services for students?
- Did current policies and procedures for accessing accommodations on campus include and/or recognize “episodic disabilities”? The scan included looking at documentation related to types of disabilities institutions acknowledged and in terms of the prognosis expected.
- What information is required to access accommodations? The larger blanket of episodic disability includes mental health conditions, as many can manifest in unpredictable and recurrent ways. This scan also sought to understand if students with mental health disabilities were required to provide a diagnosis of their condition to access accommodations or were they able to report on functional limitations instead, as recommended by the Ontario Human Rights Commission (http://www.ohrc.on.ca/en/news_centre/new-documentation-guidelines-accommodating-students-mental-health-disabilities)

A table was produced documenting the evidence collected. As well, links to documents related to required documentation and accessibility/accommodation policies are included in the scan.

Scan Results

Disability Services are Available

All universities and colleges sampled do have offices dedicated to supporting students with disabilities through accommodations when needed.

Episodic Disability Conceptualization is not Consistent across Institutions

Recognition of “episodic disability”, where it exists, occurs in a wide variety of ways and is used to indicate many different things. Several institutions do not reference episodic disability at all in any of their publicly available documents. A number of institutions reference “episodic” on their student documentation forms, in order to allow the student to designate a prognosis or to indicate the duration of expected disability. In some cases, the term “episodic” is used as an indicator to differentiate between whether condition is permanent or temporary with episodic being considered ‘not permanent’ in at least one case. Other institutions say explicitly that a permanent disability can have episodic symptoms and provide options to select this. The designation of episodic disability as not permanent is a significant finding as most institutional policies only provide accommodations to students with permanent disabilities. Ironically, most episodic disabilities are permanent and chronic health conditions that have episodic flares in symptoms so there is a mismatch between this understanding of episodic disability and the conceptualisation of episodic disability as temporary.

Medical Disability Applicability

When thinking about the types of conditions that are considered by the Episodic Disability Network to be ‘episodic’ (see: http://episodicdisabilities.ca/docs/EDN_Episodic_Disabilities_List_2015.pdf), there is some consistency to how these conditions are classified or considered from institution to institution. For example, a student living with HIV at Carlton would fall under consideration within the “Chronic Medical Disability” category, and at the University of Toronto, the same student would be considered under their Chronic Medical Condition category. However, within the ‘medical disability’ categories it is not always possible to indicate that some permanent and chronic health conditions can manifest episodically.

Requirement for Diagnosis Disclosure

Across the board, all institutions require medical documentation of disability in order to access accommodations. There are some exceptions related to mental health disabilities, however students living with other episodic disabilities are required to disclose their diagnosis through documentation forms filled in by both themselves and by medical professionals. It is important to note, for example, that in all cases of a student living with HIV seeking accommodations in an Ontario post-secondary institution, the person living with HIV would be required to disclose their diagnosis as a condition of accessing accommodations. In employment settings it is generally acknowledged that diagnosis is not required for accommodations; this is in stark contrast to the requirement for diagnosis understood as standard procedure in the post-secondary sector.

Need for Diagnosis Inconsistent as related to Mental Health Disabilities

Mental health conditions have traditionally been included under the umbrella of 'episodic illnesses'. In 2017, a human rights complaint was brought against York University by a student with a mental health condition, who argued that the requirement to disclose a DSM V diagnosis as a condition of being able to access accommodations was discriminatory. The OHRC intervened in this case and a settlement was reached. As a result of the complaint and also resulting from research that was undertaken at the same time, the OHRC recommended that post-secondary institutions in Canada no longer require a DSM diagnosis in order to access accommodations. They also made additional recommendations aimed at addressing potentially discriminatory practices impacting students living with mental health conditions.

These are below:

1. Eliminate mandatory disclosure of diagnosis
2. Provide interim accommodations
3. Accommodate temporary mental health disabilities
4. Consider retroactive accommodations where appropriate
5. Arrange for accommodation through centralized process
6. Implement clear communications and training

Although all of these recommendations are relevant to equitable access to accommodations, our scan looked only at whether or not a diagnosis was required to access accommodations for mental health conditions. Again, a lack of consistency characterizes these findings. Some institutions have substantially overhauled their accommodation processes and make clear that they are only interested in understanding the functional limitations associated with a mental health condition and reference the

OHRC measures. Others reference the measures, and let students know that a diagnosis is not required, but ask for it anyway. Among the reasons given for the diagnosis request are that students will not be able to be considered for OSAP without a diagnosis and that knowing a diagnosis means that accommodations will be better suited to their needs. Both of these reasons are untrue; OSAP no longer requires a mental health diagnosis, just documentation that indicates that the student is experiencing a mental health related condition, and as the OHRC and others have asserted, knowing a mental health diagnosis does not mean better accommodations will be provided. From person to person, a mental health condition can manifest in highly personalized ways. There are still institutions that require a mental health diagnosis and do not indicate that the student can choose to opt out of this.

FINESSED Project Survey Results 2018

In 2018, faculty and staff in Ontario post-secondary institutions were surveyed by *Realize* regarding their knowledge of episodic disabilities. Sixty (60) respondents replied to the survey with all indicating that there is a considerable knowledge gap related to students with episodic disabilities and very little training provided.

The largest percentage of respondents were professors/teaching staff (48.33%), with administrator and/or program staff within a post-secondary institution (28.33%), and staff within the Office for Students with Disabilities (10%) also responding. A number of individuals identified as Other (13.33%), including members of academic organizations and social workers.

The majority of respondents (81.67%) were familiar with the term “episodic disabilities”, and also acknowledged teaching/assisting students with episodic disabilities (93.33%). Respondents also noted that staff are Not (40%) or are only Somewhat (48.33%) knowledgeable about the needs of students with episodic disabilities. Faculty knowledge of episodic disabilities was also rated quite poorly, with Not (38.33%) and Somewhat (46.67%) again being the majority answers.

Training on episodic disabilities does not seem to be available, as the majority of respondents answered No (50%) to a question inquiring about whether or not staff/faculty received training on episodic disabilities.

Finally, an overwhelming majority of respondents answered Yes (76.67%) to the question “Is there stigma associated with episodic disabilities?”

This recent survey clarifies our earlier findings that staff/faculty in post-secondary institutions in Canada struggle to understand the needs of students with episodic disabilities. This is at least in part due to a lack of training opportunities. Considered against a backdrop of stigma being associated with episodic

disabilities, this lack of awareness is particularly concerning for students with episodic disabilities hoping to succeed in their post-secondary endeavours.

**“In a way it is easier when someone is off and then permanently back,
rather than away on and off.”**

FINESSED Project Survey Respondent

FINESSED Project Next Steps: An Ontario Summit on Episodic Disability and Post-Secondary Education

This scan is intended to inform the development of an online training course for staff and faculty in Ontario’s post-secondary education sector about students with episodic disabilities, in order to raise awareness of the impact these largely invisible disabilities can have on education. The project intends to hold a summit as well to further explore the issues to be addressed in the training to be developed. At the upcoming Ontario Summit on Episodic Disability and Post-Secondary Education, set for October 3rd at the Wellesley Institute in Toronto, invited participants will be asked to consider this Discussion Paper and contribute to the development of content for an upcoming online training to be developed as part of this project that can address the staff/faculty knowledge gaps on this important issue. Participants are asked to consider the following questions in advance and be prepared to speak to them in the day’s discussions.

Questions for Discussion:

What are the priority issues related to raising awareness of episodic disabilities in the post-secondary context?

What one action would you recommend to raise awareness of issues impacting students with episodic disabilities?

What are the most important points to make in any training intended to raise awareness on this issue?

What can post-secondary institutions do to make navigating programs and services easier for students with episodic disabilities?

What do professors, instructors and teachers need to know about students with episodic disabilities?

References:

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