

Exclusionary Inclusion?: The Realities of Academic Accommodation at  
University for Students with Invisible Physical Chronic Conditions

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## **Abstract**

The following thesis is a case study that discusses the various impacts of academic accommodations for undergraduate students who self-identify as having invisible physical chronic conditions (IPCCs). This research draws on qualitative data from interviews with undergraduate students and academic accommodation centre staff. Using a symbolic interactionist perspective, I explore why students who identify as having IPCCs either use, or do not seek out, academic accommodations. I investigate how students' identities are impacted, arguing that there is negative impact on identity for some students, particularly vis-a-vis how they are viewed within the University community. The research further uncovers the current academic accommodations system's challenges, and opportunities for positive change in terms of improving the access and experience of academic accommodations for students. The research discusses the concept of the "continuous assessment" model as an alternate design and practice of academic accommodation that arguably would benefit all post-secondary students.

Keywords: disability; invisible physical chronic conditions; academic accommodation, university; biomedical model

## Acknowledgements

The research for the thesis took place on unceded Algonquin territory.

I once heard a quote that struck me, and it went something like this: “If you haven’t yet read the book you want to read, you have to write it”. In my research of the literature within the field of critical disability studies, I had not come across the research I was most interested in reading, therefore, I embarked on my own research to answer my lingering questions.

This thesis research is dedicated to those who self-identify as having an invisible physical chronic condition(s) whether they identify as disabled or not. I owe my participants, both students and staff a big thank you. Without your voluntary participation, this research would not have been possible. I also would like to extend my appreciation to my committee members: Dr. Michael Mopas and Dr. James Deaville, who took the time to listen to my interests and supported me through the thesis process. To Dr. Jesse Stewart thank you for your thoughtful input as my external thesis examiner.

When I interviewed the staff at the academic accommodation centre, I observed that these women were some of the most compassionate people that I have met. They genuinely cared deeply about the students who they saw on a daily basis. They truly showed me how much they cared about the success of “their” students and it was very obvious that each of these individuals were dedicated to their jobs and had a passion for helping students. These staff members were clearly committed to their profession, and it was evident that they love what they do for a living. I do not believe their job is necessarily easy all of the time; in fact, they shared with me some of the on-going bureaucratic struggles they faced in their career; but it was obvious that these staff members do their very best to help students at the University in any way that they can.

Thank you to my Mom, Dad, and Lochlann for their loving support throughout my Master of Arts Degree, and to my graduate peers; Hanna Stewart, Olivia Stavretis, Kat Huybregts, Stephanie Rocha, Natalia Manning, and Rowan Murphy who motivated and gave me advice many times. I could not imagine traveling the graduate school journey without such incredible scholars in the making.

The writing and editing of this thesis took part largely through unprecedented times, during the pandemic of the COVID-19 virus. As challenging as these times were, -overall COVID-19 had a more personal impact on me. I sadly lost my grandmother to COVID-19. Then, to have the unthinkable occur in my home county of Colchester, Nova Scotia. The 22 victims of the worst mass shooting in Canadian history happened literally, “down the road” from my home. I have never been prouder to be from Colchester County, we are, and will continue to be Nova Scotia strong. To say that it was challenging to complete the thesis among all of the tragedies is an understatement.

To the faculty throughout my undergraduate degree who made me realize that the themes of my research for the thesis I pursued were real and legitimate, I thank you for pointing these out. Thank you, Dr. Riley Chisholm, for the advice you gave me as I wrote my undergraduate thesis. The advice continued to be very helpful at the graduate level. You encouraged and motivated me to want to continue my research within this field at the graduate level.

“Disability is not only here, it is everywhere and is so even when we ‘see’ it nowhere.”

-Rod Michalko

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## **Prologue: The Promise Versus the Reality of Academic Accommodations**

*The following prologue is from primary research completed on a similar topic from the researcher's undergraduate thesis.*

It was the beginning of their second semester of their first year at university. They knew they needed assistance moving forward in their studies. They had deferred their December examinations until January, because they did not feel well enough to write the examinations as originally scheduled. Deferring the examinations was out of necessity and not a choice they really had. Moving forward into the second semester of university, it was recommended to them that they should seek out academic accommodation. They did not even know what academic accommodation was. They figured accommodation was for students who had previously established accommodation in high school, and needed continued support for such issues as dyslexia, or attention deficit hyperactivity disorder (ADHD). They never thought academic accommodation could be for someone like themselves, who had just graduated from high school with awards and distinctions. They had no idea that academic accommodation was also for students who lived with invisible physical chronic health conditions (IPCCs) and never had any type of assistance in school before.

In the academic accommodation office, while meeting with a coordinator, information was being thrown at them. While the coordinators were well intentioned, the student seeking help was simply overwhelmed. They were in recovery from a difficult flare-up,<sup>1</sup> and at the time, they were barely able to get through their days. The best way they could describe how they were

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<sup>1</sup> A flare-up is an unexpected exacerbation of a medical condition.

feeling to others was that it felt as though they were “trying to swim through thick white liquid glue”. They felt horrible, but they looked “fine” on the outside. They were living with an IPCC.

At this initial meeting at the academic accommodation centre, it was the first time they ever heard the term disability associated with themselves. They never had any medical professional tell them they had a disability, and they did not self-identify as living with a disability. They lived with a chronic invisible physical condition; they knew that they had a flare-up, and it was going to take some time before they would be able to recover from it, but they also knew it was not going to feel like this forever.

“Did they have a disability?” They kept contemplating whether this was true. Academic accommodation administrators seemed definite that they were a disabled individual and told them so. They began to consider if they were, in fact, a person with disabilities. They had never previously considered themselves to be a disabled person, but now they were being told that they were. Talk about an identity crisis! They were really at a loss as to how they should identify. Someone was telling them to identify as having a “disabled identity,” but this did not seem to fit with how they or their family and friends viewed them. At the time, they questioned whether they did have a disability and after a while, and some serious thinking, they realized that they were not disabled, they were simply a person who lived with a chronic invisible physical health condition which for most of their life did not impact them at all, but that for right now, they needed help.

As the semester continued, they did receive support from the academic accommodation centre, but it was not the solution they had hoped for. They felt stripped of their self-identity (the way they wanted to be known by others), and they had been categorized by the university into a group which many people in society believe is less desirable... “the disabled”. They were now

known as a student with a “problem”, who was not “good enough” to be able to take classes without some kind of academic accommodation support. Some classmates snickered at them when they wrote their tests in another space away from the rest of the class. They were singled out and literally pointed at by professors. They even had one professor tell them that they should have written the midterm longer in page length because they had received “special accommodation”.

It is an understatement to say that they felt stigmatized. Their identity had been stolen by the very institution they had paid to attend. They never wanted to be singled out, to be labelled, to be segregated from their classmates, or given a new identity. These were some of the “outcomes” of receiving academic accommodation. They were furious, but they were too ill at the time *not* to receive the support from academic accommodation. They were also irritated at the “unintentional impacts” that these “accommodations” were having on them. When they felt well enough that they did not need the academic accommodation, they immediately stopped all “supports” and entirely disassociated themselves from the centre. However, they soon realized that the damage academic accommodation had created for them was still going to haunt them. The professors still knew them as the student who needed “accommodation”, and the classmates still knew them as “the one who needed ‘special treatment’”. They felt permanently labelled and could not rid themselves of that “disabled” label, identity, and feeling. Accommodations became their own personal Hobson’s choice (Glenn 1994). They could either accept the accommodations and various labelling issues that arose from the accommodations, or receive no accommodations at all, which would have resulted in poor academic performance. Therefore, there really was no other alternative for them, --they needed academic accommodation at university.

## Chapter One: Introduction

Through the activism of disability rights organizations such as the Council of Canadians with Disabilities<sup>2</sup>, we now have accessibility and inclusivity standards in Canada which must reflect equality for people with any type of disability. What emerged as one outcome of disability rights advocate groups were new initiatives to make education more inclusive (Jung 2003: 94).

One initiative that was developed specifically for post-secondary education was the more widespread establishment of academic accommodation centres in the 1980s and 1990s (Jung 2003: 100). Academic accommodation centres provide services where post-secondary students with documented disabilities may receive various types of support to help them succeed in university. The types of support the academic accommodation centre can provide usually include: writing tests and examinations in an alternate location (for example, a quieter setting away from the classroom) or typing on a computer, (rather than writing by hand), having ergonomic furniture in the classroom or test setting, or having a note-taker during lectures. These supports are designed to “level the playing field” at university for students who have documented disabilities. Documented disabilities that are considered “acceptable” in order to receive support from the academic accommodation centre include<sup>3</sup> visual impairments, learning disabilities, hearing impairments, medical disabilities (such as fibromyalgia, arthritis, epilepsy), acquired brain injury, mental health disabilities, autism spectrum disorder, attention deficit/hyperactivity disorder (ADHD), and documented disabilities requiring service animal access to buildings on campus (The Academic Accommodation Centre 2019).

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<sup>2</sup> The Council of Canadians with Disabilities is a disability rights organization which was formed in 1976 by people with disabilities.

<sup>3</sup> This list of disabilities is from the academic accommodation centre website.

## 1.1 Overview of the Research Topic

According to the academic accommodation centre staff I interviewed, ninety-percent of the “disabilities” students have who seek out academic accommodation at the University academic accommodation centre where I conducted my research are invisible, conditions that cannot be seen by observing the individual. For a post-secondary student to receive academic accommodation, the student must provide medical documentation of their disability or disabilities and the documentation must indicate how the students’ disability or disabilities limits his or her academic potential. The medical documentation must be current and from a medical professional such as a family physician or medical specialist, who is in an established doctor-patient relationship with the student. The process of documenting a student’s impairment(s) by a physician relies on what is known as the biomedical model.

The biomedical model is used by physicians to diagnose individuals with medical conditions (either acute or chronic), and the physician in turn treats the condition(s). This custom of practicing medicine from a biomedical model perspective is especially prominent in Western countries (Clarke et al. 2003: 162). Biomedicine focuses primarily on curing and fixing the sick and by doing this, Wendell argues that the approach has a tendency to overlook people with chronic illnesses (Wendell 1996: 94). Simpson similarly argues that Western medicine and hospitals are still largely organized around acute, episodic illness and injury, rather than chronic conditions (Simpson 2012: 328).

Within the critical disability studies literature there is research discussing “chronic illness” (Jung 2002, 2003; Lewis et al. 2016) and other research discussing “invisible disabilities” (Kattari et al. 2018; Mullins and Preyde 2013). In my research, I am bridging these two similar terms together, and focusing on particular chronic conditions, which I call invisible

physical chronic conditions (IPCCs). I interpret the word “invisible” to mean that the chronic condition is largely not seen from the outside in ordinary social contact with someone. For example, an individual living with lupus lives with an “invisible” condition. There may be times when the condition has a flare-up, and the condition may become visible in ordinary social contact. If the condition is episodic, however, flare-ups are often unpredictable and may only occur rarely (Lightman et al. 2009). For example, someone with diabetes may have an exacerbation of their condition, and it becomes “visible” because they require an insulin pump (the insulin pump making the condition visible). In another example, a person with arthritis may have a flare-up and their joints could become visibly swollen, making the condition visible. By using the term “physical conditions”, I focussed on students who self-identified as having physical conditions, not conditions associated primarily with a psychosocial disability. For example, I did not interview students who identified as having an anxiety disorder, which is considered a psychosocial disability (Anderson et al. 2015). However, I realize that there is often an overlap with people who have a physical condition(s), who may also have a mental health issue associated with their physical condition(s).

Finally, I want to clarify what is considered a chronic condition as opposed to a debilitation that should improve over time. Chronic conditions or chronic illnesses are long lasting and not necessarily curable, but sometimes treatable. The illness(es) often have an unpredictable nature and may worsen over time (Lorig et al. 2007: 2).

## **1.2 Research Questions**

As reviewed in the prologue, my earlier research compelled me to conduct further research to discover unanswered questions about the circumstances of students who have IPCCs at university. The prologue helped frame my research questions because I wanted to know if the

experiences the student had were also experienced by other students in a similar circumstance. I was also interested in the following research questions because I had been a witness during my undergraduate degree to some of my fellow peers be singled out by our professor (in front of the entire class) because those students received academic accommodation. I was curious how those students felt being labelled in front of everyone.

This thesis addresses the following question: **why do some undergraduate students who self-identify as having an IPCC(s) *not seek out* academic accommodation? And, of the students who self-identify as having IPCCs *and do seek out and use* academic accommodation, what are their experiences with academic accommodation?** From this broad question, there are three subsequent research questions that follow. The first relates to the theme of identity: namely, how are students with IPCCs managing their “public” identity within the University community?

The second relates to any weaknesses in the university academic accommodation model, from the perspectives of both the student and the staff participants. Further, what changes to the academic accommodation model do staff at the accommodation centre recommend, and why. Within this discussion, I offer an example of a model of “continuous assessment” which has gained interest in some European countries (Bjælde et al. 2017). The third and final research question that mirrors the above question for the staff is what would *students* desire to change about academic accommodation, and why?

### **1.3 Thesis Arguments**

In this thesis I make the following three arguments. First, I argue that concerns of students’ self-identity (while they are registered as a student at the academic accommodation centre) are not fully considered by the academic accommodation centre; and the provision of

academic accommodation can compromise a student's identity within the University community. Second, I maintain that students who live with IPCCs must negotiate between two positions, and that is whether they identify as disabled or not. Third, I argue that students who live with IPCCs and *seek out and use* academic accommodations are categorized and labelled into a category of disabled students by the University. This group sorting may be stigmatizing for those who receive academic accommodations. This negotiation of identities continues throughout the entire time a student is registered with the academic accommodation centre.

In the second analysis chapter, Chapter Four, "Limitations of Academic Accommodation Services", I also present three arguments that relate to barriers that the academic accommodation model creates. While the academic accommodation centre purports to assist students, the model used within its structure creates barriers for the students. First, I find that one of the key weaknesses of the biomedical model is the requirement for physician verification of IPCCs and that this creates an access barrier for students seeking support at university. A physician with an established relationship with the student must have evidence (usually by performing testing) that the student actually does in fact have an IPCC(s). Second, I show that the staff who work at the academic accommodation centre experience systemic bureaucratic challenges in their day-to-day work. And, finally I argue that the University does an inadequate job in informing students of academic accommodation services and this is a barrier for student access.

## **1.5 Overview of the Chapters**

The following section provides a brief overview of each of the chapters in this thesis. Chapter Two concentrates on describing the methodology and theory used in the development of the thesis. Erving Goffman's symbolic interactionism and his work in *Stigma: Notes on the Management of a Spoiled Identity* (1963) and *The Presentation of Self in Everyday Life* (1959)

are the main theoretical frameworks I use. The methodology for the research uses one-on-one semi-structured interviews, and in Chapter Two I develop the reasoning behind why this method was chosen.

Chapter Three is the first analysis chapter, and here I expand on issues related to identity that were discussed by the research participants. Here I focus on whether academic accommodation support compromises a students' self-identity. We also learn in Chapter Three which students who have IPCCs do and do not identify as disabled. My analysis explores the students' responses to assess why students choose to identify as disabled or not. Finally, Chapter Three describes what we learn from student participants who seek out academic accommodation regarding if they feel categorized and labelled by the University, and whether this is a negative experience.

Chapter Four is the second analysis chapter which will focus on the limitations of academic accommodations from the point of view of both students and staff. Chapter Four will first discuss the weaknesses of the academic accommodation centre. Secondly, we will hear student and staff perspectives on the current model for accommodating students and learn from them how best to address systemic issues. Finally, Chapter Four addresses a gap in communication from university services that student participants acknowledged (academic accommodation services).

The concluding chapter (Chapter Five) will review the key findings and discuss the conclusions of the research, linking both back to the theoretical framework. Chapter Five will offer possible improvements that could be made to enhance support for students who have IPCCs and who need academic accommodation at university. I will highlight some possible improvements for the academic accommodation centre that were mentioned by students. Of

note, these same improvements could improve the working lives for the academic accommodations staff as well. Through a recap of the weaknesses of academic accommodation, I will conclude with some recommendations for how to develop an effective academic accommodation model. I will finally discuss some of the limitations of the current research case study and will highlight some opportunities for further research inquiry.

## **Chapter Two: Methodology and Theory**

This chapter provides a broad overview of the methodology and theory used in the research. First, I will highlight details about why this research is important and the reasons for pursuing the research. Second, this chapter discusses the major research questions that will be addressed by the research. Third, I highlight some of the challenges that I experienced while trying to recruit voluntary participants for this research. Fourth, I explore the details of my data collection and some of the strategies for the data analysis. Finally, this chapter explores the ethical considerations that I undertook before commencing this research.

### **2.1 Research Methodology**

The research took place at a large Canadian University in the province of Ontario. Throughout the thesis, the University will not be named to protect the privacy of the participants, and consequently, will be referred to as “the University”. The academic accommodation centre at the University will also not be named to protect the confidentiality of staff and students and will simply be called “the academic accommodation centre”. This research included a total of nine semi-structured interviews, all of which took place during the fall of 2019 in a private office or boardroom on campus. Student participants were all voluntary, solicited by posters placed in numerous common areas throughout the University. The criteria for students to participate in the research was that they had to self-identify as having an invisible physical chronic condition (IPCC) and be a current student at the University completing an undergraduate degree. To be interviewed for this research it did not matter if the students were registered at the academic accommodation centre, had *previously* registered at the centre, or had *never* registered at the academic accommodation centre. I also interviewed staff who work at the academic accommodation centre. Staff were informed and invited to participate in the research through a

letter of invitation. The criteria for staff to participate was that they had to be current disability coordinators there.

Five interviews were conducted with undergraduate students (ranging from first to fourth year of study), and four interviews were conducted with academic accommodation centre disability coordinators. The IPCCs identified by the student participants varied, but some had the same IPCC. The table below (Figure One) “Details of the Interviewed Student Participants and their IPCCs” indicates the name of the student (all names used are pseudonyms), the current year of study, the type of chronic condition(s) the student self-identifies as having, and whether the student receives support from the academic accommodation centre.

As shown in Figure One, there are five student participants, four female and one male. Three of the student participants; Rose, Ella, and Lucy, receive support from the academic accommodation centre; however, Lucy does not receive support for her IPCC(s), but rather for her learning disability. Rose and Ella do receive academic accommodation for their IPCCs. Two students, Molly and Max, had never registered for the academic accommodation centre support at the time of their interview.

One student was in their first year of university, another student in their second year, two students were in their third year of university, and one student was in their fourth year. The following IPCCs are conditions the students self-identified as having: fibromyalgia, lupus, non-inflammatory arthritis, irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), chronic pain, scoliosis, psoriatic arthritis, and cold-induced urticaria.

**Table One: Details of the Interviewed Student Participants and their IPCCs**

<b>Name of Student (<i>All names used are pseudonyms</i>)</b>	<b>Year of Study</b>	<b>Name of IPCCs</b>	<b>Student Receives Support from Academic Accommodation for their IPCC(s)</b>	<b>Student does not Receive Support from Academic Accommodation for their IPCCs</b>
Rose	Third year	Fibromyalgia	Yes	
Ella	Second year	-Lupus -Non-inflammatory arthritis -Fibromyalgia	Yes	
Lucy	Third Year	-Irritable Bowel Syndrome (IBS) -"unknown" colitis -Gastroesophageal reflux disease (GERD) -Chronic Pain (from a previous tail bone fracture) -Scoliosis		No, does not receive support for her IPCCs, but does receive support from academic accommodations for a learning disability (which is not an IPCC).
Molly	Fourth year	Psoriatic Arthritis		No
Max	First year	Cold Induced Urticaria (allergy to cold weather)		No

Table indicating student participants' IPCCs and if academic accommodation was received for their IPCC.

There is little research about why undergraduate students who have IPCCs *do not use* academic accommodation. There is literature regarding students who have learning disabilities and mental health issues and the use of academic accommodation at post-secondary institutions for those specific types of conditions (Weis et al. 2016; Quinlan et al. 2012; Sokal 2016). But, overall, the literature lacks research about students who have invisible physical chronic conditions and use academic accommodations. I wanted to know more about why students with any IPCC (which are often common conditions), *do not use* academic accommodation. And, of the students who self-identify as having IPCCs who do seek out and *use* academic accommodation, what are their experiences?

The questions posed to students are similar, but distinct to the questions posed to staff. Student and staff participants were asked different interview questions reflecting their different positions associated with academic accommodations at the University. The staff interviews reveal perspectives on the macro protocols they must follow in addressing the IPCCs presented by students seeking accommodation. Interviewing students and staff within the same topic area provided different perspectives that enriched the data. This topic has not been fully developed within academic literature. In my personal experience of being a young adult in university, much of the focus in recent years at university has been advocating for other invisible conditions (mostly mental illnesses) to be more recognized and less stigmatized among young adults. While it is laudable to have increased support for students who live with mental illness(es), it is also important not to neglect other invisible conditions that are equally important. Thus, the research questions that are addressed in this thesis are new and unique to the broad theme of inclusive education at universities.

## **2.2 Purpose of the Study (Research Problem)**

The rationale for this research is to gain insight into how universities can better accommodate students who have IPCCs. The goal of this research is to learn directly from undergraduate students who live with invisible physical chronic conditions (IPCCs) and discover how they navigate university with, or without, academic accommodation.

In addition to interviewing undergraduate students who live with IPCCs, I also interviewed staff who work as disability coordinators at the academic accommodation centre. Learning of the systemic bureaucratic issues staff experience will help us further understand how academic accommodation centres operate at universities.

## **2.3 Major Research Questions and Themes**

My research will question whether the biomedical model should be relied upon so heavily at university academic accommodation centres in order for students to be approved for the use of academic accommodations. The research suggests that the reliance of the biomedical model at academic accommodation centres (medical documentation of IPCCs) can impact students' self identities negatively. In particular, the research shows that if the student does not desire to be known as "disabled," the "disabled label" can in turn potentially cause stigma. This can result in a situation in which instead of positively "helping" students, the accommodations may result in the creation of a social dynamic where students may experience negative consequences from this "help". I explore these themes in my student interviews. Further, staff at the academic accommodation centre also have to rely on the medical documentation from students' physicians before they can provide academic accommodation to students, and this can in turn cause delays because some students may not be able to access their physicians in a time-efficient manner to receive the written documentation of their IPCC(s).

The research contributes to our understanding of an alternative model (continuous assessment model) that academic accommodation centres could rely on instead of the biomedical model. I inquire what students and staff would change about the current biomedical model. The students and staff I interviewed for this research provided some recommendations for different practices and ways to receive academic accommodation. Other issues my research addressed include some of the consequences that arise because universities rely on the use of the biomedical model. For example, something which the biomedical model of disability does not account for is the experience of stigma and their potential impacts on the individual (Goffman 1963); this will be explored in this research.

The first research theme I explore is self-identity. Some students with IPCCs self-identify as non-disabled, yet when “accommodated” are thrust into medical validation exercises that can alter students’ self-identity from non-disabled to disabled. I explore how these students “manage” their identity. For example, how are students with IPCCs managing their “public” university identity if they self-identify as non-disabled when they use academic accommodations? Because the academic accommodations centre requires a student to provide medical documentation of their disability, the student is supposed to take on a disabled identity at university whether they want to or not (Mullins and Preyde 2013; Kattari et al. 2018).

I wanted to research how students cope with their (possibly) new prescribed identity and inquire as to whether some may “pass” as able-bodied if a disabled identity is not how they self-identify. “Passing” is a complex issue related to identity (Brune and Wilson 2013). For example, someone may either “pass” as able-bodied or disabled. Someone may desire to “pass” as able-bodied because they may have been exposed to negative social reactions from their peers when they were known as “disabled”. Or a person may desire to “pass” as disabled when they

really do not have a biomedically diagnosed disability in order to get advantages. For instance, someone may try and “pass” as disabled to receive extra time on an examination. My focus on identity helps us understand why some students with IPCCs do not seek out academic accommodation and also helps explain the experiences of these students (with IPCCs) who do have academic accommodations.

The second research theme I explore is the bureaucracy of academic accommodation. What do the staff and students want to change about the bureaucratic system for accommodating students? The questions I am interested in asking the academic accommodation centre staff draw on their experience working and helping students who have IPCCs. How do staff determine if a student is eligible to receive academic accommodation? Have students ever expressed any concerns to the staff with the required documentation of their disability? How do staff handle cases where students do not meet the criteria to receive academic accommodation? Do staff want to change anything with the current system for accommodating students? What would staff want to change? In this section of the research, I seek to understand the reasoning behind the changes recommended by staff and students which helps us explain the experiences of students who use academic accommodation.

In addition to the key research themes above, my research uncovers several other themes, which are highlighted, but not extensively discussed. These include topics related to categorization and labelling and their impact on stigma, masculinity and cultural differences. We discuss the reluctance some students have when considering academic accommodation, and bureaucratic challenges which academic accommodation centre staff experience.

## **2.4 Scope of the Research**

For the purposes of my research, I am choosing not to include mental illness(es) as part of what I consider IPCCs. There are two reasons for this. First, I wanted to distinguish my research from other scholars' work who have published in this area (Mullins and Preyde 2013; Dunn 2019; Marshak et al. 2010; Riddell and Weedon 2014). Second, I wanted to reduce the scope of my research to include a narrower set of conditions, namely those that are invisible and physical such as fibromyalgia, connective tissue disorder, or Lyme disease. I fully recognize that often psychosocial disabilities and IPCCs will overlap with each other. A person who has an IPCC(s) may also have a psychosocial disability, which could be correlated with, or even caused in part, because of the IPCC(s). My observations being a young adult is that psychosocial disability(es) is more widely discussed (especially at university). I agree that psychosocial disability is important to discuss; however, we must not forget these other invisible illnesses (IPCCs) that are still stigmatized and not as widely discussed.

My research is original because it concentrates on a specific group of disabilities (IPCCs) that (as far as I am aware), have not been widely researched. My research contributes to learning more about issues that undergraduate students with IPCCs face at university. With the findings from my research, we will be able to learn which aspects of accommodation policies are currently working well for people who have IPCCs at university. We will also learn where to improve and to help not only students who have IPCCs, but also the academic accommodation centre staff.

## **2.5 Theory**

My thesis is informed by the dramaturgical model as expressed in Irving Goffman's work. In this current research I mainly draw from Goffman's *The Presentation of Self in*

*Everyday Life* (1959) and *Stigma: Notes on the Management of Spoiled Identity* (1963).

Goffman's work is based primarily on symbolic interactionism; symbolic interactionists learn directly from those they research. Learning directly from the point of view of the people whom I am researching was important, and thus, symbolic interactionism was an appropriate theory to use for this thesis research.<sup>4</sup> The participants are the experts of their own experiences, which is why it was fitting to rely on symbolic interactionism throughout this research.

Goffman's theory focuses on the micro aspects of sociology, and I am concentrating on small scale face-to-face social interactions in my research. Particularly, my research focuses on identity management, which Goffman explores in his work. Goffman's "front stage" and "back stage" of dramaturgy are aspects which fit well within my research. In the front stage, we see people socially interacting with others, presenting themselves and their identity a certain way. Within the front stage, people are "performing" in front of others. For example, a person who has an IPCC and receives support from academic accommodation, presenting themselves at the academic accommodation centre, is performing in the front stage in that context. In the front stage, the "audience" is perceiving the performer. The audience in this case may include other students in the academic accommodation centre waiting room as well as academic accommodation centre staff. In contrast, within the backstage of dramaturgy, people are not "on stage" in front of an audience, and as a consequence may be acting more like their true selves. For example, when a person who lives with an IPCC is in the comfort and privacy of their own bedroom within their own home, they are in the back stage because they are not having to perform in front of others. While in the back stage, people are not necessarily acting as an "other" personality, because they are not on display for others to view and perceive. By

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<sup>4</sup> The symbolic interactionist approach is still widely used today in current sociological research (Mullins and Preyde 2013).

including the dramaturgy perspective in my research, we can examine whether students are having to navigate a performance of their identities.

By applying a symbolic interactionist approach, I was able to largely use a “bottom up” method with my participants. The applied community development social activism embodied in the Antigonish movement and exemplified in the practice of the Coady International Institute demonstrates the practice of “bottom up” social inquiry (Johnstone, H. 2019: 16-18).<sup>5</sup> Although they were prompted by interview questions, the participants could decide what they wanted to share or not share during my interview. Knowing my participants were providing data for this research, I also knew that they had some of the power to be able to discuss topics that they thought were important in relation to the topic of IPCCs and academic accommodation.

## **2.6 Sample**

For this research, I completed a qualitative study. The research design incorporated semi-structured interviews with staff at the academic accommodation centre and self-identified student participants who, as described further below, were recruited through posters positioned at the academic accommodation centre and at other prominent locations on campus. An additional strategy to recruit prospective research participants involved E-mailing instructors in various faculties requesting the faculty to bring the information about my participant recruitment to students in their classes.

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<sup>5</sup> Johnstone refers in his book *Boundary Exploration: The Entrepreneurial Experiments of Fr. Greg MacLeod* to applied activist social research from the Antigonish movement in and around Canso, Nova Scotia, in which the people affected by the control of their fishery, both by large banks and large fishing businesses, exerted control over the community’s economy. Through “bottom up” social research conducted by the Extension Department of St. Francis Xavier University through the Coady International Institute, the establishment of a local Credit Union cooperatives and locally controlled fishery operations, established a new business model for the community.

I wanted to recruit approximately eight to twelve participants in total for this research by putting up posters (to recruit student participants) in high use pedestrian areas in buildings on the University campus and at the academic accommodation centre. To recruit staff at the academic accommodation centre, I E-mailed them an invitation to participate. In total, I interviewed nine participants; five undergraduate students ranging from first to fourth year, and four academic accommodation staff. Given the student participants had to be current undergraduate students in their second, third, or fourth year,<sup>6</sup> registered at the university to participate in the research, it seemed logical to advertise for student participants on the campus. I made an exception for one participant who was in their first year of university, as their IPCC qualified for the study and they had meaningful experiences to contribute. I also used the “snowball” sampling method, requesting the student participants I interviewed to let their peers know of the research (Cohen and Arieli 2011). In addition, I E-mailed professors from a variety of departments at the University, requesting that they let their undergraduate students know about my study by posting my electronic poster to their class webpage or by showing my electronic poster during one of their lectures to undergraduates. If students were interested in participating, then I requested (in the poster) that they directly contact me by E-mail.

To recruit staff participants, I sent all eleven of the disability coordinators who work at the academic accommodation centre an invitation to participate by E-mail, asking for two or

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<sup>6</sup> In a previous qualitative research methods course, I interviewed a first-year university student about their experiences with academic accommodation at university. However, this student reflected on their experiences with academic accommodation support in high school, as the student had not yet had experiences with academic accommodation at university, thus the reasoning for primarily recruiting second to fourth year university students for this research.

three voluntary staff participants to discuss their experience working with students who have IPCCs.

## **2.7 The Challenges of Recruitment**

Recruiting voluntary participants for this research was not easy. Given the large student population at the University where I was completing my research, I did not anticipate that finding and getting in touch with participants would be a challenge. As it turned out, maybe the large size of the University was actually a contributing factor to why I had trouble finding voluntary research participants.

Within my ethics application, I received approval to put up posters around the university campus to try and recruit undergraduates. To recruit academic accommodation staff, I wrote an E-mail invitation to the academic accommodation disability coordinators.

### **Recruiting Undergraduate Students**

Unfortunately, in the days after I put up my posters, I walked by the posters and noted that many of my research posters had been covered up by much larger posters. It took seven weeks before an undergraduate student contacted me.

After many weeks had passed and I had only one student participant contact me, in consultation with my supervisor, I decided to buy ten-dollar Tim Horton's gift cards for participants. I felt that having a ten-dollar gift card would encourage the students to participate, and as it turned out, it did. Eventually, by the end of November I had been contacted in total by five voluntary student participants. In the end, I had to turn away potential volunteer student participants as I was still receiving E-mails from potential participants well into the winter semester of 2020, and at that point I had enough participants for this research.

## **Recruiting Staff at the Academic Accommodation Centre**

I knew going into this research that making contact with the staff at the academic accommodation centre in the month of September would be challenging. September is the month when undergraduate students begin classes at the University; thus the disability coordinators are busy meeting with incoming students needing and setting up academic accommodations. I sent the staff a letter of invitation to voluntarily participate in my research. I was very grateful that I eventually received four E-mails from interested staff participants at the academic accommodation centre. I would later learn during my interviews that, as I had expected, part of the reason they were not able to get back quickly to me is because of their high caseloads of students. In total, I interviewed four academic accommodation centre staff, which is a significant number given they currently have eleven disability coordinators.

## **2.8 Data Collection and Analysis**

I collected my data from both students and staff through in person one-on-one semi-structured interviews lasting up to one hour in a private setting, such as in an office or boardroom. With the participants' written permission, for the purposes of transcription, the interviews were recorded using an audio-recording app on my phone, which was password protected.

One of the problems that I anticipated during the data collection was that participants might not exactly fit the criteria for the research. Fortunately this did not happen. All student participants fit my research criteria. And the staff at the academic accommodation centre were all working with students, which was my criteria for the staff participants. Another problem I thought might occur was that students may not have had full vocal capacity to be able to speak during the interview, a situation that also did not occur.

After completing the interviews with all nine of my participants, my next step was to transcribe all of the interviews in a private room where I was the only one listening to them. I then coded and grouped all of the interviews by sorting the quotations from my participants into two main themes, which were issues associated with identity and the limitations of academic accommodations. I coded the data by highlighting it in different colours, each representing a theme of the research. I began sorting quotations from participants by copying and pasting the quotations that belonged to separate themes into independent word documents, ensuring I made note of the pseudonym of the participant next to the quotation.

## **2.9 Ethical Considerations**

Before I had any contact with any potential participants, I had already secured ethics approval from the University's ethics committee. The safety and protection of privacy of the participants and observing ethical research guidelines was important to me. After the ethics committee gave me the approval for the research, I made sure all of my participants signed a consent form before I began the interview with each participant. I provided a copy of the consent form for the participant. The consent form was signed by me (the researcher) as a commitment to the accountabilities I outlined in the form. I also retained a copy of the signed consent forms for my own records, which are stored in my locked desk drawer.

There was no deception involved in my research. I promised and ensured anonymity for each participant by explaining at the outset of the interview that each participant would be given a pseudonym, no participant would be identified, and that all data would be stored on a password protected computer. The transcription recording would be deleted after transcription.

## 2.10 Methodology and Theory Conclusion

From this research I received a range of responses from undergraduate students with IPCCs and from the academic accommodation centre staff. I anticipated that students would draw from their experiences receiving academic accommodations or not and would likely explain both positive and negative situations that they experienced concerning accommodations. I also expected staff at the academic accommodation centre to discuss some of their frustrations with the current system set up to help students at their centre. I also believed that staff at the academic accommodation would explain their concern of the lack of staff to support the number of students that come into the centre and who need and seek support. I further anticipated that some staff may defend the status quo of their work as disability coordinators at the academic accommodation centre.

The knowledge generated from this research will teach us what is and is not currently working to help accommodate undergraduate students who have IPCCs from the perspective of the students themselves.

By hearing the voices of people involved with academic accommodations --the students and the academic accommodation staff --we hear a variety of perspectives. These views provide insight on how best to approach the practices related to academic accommodation, so that we can better support students as well as the academic accommodation centre staff. This research will help highlight the practices that need to be improved to meet the needs of students, and the challenges the academic accommodation centre staff experience in meeting those needs. From the research, we will also discover an alternate approach to help students who have IPCCs, an approach that does not entirely revolve around the biomedical model. As we turn to our analysis of identity, this is framed by our theoretical lens and methodology.

### **Chapter Three: The Complexity of Identity and The Bureaucracy of Academic Accommodation**

In this analysis chapter I discuss the complexities of identity through the bureaucracy of academic accommodation. I investigate how students' identities are impacted by academic accommodations, arguing that there is a negative impact on self-identity for some students. This explanation of academic accommodation and identity begins to explore the central question of why some students who self-identify as having IPCCs do not seek out and use academic accommodation. First, the chapter will explore the self-identity of students seeking academic accommodation, and will further inquire whether its provision can negatively impact a student's identity within the University community. Second, this chapter argues that students who live with invisible physical chronic conditions (IPCCs) must negotiate between two positions, whether they identify as disabled or not. Third, the research highlighted in this chapter argues that students who live with IPCCs and seek out academic accommodations are categorized and labelled for groups of able-bodied and disabled people by the University. As a result, this group sorting is stigmatizing for those who receive academic accommodations. These aspects of identity contribute to our understanding of why some students do not seek out and use academic accommodation.

To unpack this narrative, there will be a discussion of the meaning of self-identity and the process for students to receive academic accommodation at the University. The chapter will hear perspectives from students who have IPCC(s) who were registered at the centre. It will also examine perspectives from students with IPCC(s) who were not registered, and, we will listen to the perspective of four disability coordinators who work there.

The research also uncovered themes of stigma, masculinity and disability, which are cultural barriers in seeking academic accommodation and the “coming out”<sup>7</sup> from the disability closet. These themes, while insightful, were unexpected.

According to the University, 11% of the student population receives support from the University academic accommodation centre. In 2018-2019, the University saw an increase of 375 students register at the centre, which is a growth of 12.4% from the previous year. According to the University’s academic accommodation centre, the purpose of academic accommodation is to “foster equal access to the university experience for students with disabilities while maintaining academic standards through provision of academic accommodations and support services, in partnership with the university community” (The University Academic Accommodation Centre, mandate para 1, 2018)<sup>8</sup>. As I confirmed with the staff during the interviews, the responsibility of the academic accommodation centre staff is to provide adequate support for such a large number of students is significant, particularly when each academic year there is an increase in the number of students registering at the centre without a corresponding increase in staff.

The model that the academic accommodation centre uses relies on the biomedical model of defining, understanding and responding to IPCCs. In a university setting, there are expectations that students should participate in classes and tutorials, complete courses, and pass exams. If a student is unable or unwilling to identify themselves as “disabled” when they really need access to academic accommodation in order to help them succeed, then these university

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<sup>7</sup> When a person discloses that they live with a disability, it can be referred to as the “coming out” of the disability closet discourse.

<sup>8</sup> In order to ensure the privacy of the participants who were interviewed for this research, the name of the academic accommodation centre will not be disclosed and will be known as “the academic accommodation centre”.

expectations may not be achieved (Hibbs and Pothier 2006: 197). This helps inform our central question of why students who have IPCCs do not always seek out and use academic accommodation.

### **3.1 The Biomedical Model**

The biomedical model is the common approach used in Western countries and at Western universities to define and describe disability (Altman 2014, Michalko 2009). Even while alluding to the social nature of disability, it is the medical model that is dominant in contemporary discourses and interpretations of disability. The biomedical model focuses on medical professionals (physicians) diagnosing and curing the sick, a model that neglects to consider those who live with IPCCs who cannot necessarily be “cured” or “fixed” (Michalko 2009: 66; Wendell 2001). In contrast to the biomedical model, the social model of disability frames disability as something which is caused by cultural barriers and the physical environment (Oliver 2004 as cited in Barnes and Mercer 2015: 30). In other words, it is our physical environment which disables some people.

The biomedical model is the dominant way our society validates medical conditions (Jung 2002). And, in the case of academic accommodation, in order to receive it, a person has to provide biomedical proof of their IPCC (Kelepouris 2014 as cited in Grimes et al. 2018: 2). This is the requirement at the University where I conducted my research. Often for a physician to be able to provide the medical documentation, the patient must go through medical testing to biomedically prove the medical condition in question. Providing biomedical proof of one’s IPCC requires the student to secure written documentation from their doctor which must describe the functional limitations the student experiences because of their IPCC. Through the application of the biomedical model, professionals (doctors) hold a great deal of power over the

students' prospective identity (at the University) (Watson 2002). It is within this context that we further explore "identity".

### **3.2 Self-Identity**

Self-identity is the way we interpret ourselves. To do this, we rely in part on how others perceive us. According to George Herbert Mead, "The organization of the social act has been imported into the organism and becomes then the mind of the individual" (Mead 1971: 267). Social acts, when we interact with others, are situations where we engage in gestures and performances of ourselves. As Mead indicates in his work, the way we interact in social situations is in part how we see ourselves within those social contexts (Mead 1971: 269). How we interpret ourselves is not only what we develop in our own minds, but rather the influence of how we are perceived by others in social contexts, adding to how we develop our self-identity (Mead 1971: 269). In other words, it is not only the individual who is creating their self-identity; how we act in front of others, and how "the others" perceive us, and how we perceive others to understand us, all contribute to our own understanding of self-identity. In short, we incorporate how others perceive us in social contexts into our own self-identity.

Students receiving support from academic accommodations do not necessarily self-identify as disabled. Similarly, self-identifying as having an IPCC is different from self-identifying as disabled. The distinction between identifying as disabled versus identifying as having an IPCC is important because often the term "disabled" is viewed by society as something inferior, negative or, in need of "fixing" (Dirth and Branscombe 2019). On the other hand, avoiding the word "disabled" when describing oneself or one's self-identity leads to less negativity or perceived negativity. According to two of the academic accommodation centre staff I interviewed, students have to "self-identify" as "disabled" before receiving support from

the academic accommodation centre. This is an interesting and surprising revelation which I reference numerous times in this chapter. As Faye, a disability coordinator explains, “they [the students] need to self-identify so that’s the biggest difference I think from high school to post-secondary, is that quite typically, a parent will set up accommodations in high school or the IEP [individual education plan] will follow them [the student] from elementary to high school but, in university or college, the student needs to self-identify as having a disability”.

Staff say students must “self-identify as disabled” in order to receive academic accommodation, but evidence from my research in interviews with students and staff questions whether students really must actually “self-identify as disabled” in order to initiate the process of academic accommodation. In the case of one student participant I interviewed, Rose decided that even though she did receive academic accommodation for her IPCC, she did not identify as disabled. In the coming pages, we will read more on this topic of identity from Rose and the other student participants. The staff at the academic accommodation centre used the words “self-identify” repeatedly. Most likely, “self-identify” is what the staff are trained to say when students inquire how to become registered.

### **3.3 Complexity of Identity**

Two out of the five undergraduate students I interviewed (Molly and Max) had been biomedically diagnosed with an IPCC, and chose not to receive academic accommodations at University. Another participant interviewed, Lucy, said that although she did not receive academic accommodations for her multiple IPCCs, she did receive academic accommodation for her learning disability which is separate from her IPCCs. Lucy did not know she could potentially receive support for her IPCCs at the academic accommodation centre. After learning about my research, Lucy was considering trying to get academic accommodations for her IPCCs.

Two other participants, Rose and Ella, receive academic accommodations at University for their IPCCs which were also biomedically diagnosed.

Molly, a student who has an IPCC but does not receive accommodation, has a complex relationship with the concept of a disabled identity. Molly explains that:

Yeah, it's something that honestly, in an academic setting it's something I have been coming to terms with because I have always said that no, I wouldn't identify as a person with a disability. No, I have never used that title, I have never wanted to, especially before my diagnosis. Because before, I was like, no, I don't want to do that. And I always thought that I was kind of... because I was like... I don't want to make claim to an identity, kind of a fear of offending others. But recently, the classes that I have been taking, I am kind of starting to wonder is that really why? Or is it because I have kind of internalized ableist understandings of what disability is and what it means as like something that is like sad and you shouldn't claim...that's not how I feel, but I am wondering if partly I may have internalized that? [Is it] something that I want to distance myself from? When in reality it just means that I kind of have to navigate things a different way.

It seems that Molly is navigating what mainstream society has taught her about what having a disability should be like. In Molly's words, living with a disability is "sad" and Molly does not feel "sad" about having a chronic condition. She is not sure she identifies with having "sad thoughts" about her disability and, therefore, does not identify as disabled. Because of the negative connotations associated with the "disabled" label, she rejects the idea that she is disabled. However, Molly did say that after taking university courses about disability, her perspective has since changed, and that having a disability does not always equate to being in an unhappy state and feeling sorry for yourself or having others pity you.

As this quotation from Molly demonstrates, Molly now confronts what she sees as a dilemma in identifying herself in terms of both the "front stage" (how she presents herself in front of others) and the "back stage" (how she actually sees herself) with an identity she has previously rejected (Goffman 1959: 17-22). Molly is questioning whether the "sad"

connotations “disability” stereotypically have been associated with actually represent how she wants to identify to others.

Max is another student with an IPCC and someone who does not receive academic accommodations who is also grappling with the concept of a disabled identity. He explains, “I would identify as having an invisible chronic disability. And, the thing is, my chronic disability, I see it as a disability, but it is hard to even classify myself as disabled because it is such a rare disorder...” However, Max further said he is not sure he actually has a disability because his chronic condition is extremely rare. Max questions whether he is disabled by his condition. He explains further:

In fact, I have troubles [thinking about my “disability”], am I disabled? Or am I not? But there are things that I am genuinely disabled by, and I am someone with cold-induced urticaria, which in layman’s terms, I am someone with an allergy to the cold [weather]. Any cold contact, I have an allergic reaction to. This varies from individual to individual, for me hives starts anywhere...for me, any type of rash starts if anything is below room temperature, which is a huge margin.

From the data, we see that Max does not necessarily identify as a “disabled” person publicly, but recognizes that his chronic condition does “disable” him in some ways at particular times, such as when the temperature is below room temperature. Max does say he sees cold-induced urticaria, (a hive-like condition) as a disability to himself, but given the rarity of that condition, it is apparent that Max questions whether other people would also see his condition as a legitimate disability. Max is also struggling with the idea that the word “disability” could be used to describe his condition.

The prospect of Max making his IPCC part of his front stage persona is challenging. Much of the time, Max’s IPCC is hidden from others even when he is experiencing a flare-up, because he wears thermal underclothing to try and prevent a flare-up from happening and from being seen if a flare-up were to occur. His goal therefore; is to prevent his back stage persona

from publicly appearing in his front persona. In *Stigma* (1963), Goffman describes those dealing with stigma in terms of “covering”; he offers another analysis of the processes whereby identity is socially manufactured for observers (Goffman 1963: 102-104; Goffman 1959: 17-22).

For Lucy, her identity is more clear to her now than it had been before. “Yeah, I have recently been trying to embrace that [disability] label more. I don’t most of the time don’t feel fine [sic], but most of the time that’s my life. This is how I have been all the time. Because I am technically disabled, but it is only recently a term that I am like: ‘Yeah, I am a disabled person’. I am trying to be more comfortable [with my disabled identity] ‘cause lots of people have these problems [IBS and colitis].”

Lucy further explains, “...I would say I am a disabled person. I don’t want to hide it anymore, but it’s ‘cause people would talk to me and [I would say] ‘Oh yeah. I am pretty sick all the time’. This will work for that [the disability label]. You are disabled, you have problems.”

Lucy explained that at one time she did not consider herself disabled. She seemed quite confident during the interview that she does now identify as a disabled person. Her tone during the interview was quite positive and uplifting and it was clear that Lucy did not think having a disabled label was necessarily negative. Although it was not the focus of my interview to find out when exactly Lucy began considering herself as a disabled person, I gathered this acceptance of a disabled identity was relatively recent. Lucy mentions that the conditions that she lives with are fairly common and that she has accepted that the conditions do impact her health, for most of the time, she does not feel very well.

Lucy presents yet another dimension of the academic accommodation and identity issue. Lucy used to present her “front stage” identity so that she could “hide” her disability. At present, Lucy has more fluidity between her “back stage” identity and “front stage” identity (Goffman

1959: 17-22). Further, Lucy mentioned that she used to hide her disability, or at least tried to hide it. Although IPCCs are largely invisible, sometimes when living with an episodic disability such as IBS and/or colitis, a flare up of the disability can occur at any time without any warning which can cause the disability to become more detectable to others. With such conditions as IBS and/or colitis, the person may look fine, but the act of having to use the washroom frequently, and sometimes for long periods of time, can reveal the person to be visibly disabled. For Lucy, when she disclosed that she lives with a disability, others were less likely to question why she would have to use the washroom often, or why she was not able to be present in class every day. Lucy explained during her interview that her experience was that other people such as professors and classmates were more understanding after they knew Lucy had a “disability”. I think for those reasons, Lucy feels more comfortable now after she disclosed her disabled identity. She can excuse herself to the washroom when needed without as much questioning.

For, another student participant, Ella, it took time for her to accept her disabled identity. Ella did not previously consider herself disabled until she had a biomedically confirmed diagnosis of lupus, arthritis, and fibromyalgia. Ella says “last year I wasn’t [comfortable with my disabled identity]. I kind of took the year to get used to it ‘cause I was diagnosed back at the end of high school and then kind of getting used to it and then kind of coming to terms with you know, the new identity. I think now I am comfortable [with that identity]. I don’t advertise it [the disability]. If someone asks, I’ll tell the truth.”

Ella, who was in her second year of university at the time of the interview and receiving academic accommodations, explained that after her diagnoses in her first year of university, she took the better part of a year to come to terms that she has IPCCs, and in turn, she now has adopted a disabled identity. It was Ella’s decision to identify as disabled. This shows that an

individual such as Ella, has some control over her identity as disabled or not (even if she receives academic accommodations).

A diagnosis from the biomedical model may or may not determine an individual's self-identity. A biomedical diagnosis of having an IPCC does not require an individual to adopt a disabled self-identity. It is a personal choice whether you want to identify as disabled or not, regardless of whether you have a biomedical diagnosis of a disability(ies) or not. Even if a person does not have a verifiable, biomedically diagnosed chronic condition, an individual can still choose to identify as they wish (Crooks et al. 2008: 1842), although they may be labeled as something else.

Ella reiterated that she does not “advertise that she has a disability”; which means that Ella does not identify as disabled to everyone, but to select individuals, depending on the situation and the relationship. Ella's front stage persona is presented or acted in a particular way depending on who she is performing in front of. At times, she may perform as though she does not have an IPCC, and other times, Ella may perform within her “front stage” as though she does live with an IPCC (Goffman 1959: 17-22). Ella didn't seem as open about her disabilities and about her disabled identity, perhaps because living with these disabilities is still relatively new for her. However, Ella did receive academic accommodations for her IPCC.

For Rose, when asked if she identifies as disabled, she points out the bureaucracy involving the term “disability”. “I feel like ‘disabled’ is a very legislative term. Like, it's particular people who get the health insurance and the supports and benefits, and my illness is not [considered] a disability by the government of Canada.” When I asked if Rose could clarify how she identifies, she was very clear and said she does not identify as a disabled person.

However, that may be because her condition is not recognized by certain government bureaucracies.

Rose does not identify as disabled, but she does receive support from academic accommodations for her fibromyalgia. This is interesting, because according to the staff at the University academic accommodation centre, the student “must self-identify as disabled” in order to receive support from them. Clearly, Rose has proved that you can receive support and reject the disabled label that the centre staff say you must have in order to register with them.

Rose was relying on the bureaucracy to determine whether she could identify as disabled, but clearly a person has some agency over their self-identity. You should not need the approval of an organization to tell you if you have the right to identify as disabled or not. Rose evidently thought that she had to wait until the bureaucracies accepted fibromyalgia as a legitimate disability before she would self-identify as disabled.

In Rose’s case, we see both the significance of self-identification and also the power of the state through the University’s recognition of a diagnosis following the biomedical model. Rose is recognized by the academic accommodation centre, yet not by government (as I learned during her interview), which again shows the complexity of factors which influence the identification of “disabled”. One scholar who has considered the powerful influence of the state in defining individuals beyond Goffman’s micro-analysis is Michel Foucault.

There are many positions regarding identity; however, for Foucault, identity can be imposed on people by the state (Foucault 1982). Identity is influenced by society’s powerful institutions (the government for example), and also by the discourse around power (Watson 2002: 510). If we consider the University to be a state institution in this circumstance, it can hold a lot of power over their students and how the students may identify within that institution.

Crooks et al. (2008) claim that it is state institutions (such as public universities) that hold the authority to control whether a person is disabled or not. Therefore, the student does not really have a choice in terms of providing biomedical evidence when receiving academic accommodations if they have an IPCC that limits their ability in some way to succeed in university. Goffman wrote "...a discrepancy may exist between an individual's virtual and actual identity. This discrepancy, when known about or apparent, spoils his [or her] social identity; it has the effect of cutting him [or herself] off from society and from himself [or herself] so that he [or she] stands a discredited person facing an unaccepting world" (1963: 19). Actual identity is interpreted to mean how one self-identifies (within the back stage), and virtual identity is how others perceive one's identity (within the front stage). Social identity is the community's perception of that individual's identity; virtual identity and social identity are very similar.

It may well be that in some cases the student already considers him or herself "disabled" when they seek out academic accommodations, but often they did not previously self-identify as disabled when seeking out academic accommodations (Riddell and Weedon 2014: 41; Watson 2002). For example, Crooks et al, argue "The categorization of applicants as being either 'disabled' or 'not disabled' ... means not only that people in need of support find their economic (and academic) futures in the hands of medical and state authorities, but also that they are subject to powerful external pressures to accept and conform to others' interpretations of their place within society and space" (2008: 1839). Being placed and "sorted" into a new group which is associated with particular attributes can be challenging for students to accept.

Is it possible to reject a disabled label that was provided to someone with an IPCC, who in turn, received academic accommodation support? All of the students I interviewed claimed to have biomedical diagnoses of their IPCC(s) and therefore had the option of identifying as

disabled if they wanted to (although some of the students may not have yet considered their IPCCs as a “disability”). Some students had to think about how to answer the question before explaining their thoughts.

Within the context of the University, students may have minimal control over certain aspects of their identity, particularly over their “disabled” identity at university. While a student is attending university, Foucault argues, the university could be considered a governing body or a type of state (while the student is attending the institution). According to Anne, a disability coordinator at the University academic accommodation centre, “The decision to register with us is the students’ own decision. They have to self-identify [as having a type of disability]”.

As you will recall, a central question was how do academic accommodations negatively impact a student’s identity? Having now reviewed interviews with the five student participants, we see that the relationship between having an IPCC and academic accommodations is complex. But, overall, students expressed the concern that they would be negatively impacted by academic accommodations. Even the two students who did not receive academic accommodations (Molly and Max) were hesitant about pursuing this track, because they saw subsequent potential negative impacts on their identity from receiving academic accommodation. Students having minimal choice over choosing academic accommodations and succeeding in university reflects unfavourably on the choice of how they want to “be known” within the institution.

### **3.4 Perspectives of Staff at the Academic Accommodation Centre**

The following discussion is largely from the point of view of staff, whose interviews provide an employee’s perspective of delivering academic accommodation for students within the University setting. These individual interviews with disability coordinators were to understand the perspectives of individuals who administer the institution’s framework for

providing academic accommodations to qualified students. Collectively, the staff interviews provide an understanding of the macro approach to how the University addresses IPCCs.

According to the staff, it is the student's own decision to pursue academic accommodation. However, there are a few factors that are beyond the student's control that determine if they are eligible to receive it. One factor is that a student must have appropriate documentation from medical professionals with supporting evidence of the students' "functional impairments," said Anne, a disability coordinator. Yet through my interviews with staff, I discovered not all biomedical professionals are equal. The student also needs the right medical professional to provide the documentation. For example, as Jane, another disability coordinator said, she has seen students come in with really terrible (biomedical) documentation. Jane said having students who see a walk-in clinic doctor for ten minutes and having to diagnose a chronic illness present a difficult situation for both staff and students. In Jane's words, "it does not help us...that's not a diagnosis you can get on one date. That's hard". A student needs documentation from a medical professional who has seen the patient for a longer period of time where an established patient doctor relationship has been formed such as with a family doctor or specialist. That professional can then write a medical note detailing how the students' IPCC(s) limits their ability to perform academically at university (the students' functional impairment).

### **3.5 Process for Receiving Academic Accommodation**

The process at the academic accommodation centre reinforces self-identity. From the four disability coordinators, I learned the details of the processes undergraduate students who have an IPCC must go through to secure academic accommodation at the University. The student must "self-identify" as disabled and come to the academic accommodation centre with supporting medical documentation from a physician who has an established relationship with the patient.

The medical documentation does not necessarily need to detail the disability(ies) itself, but rather, how the disability functionally impacts the student. After the student provides the medical documentation to the centre, the administrative staff will arrange a meeting for the student with one of the disability coordinators. At this meeting, the student and disability coordinator will discuss some possible academic accommodations. And from that point on, the student will have academic accommodation support for that semester. The process for students to receive academic accommodation is deeply rooted in biomedicalization by students having to provide the medical documentation from their doctor (Mullins and Preyde 2013; Riddell and Weedon 2014; Grimes et al. 2018).

Cora, one of the disability coordinators, said: “if a student comes in, they need to have a diagnosed disability and depending on the documentation they bring in, we can set up accommodations based on the functional limitations that they experience associated with their disability”. As was already mentioned, Anne, another disability coordinator said; “the decision to register with us is the students’ own decision. They have to self-identify [as having a type of disability]. They would contact the front desk to schedule an intake appointment with a [disability coordinator] and they would be required to provide documentation and at the intake [appointment] they also fill out an assessment of their functional impairment. During the intake appointment, we would discuss what are the functional impairments related to the disability and what accommodation support services are available at the University to meet those needs. We say that this is a starting point and we will be willing to revisit those needs as they progress.”

Jane, another disability coordinator, indicated that students need to present some sort of documentation of a disability to the reception at the front desk. The staff at the front desk will book that student in with a disability coordinator. However, Jane mentioned that sometimes

students show up without any paperwork and as a result will not necessarily receive academic accommodations from the first meeting with a disability coordinator. Jane, similarly, to Anne said;

And, by doing that, they would either need to bring documentation or have a doctor fill out our [medical] forms online for documentation. And, essentially all that needs to state is that they have a diagnosis. For a lot of disabilities it does not need to be specific as to what that diagnosis is, that being said, the more information the student could provide, the better able I am to assess or predict what supports and services might be needed for students because I find that if you overwhelm somebody with too many resources that they don't need, that it is really hard for them to kind of navigate what it is that they should be using.

Since the students' medical note does not have to include the name of the IPCC(s), then it leaves room for the student to determine how they wish to be known by others (the student's identity). For example, if they have fibromyalgia, and their doctor only explained in the medical documentation that they have difficulty taking notes/ writing tests and exams because they have joint pain, this in turn leaves room for the student to choose not to disclose to the University community that they live with fibromyalgia. All four of the disability coordinators interviewed were in agreement regarding how students become eligible to receive academic accommodation. However, the identity of the student is not fully considered during the process for registering at the academic accommodation centre.

### **3.6 Resistance from Students from the Point of View of Staff**

Overall, all four staff had very few experiences where students who needed academic accommodation were reluctant to seek out medical documentation, which is key to identifying as disabled. Faye said, "there have been a few cases where some students question the need to get documentation. For us, it is a legal obligation to have something documented. The exact diagnosis for some disabilities does not need to be there, just the presence of a diagnosis just indicating that [the student has functional limitations]. I would say very seldomly do we get that

push back from students.” Faye additionally said she has seen a few students over the years who “had difficulty accepting their diagnosis or not wanting their disability to be a label that they have, so maybe [as a consequence] they haven’t followed through with accommodations”. This is suggestive of the complexity of identity and the concerns of students for potentially having negative impacts on their identity from receiving academic accommodations. While a “legal” obligation is over-stated, it is clear that there is an absolute requirement for specific medical documentation.

For example, if a student with severe arthritis needs to see a doctor, it can be physically painful. Furthermore, if a student was having to take time off from school to see a doctor, this compromises their ability to succeed and may cause additional stress. In part, “disability” acceptance may have little to do with the diagnosis and more to do with the acceptance of the label of “disabled” in some cases. The disability label has not historically been associated with positive attributes. Cora described that although she has not personally had students who are reluctant to receive academic accommodations, she knew that some of her colleagues did have experience with “push back” from students. Cora did say that she has had students in the past say they did not want to have their doctor fill out the medical forms required for the academic accommodations centre because it was expensive. Jane, on the other hand, said that in her many years working at academic accommodation centres at two different universities, while she had seen some push back from students reluctant to provide the medical documentation, “99% of the time” she does not receive any push back from students themselves.

It is significant to recognize that although some students disapprove and dislike the academic accommodation centre’s processes for receiving academic accommodation, students who feel they require academic accommodations generally comply with the regulations and

policies so that they can receive support. This outcome leads to the question of why students who do not approve of the academic accommodation policies do not question the practices of the academic accommodation centre? Further research inquiry would question why students who are uneasy about the process of receiving academic accommodation do not refuse academic accommodation. Because the biomedical model is so widely accepted by students, it goes unchallenged.

### **3.7 Categorization and Labelling**

In addition to the issue of navigating sometimes a new “disabled identity”, when students with IPCCs seek out academic accommodation, they are subsequently categorized by the University into groups, such as “normal” or “abnormal” or able-bodied or dis-abled (Crooks et al. 2008; Marshak et al. 2010). Further, according to the students, they are then “known” to others (classmates and professors) within the institution as “disabled” if receiving academic accommodations. This experience can be stigmatizing for the student, particularly in small classes or group work. As Jane, one of the disability coordinators, said during her interview, she sometimes will have students come to her for advice on how to deal with having to tell other students in their classes that they receive academic accommodations. Jane said, “I do still have students who ask me, how do I explain to my friend, like the person in my study group, and I sit next to everyday, that I am not there for the exam because I get accommodations. And, the friend presumes that means extra time, and then the student presumes they have to tell their friend that they have to justify that they are getting good grades, not because of the extra time, but because they studied and earned their good grade.” Jane’s example illustrates that students who do receive academic accommodation feel the need to constantly “justify” why they receive it, and this is especially true for people who have IPCCs. Classmates are sometimes quick to

judge their peers regarding why they may need support from academic accommodations and subsequently may silently judge the student, because on the outside, their peers look “normal” (Mullins and Preyde 2013: 154). Rose, (who is registered at the academic accommodation centre), said that part of her accommodation is to have a note-taker who is already taking the same class. Rose said, she will try to hide the fact that she receives note taking accommodations by taking some notes herself during class. For example, Rose said, “in small classes where it is one other person taking the notetaking for you, I’ll write things down and look like I am not a lazy person or something”. However, later during the interview, she said that she does not worry about what her friends and family think of her receiving academic accommodations. Rose said her close circle of friends and family is supportive of her getting the support she needs.

According to the academic accommodation centre staff, 90% of their registered students have invisible disabilities. Because of the nature of IPCCs, which are largely invisible, students who do receive academic accommodation are frequently questioned because they may be “working the system” to take advantage and get ahead of other students. However, given the lengthy biomedical process of registering with the academic accommodation centre, it is unlikely students would even have the option of taking advantage of the system.

Fortunately, both the staff and students whom I interviewed said that professors with whom they interact, tend not to question why the student receives academic accommodations. Jane, who has many years of experience working at the academic accommodation centre, said that years ago she did have to deal with professors because they did not understand why certain students were receiving accommodations, but now a professor rarely contacts her for that reason. This data suggests that students receiving academic accommodation are starting to become normalized within the University.

Similarly, the students said their professors were understanding that they registered with academic accommodations. Molly, a student who did not register with academic accommodations, said when she has shared with professors that she lives with chronic pain, they have been really understanding. Lucy, who does receive academic accommodations for her learning disability but not for her IPCCs, said “that they [the professors] are more accommodating maybe because they know [about the disability].” Lucy further said that she is very good at judging whether she believes a professor will be willing to accommodate her for her IPCCs, and as a result has only received positive outcomes; “I have only had professors say if you ever need anything, let me know.” In Lucy’s case, when her professors are aware that she had a “problem,” they are even more accommodating to her needs. Thus, there are students who seek and receive accommodations for IPCCs they have but these accommodations are independent from the academic accommodation centre. They are arranged individually between the student and the professor. Ella, on the other hand, worries that after her professors know that she is registered with academic accommodations, they may treat her differently. Although this type of situation has not yet happened to Ella, she says “sometimes once that’s [the fact that she has a disability] disclosed, I feel a little bit more insecure about how professors see me”. Given Ella lives with multiple invisible conditions, it makes sense that Ella would be concerned that professors might not fully understand that she lives with IPCCs, and as a result, may question why she receives academic accommodations.

Aside from professors potentially judging students, students judging other students for receiving academic accommodations was a topic that Ella raised. “It wasn’t directly at me, but I was sitting in my program lounge, and there were some people [students] talking about how some people [students] take advantage of the [academic accommodation centre support], and get

note-takers and get extra test time for nothing, stuff like that, that made me feel a little bit uneasy” Ella mentions. This quotation from Ella illustrates that not all students have a good understanding of how academic accommodations work, and it also shows that fellow students may not have empathy towards their peers who may have IPCCs. However, Ella did say that she has overheard other students (who do not use academic accommodations) say that students with academic accommodation take advantage of their academic accommodations.

### **3.8 Experiencing Stigma**

One of the underlying themes expressed by many of the students I interviewed was the experience of stigmatization. Unfortunately, having an IPCC often results in the experience of stigma (Goffman 1963). It is not a question of whether a person who is outside the “norm”, (such as those with IPCCs) experiences stigma, it is more so how often the “abnormal” person experiences stigma in various situations (Goffman 1963: 129). Max particularly expressed the need for eliminating the stigma around disability. “People, without realizing, do micro-discrimination towards people with disabilities” Max said. It is true that often when a person does not physically appear disabled, they are more likely to be “silently” questioned as to why they say they live with an IPCC. People can silently question others with simple gestures such as the looks they give, tone of voice and general attitude. The fact that some of the students I interviewed try and hide the fact that they do have an IPCC or receive academic accommodations indicates that those students likely have a fear of being stigmatized further than they already are.

Goffman argues that managing our experience of stigma if we are “abnormal” or “disabled” is simply part of the daily grind if the society in which we live conveys “identity norms” such as “normal” and “abnormal” (1963: 130). Especially within the University

institution, we clearly see that receiving academic accommodation from the academic accommodation centre is not “typical”--it is for those students who have “troubles” succeeding in University without support. The University is a prime example of a societal institution which actually reinforces “identity norms”. Thus, if a student associates themselves with the academic accommodation centre, they are in turn (often unequivocally) associating themselves with an abnormal identity. Being known as having an “abnormal identity” can cause others to create the experience of stigma. The students who are in this category of “abnormals” may fear being stigmatized by fellow students, professors, peers and/or their family. Max for example did not want to associate himself with the academic accommodation centre partly because of his experiences with “micro-discrimination” towards disability.

### **3.9 Academic Accommodations without Proof?**

As previously mentioned in the introduction, two out of the five students interviewed had never received academic accommodations. The two students, Molly and Max, likely would have qualified if they pursued academic accommodations, but for various reasons they chose not to seek them out while attending university. When asked the question; “if you weren’t required to have proof from a medical professional to validate your condition, would you be more likely to utilize the services at the academic accommodation centre to accommodate your particular condition?” Molly’s response was clear,

I already feel on a day to day basis, very judged for my [invisible] disability. I really don’t want to enter a new setting in which I have to justify why I need accommodation and why my disability impacts me in my ability to learn and do things a certain way. I don’t want to give them my application (I don’t know the process [of receiving academic accommodation]), I don’t want to give them [the academic accommodations centre] my diagnosis and have them be like...okay why, do you need this? Or I don’t know, let’s just say they give me extra time, if I don’t use the extra time, have them be like ‘did you really need this?’ Once again, that might not be a relevant thing, but that’s just my own personal fear based on the things that I have heard.

It is evident, that Molly is not interested in having to provide any documentation from medical professionals to validate her condition in order to receive academic accommodation. In Molly's view, she should not have to defend why she feels she needs support from the academic accommodation centre. On the other hand, when asked the question, "if you weren't required to have proof from a medical professional to validate your condition, would you be more likely to utilize the services at the academic accommodation centre to accommodate your particular condition?", Max simply answered "No". This suggests that Max would still be worried about experiencing stigma if he sought academic accommodations.

Similarly, when asked the same question, Molly also said if the process of receiving academic accommodation was such that she did not have to provide documentation to prove her condition, she still would choose not to receive support from the academic accommodation centre. "For me, personally, I would say no [to receiving support], because I have a diagnosis and it hasn't made a difference. Once again, having a diagnosis for some reason was important to me because then I could try and access medication and other resources to try and help. But, it was also important because it was like this form of validation and justification. So, I guarantee for other people it does make a huge difference, like the need for proof." For Molly, although she has proof of an IPCC from a medical professional, she does not feel encouraged to seek out academic accommodations because she does not feel the need to justify her IPCC with proof.

### **3.10 Is the Self-Identity of the Student a Consideration?**

If a student has an IPCC and requires academic accommodation at university, the academic accommodation centre's registration process makes the student's IPCC(s) visible to an extent by having to provide medical documentation from biomedical professionals (Barazandeh 2005). If the student had not previously thought of himself or herself as disabled, then, the

student must now figure out how to manage this information about their new identity (Goffman 1963: 91).

While disability classification through the application of biomedical standards is clearly helpful for administrative purposes, it can create negative social consequences such as stigma for the student (Riddell and Weedon 2014: 45). Universities may cause more harm than actual benefit by providing academic accommodation for students with various health conditions. It is assumed that many people believe academic accommodations are helpful. However, the unintended consequence is that “social institutions such as universities construct disabled people” (Riddell and Weedon 2014: 46). Is it really the student’s own decision to “self-identify at the academic accommodation centre?” Does the student actually have a choice to register at the academic accommodation centre if they are living with an IPCC that is impacting their studies? Even if the student wanted to register with the academic accommodation centre, they have to identify as disabled regardless if the student actually self-identifies as disabled. However, some students are choosing to reject the disabled identity that the academic accommodation centre provides.

When the staff mentioned that the students have to “self-identify” as disabled, it made me question if the staff had the same understanding of what self-identify means to most others? For example, the student must have supporting medical documentation indicating their functional impairment related to their IPCC when registering with the academic accommodation centre. However, it is critical to recognize that having a chronic condition does not necessarily mean that the person identifies as disabled. So, it is possible with medical documentation to receive academic accommodations without having to self-identify as disabled.

### **3.11 Masculinity and Disability**

Max also discussed that masculinity is often associated with portraying certain characteristics. “I feel like a lot of people like men, guys, there is this social push towards guys to be you know, strong, fit, not just tough, but more so like ‘good’, not having any problems” Max said.

Given that Max was the only male student whom I interviewed, there was no comparison to other male undergraduate students that I could make in terms of how men portray their masculinity and/or their disability. However, the literature does suggest that men are more likely to avoid asking for help, such as when they may need medical assistance or perhaps getting academic accommodations because men are stereotypically supposed to be “tough and strong” and as Max said, “...not have any problems” (Gender Inequality, 2009). According to statistics from the academic accommodation centre, in 2018-2019 there were 1,718 (55%) registered students at the academic accommodation centre who were female and 1,425 (45%) registered students who were male. Yet the overall University undergraduate student population is 48% female and 52% male. This data demonstrates that females are disproportionately represented at the academic accommodation centre. Females are more likely to seek out academic accommodation. Additionally, these statistics also show that women may have particular medical conditions that require more support in order for the women to have success at university. Further, having more women reach out for assistance reflects a long standing tradition of old-fashioned gender roles and what are considered acceptable actions within each gender specific role. Women are more socially accepted to receive support and help because they are historically viewed as weaker than men (Sophia 1740).

Max (not registered) wanted to protect his masculinity and was choosing to keep his IPCC invisible; he did not want to jeopardize his masculinity by revealing to others he lived with an IPCC. Because Max lives with an IPCC (cold-induced urticaria), he luckily has the option to choose whether he wants his IPCC to be visible or invisible. Many people do not have the option to hide their disability because of the nature of the disability itself. Max lives with chronic hives which at times can be all over his body, but he can cover up with clothing and look more or less “normal”. If men had visible disabilities rather than invisible disabilities, would that make a difference of how “strong” their masculinity is? After talking with Max, I realized these are really important questions to consider; however, given the narrow scope of my research, these are questions to explore for another research project. Max brought my attention to a set of issues related to disability and masculinity that I had not yet considered. It may very well be that men and women have differences in how they want to “portray” their disability or IPCC(s) because they want to preserve their masculinity or femininity. The fact that my research only drew the attention of one male student yet four female students may suggest that men who live with IPCCs are less open to sharing their experiences and women are more willing and open to sharing their experiences related to their IPCCs.

### **3.12 Cultural Differences and Reluctance to Receive Academic Accommodation**

Two staff members mentioned that they have seen students who have different cultural backgrounds who were quite reluctant to receive academic accommodations, because of the required medical documentation. For example, Faye expressed;

It is more the cultural perspective in terms of the countries that they [the students] have come from, and that label not being something that exists there. Sometimes it is the fear of what that will look like despite the fact that I explain to them verbatim that your professors will never know what your diagnosis is unless you tell them. Or the fact that this [academic accommodations] doesn't show up on your transcript, this

doesn't follow you to your job or anything. When you graduate, you graduate with your degree and it is not really documented anywhere [saying] what it took for you to get that degree.

Anne, who has had over 20 years experience working at the academic accommodations centre, said in relation to mental health disabilities, some students who have different cultural backgrounds are reluctant to disclose their disability and reluctant to get help and support from academic accommodations.

I think most students' families are aware of their condition but some students especially with a mental health disability [and who are] from other cultures they...because different cultures see mental health disabilities differently, they tend to have more negative attitudes towards disability, particularly mental health disabilities. So, they are afraid to disclose to their families that they are suffering from a mental health disability.

In the students' particular culture, having a disability may be something to be very ashamed of and seen as something that should not be widely shared with others (Parsons et al. 2015). Although for my research, it was not a focus to know the cultural background of the students I interviewed, I suspect (based on the expression of interviewee answers) that some of the five students whom I interviewed had varied cultural backgrounds.

For example, Max said, "I have considered it [receiving support from the academic accommodation centre], but I ultimately did not do it because first off I feel like disability is a taboo. I even have troubles even accepting that I am a disabled person and I feel like... it is a social taboo [being labeled]. Especially with someone like myself that looks physically healthy..." Max, further said that he worries that if he did seek out and receive academic accommodation, then that label might be shown on his university transcript. The staff at the academic accommodation centre said sometimes because students have a misunderstanding of how academic accommodation at the university works, that sometimes students who would

qualify to receive it, do not try and seek it out because they fear that people such as the students' future employers would see that that student received academic accommodations in university. Staff reassure students that professors and the students' university transcript would never know or indicate the specifics of the students' disability. The transcript would never reveal anything about the student receiving academic accommodations, although sometimes certain students simply do not want to "risk" receiving academic accommodations.

### **3.13 Benefits and Risks of "Coming out" or "Not Coming out"**

For people who live with episodic illnesses, or fluctuating chronic illnesses, it can be challenging to know when or if to identify themselves ("come out") as disabled, because often they do not know when their disability will affect them (Lightman et al. 2009). In an example illustrated in Samuels' 2003 article, Gage, a woman who lives with chronic fatigue immune dysfunction syndrome, said she did not come out to her friends until after a decade after she first became ill, largely because her condition fluctuates constantly (2003: 238). For people who have episodic disabilities, they sometimes have a hard time establishing that their disability is valid to their social circle(s) because they are "not disabled enough" (Lightman et al. 2009). Given the fluctuation of how disability may limit a person, particularly when it is episodic (and invisible), people may embody different identities at different times. For example, if someone is experiencing an "episode" of their disability, they may identify as disabled; however, if their disability is not affecting them in a limiting way on that day, then they may choose not to identify as disabled. Having a fluctuating disability is really challenging when it comes to deciding whether to "come-out" or not.

In a school setting, events occur on the school schedule, such as tests and exams. If a student needs academic accommodation to succeed because of their invisible episodic disability,

the student would have to disclose their disability to the school even when their disability may not be affecting them during times when they receive the accommodation. However, if the student with the episodic disability had not disclosed their disability to the school, and then experienced a “flare-up” of their disability on a day that there was a test, then it would be too late because they had not disclosed earlier. For Molly and Max, who did not register with academic accommodations, they potentially risk not having support from academic accommodations when a flare up of their IPCCs occurs.

### **3.14 “Coming Out” or Being “Outed”?**

Sometimes a person does not have a choice but to come out as disabled. As mentioned earlier, people who need academic accommodation must provide biomedical proof of their disability (Grimes et al. 2018). In certain situations, such as in a university setting, receiving academic accommodation can mean that the student has come forward with biomedical proof and identify as disabled. In the research of Marshak et al, one of the main barriers as to why students chose not to receive academic accommodation is because of issues related to identity (2010: 154). For two students I interviewed who chose not to receive academic accommodations in university, the loss of control over their own identity was a major consideration concerning why they chose not to get support. Additionally, for Max, he may risk jeopardizing some of his masculinity if he wanted to do so. Unfortunately, if a student really does need academic accommodation to succeed at university, they must “identify as disabled” through the provision of appropriate medical documentation confirming the student’s IPCC to the academic accommodation centre. However, it is not really an individual’s (or any institution’s) right to decide the identity of another person. The accommodations centre clearly requires evidence from biomedical professionals that unequivocally establishes that a student has a condition or

conditions which would make them eligible for accommodations, thus it is clear that it is the biomedical model which determines whether a student can receive accommodations or not.

Despite the assertion from staff that they require the students seeking accommodations to self-identify as disabled, this is clearly not the case, and the student may or may not self-identify as disabled. Therefore, this shows the power that institutions such as universities have over their students. It should be the decision of the person in question who determines their identity.

### **3.15 The Bureaucracy of Academic Accommodation and the Complexity of Identity**

#### **Conclusion**

Even though three out of the five undergraduate students (Lucy, Rose and Ella) I interviewed were registered at the university's academic accommodation centre, only two out of the three students identified as disabled (Lucy and Ella). Rose and Ella were registered because they had documentation supporting their IPCCs. Lucy was registered for a learning disability, although she wanted to look into potentially receiving support for her IPCCs as well. Molly and Max both had IPCCs, but chose not to receive academic accommodation for various reasons. Molly did not want to have to justify why she felt she needed academic accommodation support and did not want to have to bring proof of her IPCC to the staff. Max did not want academic accommodation support because he was concerned that others (such as, future employers) would find out. Max also explained hesitancy because he was never informed of the process of how to register. He expressed that there should be more advertising and a clear poster with each step of the academic accommodation process explained. Max also did say he was not sure how he could be accommodated for his IPCC. He did not know what the centre could do for him to help him succeed in university aside from the centre perhaps providing a blanket for him to use in colder classrooms.

Both Molly and Max had complex relationships with the concept of self-identifying as disabled. Identity is a very complex matter that is sometimes out of the control of the individual (Goffman 1959: 15). Although Lucy was registered at the academic accommodation centre for her learning disability, she identified as disabled because of her IPCCs. It was apparent that some students were reluctant to accept a disabled identity even when they live with an IPCC. The label of “disability” has often historically been associated with negative connotations and it is evident that some of the students I interviewed were fearful of living with the label of disability (Goffman 1963: 42). Lucy said that she felt more at ease when she told other people that she lives with IPCCs. In her case, it was easier for her to “come out of the disability closet” than to consistently try and hide her disabilities (Samuels 2003)<sup>9</sup>.

For Ella and Rose, who were both registered with the academic accommodations centre for fibromyalgia, and Ella with the additional conditions of lupus and arthritis, they differed when they were asked if they self-identify as disabled. Ella, without question, identifies as a disabled person. Rose clearly indicated that she did not self-identify as disabled, which could have been because fibromyalgia is not yet widely accepted as a confirmed disability. It is interesting that two individuals with the same type of condition would have different points of view on how one should identify when living with fibromyalgia.

For others, it isn't so easy to simply tell others that they live with a disability or an IPCC. Max, who has chosen not to register with academic accommodations, described that when he has told people in the past that he is allergic to the cold weather, he often receives laughter as a response. For Max who lives with chronic hives as a result of his allergy, reiterated that living

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<sup>9</sup> This citation supports a similar analysis of “coming out”.

with his IPCC is not a laughing matter. Max said that his IPCC is so rare that most people have never even heard of it, and because it is rather unusual to have an allergic reaction to the cold weather, they think it is laughable. “When I tell people that I have this allergy, and I don’t really tell too many people, but if I tell someone usually, I get a laugh. People think that I am joking.”

As we can see from the above chapter, identity is a very complex issue. Particularly one’s “self-identity” is an intricate, complicated concept. Their self-identity is not fully a consideration when a student with an IPCC is receiving academic accommodation at university. The institution (the University) holds some power over that student’s identity. The student is placed in a category of “disabled” at the University if receiving academic accommodation. They are left with little choice but to identify as disabled when placed within this “disabled” category. However, as we have seen, some students reject that disabled label which the University prescribed.<sup>10</sup>

The students I interviewed, regardless of whether or not they receive academic accommodation, all had experiences with stigma or fear of stigma related to having an invisible physical chronic condition. Having a stigma attached to one’s persona interferes with daily life and results in insecurities during social interaction (Goffman 1963: 138). There is no question that having an “abnormal” identity within the University unintentionally invites experiences with stigma caused by other “normals” (non-disabled). The academic accommodation registration process can be stigmatizing in and of itself, by making students prove and validate their IPCC(s) with biomedical documentation from their physicians. When I asked the two students I interviewed who never registered with the academic accommodation centre if they would

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<sup>10</sup> The student really does not have to identify as disabled if receiving academic accommodations, they just have to disclose a disability through the medical documentation, or just the functional limitations associated with their IPCCs.

consider registering with the academic accommodation centre if they did not have to prove their chronic condition to the centre staff, both students said no. The hesitation for why these students did not want to register with the academic accommodation centre was largely because they feared losing the ability to choose how they wanted to be known within the University, losing the ability to choose how they want to self-identify, and the fear of experiencing further stigma. This chapter also briefly highlighted topics of disability and masculinity, cultural differences and reluctance of receiving academic accommodations, and the “coming out” of the disability closet discourse.

In Chapter Four we will hear from students and staff about the limitations of academic accommodations. In particular, we will hear from individual staff members who will reflect on practices that do not always fall within the current parameters of the institution’s bureaucratic framework of providing academic accommodations.

## **Chapter Four: Limitations of Academic Accommodation Services**

This chapter discusses student and staff perspectives of the current biomedical model instituted at the academic accommodation centre. First, student participants argue that the current biomedical model in place for accommodating students who have IPCCs at the university academic accommodation centre has weaknesses. Secondly, staff argue they experience systemic bureaucratic challenges in their work. Finally, student participants argue that it is the duty of the University to improve their communication to students of the services of the academic accommodation centre and the process for how to receive academic accommodation. In this chapter, I rely less on Goffman's theory as the discussion from students and staff shifts to the macro perspective, in this case, the University institution.

### **4.1 Weaknesses of the Academic Accommodation Centre**

One outcome that emerged in both student and staff interviews was the idea that the current biomedical model in place for accommodating students with IPCCs at the University academic accommodation centre is flawed. The students I interviewed highlighted some issues related to academic accommodation that they wish could change. Some student participants said that requiring less formal documentation from medical professionals (which is a very individual practice) would make it easier. Similarly, some of the staff working at the academic accommodation centre were critical that the system of accommodating students is extremely individual. For example, the practice for students to retrieve medical documentation from their physician is very individual, meaning the academic accommodation services focus on helping one student at a time, and not necessarily helping a collective group of students at university.

As discussed in Chapter Three, the first analysis chapter on *identity*, the process for receiving academic accommodation for IPCC(s) requires students to secure appropriate medical

documentation from a physician who has an established doctor-patient relationship with the student. As was also explained in Chapter Three, the student seeking academic accommodation should not retrieve the medical note from a walk-in clinic doctor, but rather from a doctor who has known the patient in an established doctor-patient relationship. In some cases, the student is required to have a specialist fill out the forms.

I asked student participants, “Would you change anything about the accommodation system”? The students all had meaningful answers to this question. Remember that three out of the five students I interviewed were currently receiving support from the academic accommodation centre, while two of the student participants had never received support (and currently did not want the support). The students interviewed who were registered had different points of view about what they would change about the system.

When I asked if Ella, (who does receive academic accommodation) if she would change anything about the current academic accommodations system her response was in relation to the accommodation she receives. One of Ella’s accommodations is to have a note-taker (another classmate) in her classes. It was clear that Ella hadn’t been entirely satisfied with the notes she has received through the service (from the classmate’s notes). At the University where this research was completed, note-takers are volunteers and thus not paid, so understandably, the class notes from volunteers may not be of great quality for somebody such as Ella. Ella said; “I feel like the note-taker thing, maybe have a professor do notes for that class, and even just their lecture notes would be nice. A lot of professors don’t have those. Even just to have something little.” Ella feels that her professors would provide better notes than another classmate would and even suggests that the professors could post their lecture material or PowerPoint slides to the class’ Moodle page, where students could access it on their own time if they desired. Having

unreliable class notes from a classmate is one weakness with the academic accommodations system.

#### **4.2 Support Group for Students**

When asked if she would change anything about the current academic accommodation system, Rose's response suggested that there should be an opportunity for social support from other students who get accommodations. "It's fine [the academic accommodation system], I guess it would be nice to feel like there's other people who use the [centre], like to talk with other people, you know, socialize about health problems, because struggling with university workload, and dealing with an illness is like a full time job! It would be nice to talk with other people," explained Rose.

Rose feels isolated. Having a support group comprised of fellow students who have health conditions would be beneficial to her, and no doubt, others. Discussing how challenging it can be to attend university while living with an IPCC seems like a reasonable request. As she mentions, it is not always easy to go to university while managing an IPCC. Taking comfort knowing there are others in the same position would be encouraging to her (Fullwood and Wootton 2009). Having a support group where students feel welcome regardless of their ability is a way whereby students share their strategies for handling particular issues related to university and their health (Lewis et al. 2016: 2546). There is no such group that offers peer support within the centre services for Rose. However, there is a student-oriented disability awareness centre on campus, which in retrospect is good, but perhaps Rose was not made aware of their services, or potentially she did not feel comfortable approaching it. Given the academic accommodation centre provides services on a very individual basis, Rose is feeling the impact of the "individuality" and she explains that she does not have social contact with other students who

use the centre services. Having minimal social contact with other registered students who have IPCCs is another weakness of the system for accommodating students.

### **4.3 Reducing Need for Formal Medical Documentation**

Lucy who receives accommodation for her learning disability and is looking into potentially receiving accommodations for her IPCC(s), also had some suggestions when I asked her if she would change anything about the current academic accommodations system.

Hummm, would I as someone who has used it? I want to say, less formal medical documentation might be okay. Like, if you could just get a doctor to say like, 'we're testing for this, she has some problems'. But on the other hand, I kind of understand why they have that [formal documentation] system in place because anybody can claim they have anything, you can't prove it especially if it is invisible. I don't think I would honestly, [change anything about the current system]. Currently, I am pretty content. I have had some problems with the learning disability accommodation side in the sense that sometimes the software doesn't work correctly. I have had some of my accommodations missed.

Lucy first says that having less formal medical documentation would be helpful. If she did not yet have a confirmed diagnosis of her IPCC(s), it would be helpful if she were permitted to have her doctor provide documentation for a diagnosis that is "in progress" and that medical tests were being completed to confirm that diagnosis. It would also be helpful if Lucy could receive academic accommodation while she was trying to secure medical documentation for her IPCC(s). Lucy also says; "you can't prove it [the medical condition] until it [is proven in medical documentation] especially if it is invisible". It is interesting that initially Lucy says she desires a less formal documentation process for receiving academic accommodation, but then she admits that because her conditions are invisible, she should have to prove them through biomedical professionals (her doctor(s)), in order to receive academic accommodation.

The rules for students to have access to academic accommodations currently include that they have to "prove" their disability through doctors' medical notes. The students require

biomedical proof of their IPCC(s) from a medical professional such as their medical doctor, in order to be considered for academic accommodation. The proof of the medical condition is needed because the centre (and the University in general) do not want non-disabled students taking advantage of the accommodations support. The time commitment that is required on the student's part to secure appropriate medical documentation of their IPCC(s), is significant. The students have to make appointments at the academic accommodation centre and keep professors and the centre staff apprised of their situation and academic needs. This takes a lot of time and may not be worth the effort, for it is unlikely students would try to take advantage of the support (Dunn 2019: 228-229).

Molly, one of two students I interviewed who had never previously registered with the academic accommodation centre, discussed some of the barriers of formal documentation prior to accessing services at the centre. Molly realizes that it would be challenging for the academic accommodation centre to adapt to anything other than formal documentation of students' medical conditions. However, Molly argues that formal documentation of medical conditions is not the best way to allow students to access centre services. When I talked with Molly, I asked her the following question: "So, you have heard a few things over the years about the academic accommodation centre, do you think of the limited things you have heard, would you change anything about the current academic accommodations system? Would those changes make you reconsider receiving academic accommodation?" Molly makes several good points in her extended quote below.

Yeah, it is just so hard to say. Because there are a lot of things I could say about that, but I know that there are just certain systemic forces that aren't going to make that possible for a really long time. I feel like with the [academic accommodation centre], it is very bureaucratic and very... it kind of reminds me of a government financial office, like you are making a claim for something and then you are relying on

someone to take your claim. Whereas, I feel like it would just be better if it was almost a support centre that allows students to navigate or allow students to negotiate with their professors with that person [at the academic accommodation centre] as a mediator almost. Just going in and booking an appointment with someone being like, ‘this is what I am going through, this is what is happening to me, whether I have a formal diagnosis or not I am wondering what we can do about it. What options do I have?’

If it is more of an open conversation and then maybe getting the Prof or the TA’s [teaching assistants] involved. Which also, I have been a TA at [this University] so I know it’s a lot, and that would be a lot [to navigate with the TA], and confidentiality. There are so many different pieces that would make that hard, but if it [the centre] were framed more of like ‘we are a support centre for students with disabilities both diagnosed and undiagnosed’, cause that’s another big thing, the documentation. And we [the academic accommodation centre staff] are here to help you negotiate this as opposed to like...we are here to hear your claim about what your disability is and how it affects you. And see if we are willing and able to make it happen.

There are many themes to unpack from Molly’s quote. The first theme is that Molly does not believe a systemic change could be made quickly. Molly believes that it will take a long time for change to happen and as she says in her own words, “there are systemic forces that aren’t going to make that [the move away from the required medical documentation of students’ conditions] possible for a really long time”. Molly is referring to the University policies that would have to change, such as academic accommodation services only provided for those students with medical proof of their condition, and from Molly’s previous knowledge, those policies tend not to be able to “change overnight”. Within bureaucracies, policies tend to change slowly, due to the nature of the system.

The second theme in Molly’s statement is that she compared accessing the centre to that of accessing a government finance office, a very regimented inflexible procedure, where tasks and proof must only be done a certain way and where there is a power imbalance between the person asking for funding and the person with power to give the funds. Molly says that there is a similarity to a government financial office, in that the academic accommodation centre makes people wait and see if they qualify after they have submitted their “claim” (their medical

documentation). Students rely on the academic accommodation centre for support in university, just as people may rely on the government for financial assistance. An office such as the academic accommodation centre should be more accessible to students who do not necessarily possess the appropriate medical documentation.

#### **4.4 Helping Students Without Formal Medical Documentation**

Molly's third point is a further recommendation for the academic accommodation centre. Molly suggests that the centre should be more of a support space where students with or without medical documentation of their condition(s) can receive assistance. Molly makes it clear in her quote that the centre should be for students with formal documentation of their conditions (Grimes et al. 2018: 640; Marshak et al. 2010), *and* for students who do not have formal documentation. Currently, the centre is set up primarily to help those students with formal documentation of their functional impairments of their IPCC among other conditions. Additionally, the centre can refer students who do not qualify for their support, to other services on campus that will help students. One of those services is offered through the library. The library offers the "From Intention to Action" program, which is a twelve week program designed to help students handle stress and work on their academic performance. Additionally, the academic accommodation centre can refer students to health and counselling services, which offer doctor appointments, and one-on-one counselling. However, Molly is suggesting that the centre be more inclusive to all students and make it so that every student can receive support from a "support style centre". A support style centre would allow any student who experiences any challenge related to their health, to come and receive support and guidance from the staff on how to succeed in university.

The final theme Molly explained in her interview involves a shift in the type of work the staff at the academic accommodation centre does. According to Molly, staff should act more as mediators (staff would work to mediate any conflicts students are having with their coursework and/or professors), rather than acting as the gatekeepers for determining whether students could even qualify for the academic accommodation support. Having the staff change their role to help all students is a fundamental shift that would need to happen in order to make the University more inclusive. With this shift, students could approach staff regardless of whether they have medical documentation of their medical condition or not. Students could discuss anything with centre staff including how to navigate certain situations such as discussing the format of a lecture with a professor, and talking with a TA about how to make tutorials more accessible, and making tests and examinations more equitable.

One policy Lucy and Molly want changed is to eliminate the current policy for requiring formal documentation of their IPCCs. The reliance on the biomedical model at the centre is too rigid from the point of view of the students I interviewed. If the formal documentation of IPCCs were eliminated, more students would likely seek out help--students who were too intimidated previously by the biomedical proof they had to have. Additionally, the academic accommodation centre could provide assistance to a wider roster of students. Ella wanted improved and reliable class notes as part of her accommodation. And Rose wanted to be able to have social contact with other students who are in a similar situation as her who receive support from the centre. However, due to privacy constraints, having social contact with other students in the same position does not seem feasible right now. These are some of the solutions shared to address the current academic accommodation model.

#### 4.5 Staff Perspectives on the Current Model for Accommodating Students

It was not only students who gave perspectives on the current model for accommodating students at the University centre; the staff who work as disability coordinators discussed their assessments of the system. The staff I interviewed all had a master's degree and were well aware of the expectations of university students. The staff shared that there are systemic bureaucratic challenges within their work, including managing a caseload of 500 students per staff member on average. Another one of the most interesting challenges that disability coordinator Anne mentioned is that the current academic accommodation system is focused on the individual. When I asked Anne the question; "Is there anything you wish you could change about the current system in place for accommodating students?" she reflected on her time as a disability coordinator working at the centre. Anne described that its policies have come a long way, even in the last ten years. Anne explained:

We are always trying to improve. The way that we accommodated ten years ago is different [from] how we accommodate now, how we deal with things because issues that students are bringing to us or issues that we have observed. Complexity has increased and the number of students has increased so the way that we accommodate ...we try to do as much individualization ...

One aspect that I would like to change perhaps would be to have a more universal structural and design approach. It is to really look at teaching and learning at the post-secondary sector and how professors evaluate. Right now, we are dealing mostly with accommodation on an individual basis, so it is a reactive process. By looking at how accommodation can level the playing field based on current existing practices within the institution, but I would like us to focus on more proactive systemic issues and address those so that it will reduce the need for individual accommodations. Specifically, pedagogically in terms of how professors evaluate what counts as participation and for all these kinds of things. There will be a more creative way of thinking about how to evaluate [students] and students' participation and so forth to reduce the need for individual accommodation.

Anne acknowledges that currently, the academic accommodation centre tries to adapt everything for the individual students' needs. By attempting to adapt services for every single

registered student, it no doubt is more work for the disability coordinators. However, not only is it more work for the staff, it is also more work for the students (Jung 2002). This is the case because each student has to meet with their doctor and have their doctor write a medical note, which the student has to bring to their assigned disability coordinator and agree on an individual basis what accommodations are appropriate. It would make more sense and it would be less work for all involved if there were a more universal approach to evaluating students, where professors could ensure all students are accommodated as needed (Bjælde et al. 2017). As Anne says, it would be better for the University to concentrate on addressing “proactive systemic issues”. What do proactive systemic issues mean?

#### **4.6 Addressing Systemic Issues**

Anne articulates that the current academic accommodation system is not as proactive as it could be. The “systemic issues” that Anne explains relate to the individuality of the structure of the current model for accommodating students at the centre. The academic accommodation centre is not set up to help groups of people; it is set up to help individuals. (Of course, privacy of the students is of concern both to the students themselves, and the staff at the centre and this would have to be addressed.) The staff I interviewed said many of the students registered at the academic accommodation centre have the same type of IPCC and, in turn, require the same type of accommodation: the students are treated individually, which is very time consuming for the staff. Because the staff have to individually meet one-on-one with students, the staff cannot always meet with all of their students in a timely manner.

In Anne’s quote above, she is discussing another major issue that staff experience as a result of the current academic accommodation system. Anne said that the disability coordinators have difficulty keeping up with the demand of the increase of students needing support from

them. At the academic accommodation centre, each year, the number of students registering with the centre increases. The academic accommodation centre staff I interviewed do not know exactly why the number of students registering with the academic accommodation centre has increased by hundreds of students each academic school year, although Faye speculated it could be because the University has a good reputation for their academic accommodation services. In September 2019, registered students at the academic accommodation centre increased by 700 according to the disability coordinators I interviewed. Unfortunately, there was no staff increase to help keep up with the demand for accommodating students according to Anne, Faye and Jane. Keeping up with the demand of increasing students, on top of already managing several hundred students' caseloads is a challenge for the disability coordinators and the academic accommodation centre as a whole.

Anne discusses that a more universal design approach for students and a better design approach are needed at university. A universal design approach within university would mean that the University is structured to be inclusive of all students in all aspects (for example, in teaching and in physical space), regardless of ability. One way universal design can be implemented is through a continuous assessment model. Anne says that we should "look at teaching and learning at the post-secondary sector and how professors evaluate". If professors change the method of how they evaluate their students, the academic accommodation centre services would not be needed by students as extensively. The question this poses is, how would professors change how they evaluate their students' knowledge of the subject matter? Currently, Western universities rely heavily on testing students' knowledge of the courses they enroll in (van Der Vleuten 2000). Instead of heavily relying on testing at the undergraduate level, professors could assess students' knowledge of the course themes by other means.

#### 4.7 Changing How we Evaluate Students' Knowledge

Interpreting the disability coordinators' wishes for what they want improved so that they can better support their students, this next section will discuss some of the possible alternatives to assess students' knowledge of course material. Professors could evaluate their students using alternative methods, which will be explored in this section. Currently, many undergraduate courses have a final examination. However, some courses are already designed without a final examination, but many undergraduate courses still require one. Instead of final course examinations, professors could evaluate students based on how much the student participated in online forum discussions (the class Moodle page for example), research papers, presentations, reading summaries, and group work. It is important to have many different modes of continuous evaluation of students' knowledge of the subject in each course. If you put "all of your eggs in one basket" (such as an examination), and the student with an IPCC is having a "bad day" on the examination date, then that student may not pass the course.

Similarly, there is a problem with awarding points for "attendance". For example, if 35% of the students' final grade is based on in-class participation, it is not a reasonable way to evaluate students who cannot be physically present in class regularly due to their health. Some students who live with IPCCs are not physically able to be present in classroom settings all the time during the semester because of the nature of their IPCCs. Although professors do receive notifications from the academic accommodation centre when they have students registered in their classes who receive accommodations, professors are never told the specific condition the student has. This is why professors need to recognize that sometimes they may have students with IPCCs who are taking their classes. This should be taken into consideration when determining how to weigh students' course requirements. No assignment should be worth an

extensive percentage of the students' final grade. If participation is worth 35% of the students' final grade, and a student who lives with an IPCC is only able to attend four classes the entire term, then their final grade could greatly be impacted by the participation grade being worth so much. This, of course is the case if professors are not already providing the student with some other way to make up participation points for missed classes. Professors should have the same verified method of evaluation for every student and should weigh each assignment of similar value, and not have any assignment worth a large percentage of any students' final grade.

Lucy expressed concern that when she is not able to attend her computer science class because of her IPCC(s), she will lose marks for attendance for that course. Her professor is not willing to accommodate her missed participation, even though Lucy asked if she could make up the participation in some other way. In fact, Lucy said she was "afraid" to have to ask the professor to accommodate her. Lucy explained:

In computer science, I am afraid to ask for extensions or accommodations, [be]cause the profs aren't super accommodating. Actually, I threw myself out there recently with my tutorial for my computer science prof, and I said I was really sick. I kind of got an annoyed feeling [from the professor] in the sense that he was like 'no, I cannot give you more grades, gosh'. He wrote in the E-mail and said that other people have already asked him this, and he said no. So, I felt like he was annoyed at me, but I didn't really feel...

I genuinely don't try and take advantage, I always feel like I am justified when I am sending that E-mail. And, no matter what they respond I [tell myself] that I tried, and I am not trying to take advantage, I am just suffering.

Asking professors for accommodation when not registered with the academic accommodation centre is not always successful. This quote from Lucy illustrates that professors do not always believe students if they do not "look disabled" and are requesting some accommodations. Students who are not registered with the academic accommodation centre where the students are required to have biomedical proof of their IPCC are not always trusted by

their professors that they are telling the truth (Mullins and Preyde 2013, Katarri et al. 2018, Grimes et al. 2018).

The advantage of these other modes of evaluating students (presentations, reading summaries, research papers) is that typically this work is not completed only on one day, but rather over the course of many days. This strategy of evaluating students, especially students with IPCCs, is that if the student is having a “bad day” with their IPCC, then they have the opportunity to perform better on a different day. A test (or examination) or even a make-up test is scheduled on one specific day. Students have a limited amount of time to perform well on a test, and since many students IPCC’s are unpredictable and may have a “flare-up” on the day when a test or a make-up test is scheduled. In such cases a test really does not evaluate the students’ knowledge appropriately or fairly as the student is distracted by the challenge and sometimes the physical pain of their IPCC episode.

The disability coordinator Anne said we need to revisit how professors evaluate their students. Not only would reducing testing potentially help those with IPCCs perform better in courses, it would help all students. Assessing students’ knowledge of the subject matter in a test causes a lot of unwarranted stress for the student. Bjælde et al. (2017) argue that students who write tests and examinations often only retain the information for a short time after the test/examination. As Bjælde et al. conclude in their research, many students deal with test/examination anxiety and as a result perform poorly (2017: 2). Some students like Molly, find sitting in hard chairs very uncomfortable and even painful. Molly for example, finds it more challenging to function without pain in the mornings, and sometimes tests and examinations are scheduled in the mornings. The advantage of having students work on papers and reading summaries, reports, etc. is that they can be worked on at a time when their IPCC is not

interfering with their performance. Even if the final examination or test is not worth much of the final course grade, it is still nerve-wracking and potentially inflicts unnecessary stress on students with IPCCs, as Molly notes.

#### **4.8 A Continuous Assessment Strategy**

In Denmark, a continuous assessment strategy has been implemented at universities with success. This strategy allows students to be assessed at multiple times via different types of assessments throughout the semester by their professors, rather than assessed only once or twice on a final examination (Bjælde et al. 2017: 2). Continuing assessment evaluates a student's knowledge more evenly, the knowledge the student has in relation to the subject matter of the course, rather than evaluating a student's skill in answering questions in a structured and traditional testing. A continuous assessment model contributes to the inclusivity of the universal design approach of university education. Canadian universities could adopt a similar approach to the continuous assessment model, and this could increase success rates not only for students who have IPCCs, but for any student, as it did for Danish university students (Bjælde et al. 2017: 2). Returning to Anne's suggestion of lessening the reliance of accommodating the "individual", this continuous assessment model of education does not concentrate only on helping individual students, but rather concentrates on benefitting most students attending university regardless of their health conditions.

Additionally, Anne has some of her own ideas of what she believes the University could do to better accommodate all university undergraduate students. Anne says that there are frequently requested accommodations such as extra time for tests and examinations and note-takers. In response to the question, "are there typical types of issues in your work that are repeatedly recurring?" Anne's answer reflects a sociological perspective. Anne reiterates that

she thinks some of the issues are caused in part because the current academic accommodation centre concentrates on helping the individual student rather than helping all students.

For us [academic accommodation centre staff],... if there is a way to incorporate extra time in tests and exams so that students with disabilities are accommodated under that [new design] without having to request special accommodation. Or, whether there is a way for students to share notes and this is something that a note-sharing system [could facilitate] where people can collect and contribute to a note taking pool, so that students who require the notes for a variety of reasons, some could have a disability or it could be [for] another reason, they [all the students] could have access to those resources. That is what I mean...focussing on more of...reimagining how students are evaluated, how to incorporate extra time and accessible features within evaluation and also in terms of how students access lecture material. That would help a lot for us especially.

I responded to Anne's answer to the question by stating, "I think that [Anne's suggestions] would help everybody". And Anne agreed with me, saying, "that is what I mean! Or even just the design of the environment of the exams. A small little location would help, rather than writing in a big space. I don't know if it is possible, but those kinds of things. Students have less issues if they write with their own class rather than in a big gym or rink."

The recommendations Anne suggests seem to be achievable. In fact, having professors post their lecture PowerPoints online so students could access them does not sound like it would be terribly challenging. Some professors already practice this. Similarly, having a note sharing system where all students could share their class notes (on the course moodle page for example) sounds reasonable and, again, not that challenging to attain. And, finally, having students write their examinations and tests in a smaller environment, such as their own classroom (where the course takes places), seems like an achievable objective. These suggestions are not going to require huge shifts within the already existing university policy structure. The suggestions focus on helping all university students, not primarily focusing solely on helping those who have documented IPCCs. This approach of accommodation is more inclusive than the current

practices established at the academic accommodation centre, where students must provide biomedical proof of their IPCC and then negotiate potential accommodations with a disability coordinator. The above recommendations made by Anne do not require students to provide proof of their IPCC in order to access lecture material, class notes, etc. These suggestions, if established, would accommodate most students regardless of their health.<sup>11</sup>

#### **4.9 Possible Outcomes of Changing the Practices of Academic Accommodation**

If these suggestions were taken into consideration, a positive outcome would be the decrease of stigma that students experience for receiving academic accommodations. Currently, some students have to deal with stigma from other students, and if students no longer had to receive “special accommodation” and were accommodated already by the structure of university classes themselves, then that stigma would be reduced (Mullins and Preyde 2013; Marshak et al. 2010; Jung 2002; Riddell and Weedon 2014). Additionally, students would not be singled out if they were already accommodated by the structure of classes. If fewer students required academic accommodations under the new proposed recommendations, then that would free up time for centre staff, especially disability coordinators. The disability coordinators that I interviewed all said they do not have enough time in their day to meet with every student who needs to talk with them. The number of students currently assigned to each disability coordinator is too high according to Jane and Faye. By changing the university structure of classes so that professors would post their PowerPoints, students would share their notes with one another, and exams would be held in a smaller venue or all together eliminated, then this should ease the caseload of students for the academic accommodation centre.

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<sup>11</sup> Note these suggestions if implemented within the current system are not necessarily feasible right now.

With Anne's suggestions, I think we would see a dramatic increase in positive outcomes for students' overall experience of university. University would be less stressful and more inclusive if it enacted these suggestions (Michalko 2009). If there is an opportunity to make university more inclusive and welcoming, then it should seriously consider these suggestions.

#### **4.10 Inclusive Practices at University: Universal Design**

Systemic issues within the university structure were not only discussed by Anne, but also by other disability coordinators. When I interviewed Faye, for example, another disability coordinator and learning strategist, she had similar concerns and recommendations to Anne.

When I asked Faye if she faces any challenges in her work, Faye explained;

I would say yes. If there wasn't [sic] challenges, I don't think my job would exist. We always talk about how, especially as learning strategists and even coordinators we are like the only professionals we know [of] that are trying to put themselves out of business. Through universal design for learning or universal design in general, the whole premise is to make it so [that] accommodations won't exist in the future. The more accessible services are, or classes are, the less likely somebody will need to be accommodated. But, because we are not at that point, the biggest challenge we face is getting people to see that perspective and getting people to see how to incorporate those accessibility practices into the classrooms, or into the services that they offer because, again, unless you have that lens on, you are not really thinking about it, when you are doing those services or teaching. So, I find that that ignorance piece is often the biggest challenge and I would say that we still have a long way to go in terms of being fully inclusive.

Faye illustrates a picture of the challenges that she experiences from the perspective of someone who has worked at the University academic accommodation centre for many years. It was really interesting to hear Faye say she actually would like to see the need for her profession to eventually disappear. Faye understands that the job she does actually means that the University as it currently operates is not fully inclusive—that's why her job at the centre exists, so that the University can try and make it more inclusive for those with documented disabilities.

Faye clearly believes that the solution is to implement “universal design” within university courses, which is similar to what Anne said. Given the University has set up the academic accommodation centre, the University is trying to mitigate the fact that its current design (in developing and designing courses) is not accessible for all students. As Dr. Michalko frames “special education” or “academic accommodation” he says, “...despite the commitment to inclusion, the very idea of ‘special education’ is built upon a sense of exclusion. Ironically, disabled students are excluded from their non-disabled peers by invoking the paradigmatic ideology of ‘inclusion’” (2009: 71). Having disabled university students distinctly separated from other students by having them receive support from academic accommodations is in contrast from what the centre actually strives for, which is “...to foster equal access to the university experience...”.<sup>12</sup> Segregating students who are disabled does not necessarily represent “equal access” at the University. Faye realizes that the reason her job at the centre exists is because the University is not fully inclusive. Faye would like others to come to understand how she and her colleagues believe the University system should change.

Faye says by far, the biggest challenge for her is to try and get others to think in the same way that she and other disability coordinators think. Universal design approaches are intended so that they help everyone, not just a select few. “Universal design’s goal is to make products and environments welcoming and useful to groups that are diverse in many dimensions, including gender, race and ethnicity, age, socioeconomic status, ability, disability, and learning style” (Burgstahler and Cory 2008: n.p.). Faye wants others to try and realize and consider how universal design will work in all classrooms, and if those universal design approaches were

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<sup>12</sup> This information came from the academic accommodation centre’s “Legal Policies and Responsibilities: Mission, Mandate and Philosophy” page on their website. (Accessed on August 7<sup>th</sup>, 2020.)

enacted in the classrooms, the need for academic accommodations would not exist, or least, not exist as much. According to Burgstahler and Cory, “universal design requires consideration of all characteristics of potential users, including abilities and disabilities, when developing a course or service” (2008: n.p.). Universal design is intended for all students, regardless of their “dis/ability,” so that they can access and have the potential to succeed in courses without any barriers, such as inaccessible course material. Faye further explains that some people are rather uninformed about universal design, and therefore uninterested in learning about it. Because people simply do not think about that type of educational design, Faye explains; “we have a long way to go before we are fully inclusive.”

When I asked Cora, another disability coordinator, “is there anything you wish you could change about the current system in place for accommodating students?” she explained;

I mean it would be really nice if students who required accommodations weren't singled out and have to go to a separate location. It would be really nice if more classes had a more universal design to learning that would help different types of learners and who experience different types of learning needs. So, I definitely think that that would be a good change, if it was possible, but it would be really hard to do. But with technology, it is definitely something that can be done.

Similarly to Anne and Faye, Cora acknowledges that a universal design to learning is needed so that all types of learners are accommodated at university. Cora explains that it would be a good change but that it would be challenging to implement as it would partly involve professors redesigning how they teach courses and testing students' knowledge of the course material. However, Cora is optimistic that educational universal design is something that could be attained in the future, but not immediately. By having this in place, students would not be singled out, as some students currently are singled out by having to receive their academic accommodations in a separate location from their classmates on days when there is

a scheduled examination or test (Marshak et al. 2010: 156). Students can feel alienated from their fellow classmates if they have to write their tests and examinations in a separate location from their peers. This separation can cause the separated students to feel embarrassed and labelled “abnormal” (Marshak et al. 2010: 156).

#### **4.11 Medical Documentation from the Point of View of Staff**

Jane, the final disability coordinator I interviewed, also had a perspective on what could change at the academic accommodation centre so that the system could be improved to help students. Jane gave an example of a situation: if she had come down with the flu, she does not have to provide a medical note to her employer that she will be taking a few sick days. Jane further explained that the idea to avoid having to provide a sick note is so that it will “...not burden our health care system with these short little medical one-off notes. If you are sick, just be sick, just go back to work.” Jane wants the same removal of sick notes to be implemented for students with IPCCs (who are registered at the academic accommodation centre), who experience episodes of their IPCCs. Jane explains;

...we are not allowed to put extensions on accommodation letters anymore. We were years ago. The idea is that you need to negotiate the extension directly with your prof. But if you have a chronic illness, and I know it's a flare up of your Crohn's [for example], why do you have to go and get a friggin' medical note, if I already have your medical note [on file], and I know that that's what is going on. So, I want to be their medical note. I can do that, but it is not working easily. So, the students we're talking about, not someone who gets the flu or whatever...I wish that my particular system were set up so that their weren't extra hoops at all. Like I want you to be registered with the academic accommodation centre, I want you to tell me you had a flare up, for you to tell me who on earth to reach out to and what you want, and for me to be able to do that without having the professors say... 'well that is great, but I need a note about this specific date' [the flare-up occurred on].”

Jane further explains;

Now, if every single one of my students needed that service, I can't provide it, so I also understand why we [the academic accommodation centre] aren't doing it so much. But,

there has to be a big system change around medical notes and then we have to adapt. I just don't know what that will be.”

Jane recognizes that students are already burdened when a flare-up of their IPCC(s) occurs. To ask students to get a medical note from their doctor to explain the date that it occurred exacerbates the student and the health care system further. Given students registered at the centre already have secured biomedical proof of the IPCC(s) upon registering there, it does seem redundant to have the student receive additional medical documentation when a flare-up occurs in order to get accommodation and/or extensions from some professors. Jane wants a students' episode to be treated within the University bureaucracy just the same as an employee who is having a sick day with the flu or cold. However, as it presently is, staff and students have different university policies with regard to sick days.

Jane further observes that in her position as a disability coordinator at the academic accommodation centre, if all of her students needed her to represent them and “be the students' medical note,” she would not be able to provide that service, simply because her caseload of students is far too high. Jane does believe a major systemic change has to occur for the elimination of medical notes for students' flare-ups of their IPCC. However, given that employees such as Jane no longer have to provide their employers with a medical note, there is hope that the same system (or a similar system) could be instigated for students who have IPCCs.

#### **4.12 Time Commitment to Retrieve Medical Documentation**

Receiving medical documentation from doctors does not usually happen overnight. Wait times to get in to see a doctor can often take a long time (a specialist, even longer), and as a result, can delay a student from receiving academic accommodation. Three of the students I interviewed, Rose, Lucy and Ella, said that the time it takes to get the appropriate form signed by the appropriate doctor does take up time which in turn delays the receipt of accommodation.

Rose said, “I need to get the doctors note and basically that was it. And, you have to do a little interview with the supervisor person [at the centre] and they are like, ‘okay, here are the courses, exactly what accommodations do you need?’” Rose explained that it takes up time to retrieve a medical note from her doctor. However, Rose would not have been able to access academic accommodations if she did not have the medical note.

Lucy, who does not yet have accommodation for her IPCC(s) but does receive accommodation for a learning disability, says;

I can see how having to provide medical documentation for that [IPCC] might delay the fact that I can get accommodations for that [her IBS]. [Be]cause Canada’s health care system is great, and it’s free and everything, but it’s slow. And, if they are like [the academic accommodation centre staff] you need to provide this documentation...I was lucky for psychoeducational testing [for her learning disability] we can just go private and my family can afford that. But, for this [IBS and colitis], I actually have to go to specialists, and I have to get testing. I can see myself not being able to get accommodations for that until next year if it is not taken at face value.

During the interview I followed up with this question: “Because it might take that long [until next school year] just to get in to see somebody [a specialist]? Lucy: “Yes”.

Ella also said that there were multiple steps for her to complete before she was eligible to receive academic accommodations. One step she had to undertake was to go and visit her doctor to have a medical note signed. Ella said; “...I went in [to the academic accommodation centre] and then I had to get a form filled out by my doctor. So, I had to make an appointment and go in, and get that [form] filled out. And then, I had to drop the form with them [doctor’s office] and then bring the form back in to the [centre]”. As we have heard from Lucy and Ella, it is apparent that there are too many steps for students to complete in order to access the accommodations. Students already have very busy academic schedules and deadlines, and having additional tasks

to complete for students with IPCCs is an extra burden. It is also important to note that the onus of completing these tasks is all on the student.

These quotations from Rose, Lucy and Ella reiterate Jane's point about the amount of time it takes for students to receive medical notes. However, it is not only important to consider the time of the students as well as of the doctors who have to write these medical notes. Doctors could be providing more essential care to more urgent need patients, instead of writing medical notes for patients who are university students registered at the academic accommodation centre. It is disturbing that Lucy may have to wait until the next academic school year to get an appointment with her specialist to be able to get a medical note to provide to the academic accommodation centre before she can receive academic accommodation for her IPCCs.

#### **4.13 Improving Communication of University Services to Students**

For first year students, or any new student attending the University, all of them need to be informed of important services provided by the University. One of the services that should be explained and communicated to students prior to commencing study at the University should be the services of the academic accommodation centre. Not only should they be explained, but also how to access the services needs to be clearly communicated to all incoming students. In the data provided by my research, the students argue that it should be the duty of the University to improve their communication of the services that academic accommodation provides and to also ameliorate the communication of the process for how students can receive the support.

The only first year student I interviewed, Max, did not receive academic accommodation support for his IPCC, nor did he indicate he wanted to pursue it. He explained that the services provided by the centre need to be better communicated to students. He also noted that should he ever require academic accommodations, he was not made aware of the procedures. Max gave

some helpful suggestions for the University to improve their communication to students regarding such support. As Max explains;

[The University needs] more advertising related to how it is not taboo [to get support from the academic accommodation centre]. So, what they could do [at the centre] is a push to do more advertising campaigns and say; 'it's not a taboo.' Regardless of who you are, it is not a taboo. Your disability can be visible, invisible, also make it clear the procedure of [how to be eligible to receive accommodations]. I don't remember or recall seeing any infographic that clearly laid out what the steps are. Maybe they [the centre staff] could have a poster saying like, step one; 'come and talk to us', step two; 'prove it [the disability] to us'. This is how you can prove it to us. Step three; ... it is not really clear [the specific procedure].

Max recommends that the academic accommodation centre should try to mitigate the idea that receiving support from the centre (regardless of the type of condition the student has) is a social "taboo". Max further recommends that advertising the steps that need to be taken in order to receive academic accommodation need to be made visible on posters, posted in areas where students would view them. Or, the information should be sent to students in an E-mail sent by the University to students. Max indicated that the prospective posters need to be clear and taken seriously, by explaining the procedure for each step needed to access academic accommodations. Granted Max was not informed of the procedures that he would have to undertake should he require accommodation support. He thought that if he ever wanted to pursue them, he would have to go to great lengths to prove his invisible condition: "...I didn't really know the procedure for proving it [the disability]. I didn't really want to prove it. Again, because it [the support from the centre] is a social taboo, even in the [centre], I just felt like because mine was an invisible disability, I would have to go to lengths to prove it. And, I just felt that was a burden," explained Max.

Students such as Max, who may require academic accommodation in other years of their university education, are led to believe that they have to go to great lengths to prove their IPCCs,

largely because the process for receiving academic accommodations was never explained to them when commencing university. Further, one of Max's other main concerns regards his privacy, should he ever require the need for accommodation support. Max articulated that the potential jeopardization of his privacy is one of the main reasons for why he did not want to receive academic accommodations. One thing, "...[the academic accommodation centre could do] is to ensure privacy. [Privacy is] one reason why some people may not even join the centre], because it might appear on their record [transcript]" Max explained. If the academic accommodation process and services were communicated more effectively to students, then the issues that Max is concerned about, such as his privacy, would not be lingering reasons why some students are reluctant to seek out support from the centre. If posters were advertised around the campus with each step of the academic accommodation process explained as well as the services provided at the centre, the number of students registering at the academic accommodation centre may very well increase (Chiara et al. 2009). In addition to the number of students who may seek out academic accommodation, the social stigma of the disabled label or social taboo (Grimes et al. 2018: 642) associated with academic accommodation may be reduced, if the services were more widely known.

#### **4.14 Limitations of Academic Accommodation Services Conclusion**

In this chapter I argued that the biomedical model for accommodating students who have IPCCs at the University academic accommodation centre has flaws. This chapter has included the perspectives from both students who are registered and not registered at the academic accommodation centre as well as four of the staff who work there. First, the chapter raised some of the issues with having students provide medical documentation of their IPCC(s) in order to be able to get access to academic accommodation services. Students securing the medical notes

from their doctors takes up significant time, and wait times to see a doctor can sometimes be very long. Additionally, writing medical notes takes up the doctor's time, when their medical skills could be better spent helping more urgent need patients. This chapter further argued that the process for accommodating students is very individual, and as a consequence, causes the disability coordinators to try and make time in their already overbooked schedule to meet individually with their students and provide accommodations and support.

Secondly, this chapter argued that academic accommodation centre staff experience systemic bureaucratic challenges. The challenges the staff experience include too high a student caseload per coordinator, no staff increases to compensate the influx of registered students at the academic accommodation centre and finally, staff not being able to speak on behalf of the students to professors when a flare-up of students' IPCC(s) occurs.

The staff I interviewed all provided helpful suggestions to support not only academic accommodation services, but also to improve all university students' experiences as a whole. The staff recommended implementing a universal design approach to university courses, where all students regardless of their abilities would be accommodated. The staff also suggested the concept that professors could evaluate students in different ways other than relying on testing. This would allow for a continuous assessment strategy in university courses where students could be provided with feedback on many smaller assignments (each worth a smaller percentage than a final examination) throughout the semester, and rely less on a final examination worth a large percentage of the students' final grade. The continuous assessment strategy would allow students who live with IPCCs to have the opportunity to perform better on days when they feel well enough to work on their assignments.

Finally, this chapter has argued that the University needs to improve their communication with all of their students regarding the process for how to receive academic accommodation. The University needs to make their students aware of the services academic accommodation can provide. The idea of receiving academic accommodation should not be a major social taboo, and having more advertising and spreading awareness around the idea that academic accommodations are common would reduce the idea that receiving help like that is unfair.

## **Chapter Five: Conclusion: The Purpose of my Research Inquiry**

I began this research to find out why some undergraduate students who self-identify as having an IPCC *do not seek out* academic accommodation. And, of the students who self-identify as having IPCCs *who do seek out and use* academic accommodation, what are their experiences with it? To find out the answer to my research questions, I wanted to listen both to the perspectives of the students themselves and also listen to the staff at the academic accommodation centre. While the evidence from interviewing students brings our attention to the individual perspective, the issues staff focus on largely reflect the institutional perspectives from the university's established protocols for dealing with students who present with IPCCs. Although responses from the students and staff differ, their unique perspectives suggest a shared central narrative surrounding lived experience with IPCCs within a university environment.

In this thesis I discovered that concerns of students' self-identity are not fully considered at the academic accommodation centre and that this can compromise a student's identity. Further, I learned that while the centre purports to assist students, the individualistic nature of the biomedical model used within the centre's structure creates barriers for students. I also found that staff who work at the centre experience bureaucratic challenges.

### **5.1 Answers to the Research Questions**

My research shows there are five primary reasons why students who live with IPCCs *do not seek out* academic accommodations. Further, the students who did seek out support had views about what they would like to see altered about the system.

The first reason why students are reluctant to seek out academic accommodations is because of the burden to have to prove their IPCC(s). Students said that they do not want to have

to go to the trouble of having formal medical documentation of their IPCC(s). Retrieving the documentation from physicians can be time-consuming, sometimes expensive and stigmatizing.

The second reason is that the student may not want to be known as a disabled student at university. This is especially true when the student does not self-identify as disabled. When accessing and using the centre, the student must take on a disabled label and identity. Only one student, Rose, who did acquire medical documentation for her IPCC and did receive academic accommodation, refused to accept this disabled identity. This identity, “the disabled identity,” can be challenging for students to cope with and lead to the categorization of students. Categorizing students into a group of “able-bodied” (students who do not use academic accommodations) and “disabled” (students who do use academic accommodations) is an unfortunate consequence of using academic accommodation services.

The third reason why students may not be seeking out accommodation is because the students are unaware of the services and ways to access the academic accommodation centre. One student in particular made it very clear that when he began university, he was never informed about the centre, nor was he informed about the process for how to receive support from the centre. Another conclusion from this research is that the University needs to commit to do a better job at informing all students of all of their University services, so that those who most need the support from the centre can receive it.

A further reason is because they fear others would find out. The lack of education about the privacy that is assured by the centre staff if students use academic accommodations is not explicitly clear. Students worry that if they receive accommodation, that information would be made visible on their university transcript. Although this is not true, fear of privacy breaches in the future remains for some a fear that is a legitimate concern. Students who use academic

accommodations will never have information indicating that they used them on their university transcript. However, this is a concern for some students who are reluctant to seek accommodation because they worry their future employers may find out that they completed their university degree with support from academic accommodations.

The data from the interviews in this thesis shows that students having an IPCC and who seek out and use accommodations have a range of negative experiences, from frustration over medical documentation to experiences of stigmatization.

Finally, the fifth and last reason why some students do not seek out accommodations is because of cultural differences. International students at the University who have IPCCs, sometimes need to seek out support for academic accommodations. However, sometimes in the students' home country, receiving support for their IPCC(s) is highly stigmatizing. Some international students simply do not get the academic accommodations they need in Canada because they do not want to be stigmatized and known as a "cheat" in their home country.

## **5.2 Possible Improvements to Consider**

This case study does more than simply point out the issues, observations, and concerns of students and staff. Rather than learn only about the problems, I wanted to learn what the participants themselves saw as improvements to remedy their concerns. The research provides realistic improvements for the concerns students and staff presented. I wanted to make this research more practical and learn what the students and staff actually want to do to address these issues.

Both students and staff participants generally said that requiring less or no medical documentation at all to access academic accommodation services would improve access to the centre. Further, as one student (who does not receive academic accommodation support)

expressed, it would be far more inclusive to have the service for all students regardless of “disability”. This new design would eliminate staff acting as gatekeepers and instead be more in the role of mediators to provide help to any student when needed.

Staff recommended the reduction of the need for individual academic accommodations. To do this, staff recommended a transition to the practice of having university classes offered where the bulk of the students’ grade did not rely on one final exam or midterm, but rather on a variety of other assessments over the course of a semester. As the staff said, many of the individual accommodations the centre provides to students are for a separate space for students to write their examinations, and for extended time to write them. In addition to the reduction of testing and how much the tests are worth, staff recommend having classes designed so that the lecture material is more accessible. That means having faculty create different ways for students to access course material, to attend lectures (and, in turn receive participation marks), and to participate, all the while keeping accessibility at the core. This transition to a more inclusive university environment or universal inclusive design structure is typically called “the continuous assessment model” (Bjælde et al. 2017). This model does not specifically aim to help students who have IPCCs, but actually would benefit most university students. Everyone has healthy and sick days, and having the opportunity to prove that students know the material from the course on multiple days, rather than on one date during the semester is an improvement, a better register of student learning.

Finally, it would improve the lives of some university students, if all students were better informed of the services and the process for receiving academic accommodation at the academic accommodation centre. Some who have IPCCs really require the support from the academic accommodation centre to succeed; however, because of the lack of communication from the

University, there is an unfortunate consequence that some students are left without support from the centre.

### **5.3 Importance of the Research**

My research is important because it highlights where we can improve the lives of many undergraduate students who live with IPCCs and the work of academic accommodation centre disability coordinators. If 90% of the student population served by the centre has invisible “disabilities” then it is evident that the issues this case study examines are critically important. This research matters more than ever, because at the beginning of the last two academic years (2018 and 2019), the centre has seen an increase of hundreds of students registering for support.

This research points out that some students are choosing not to seek out and use academic accommodations for a variety of reasons, including the required medical documentation and the length of time it takes to obtain the documentation. Understanding the reasons behind why students are choosing not to receive academic accommodations can lead the University to possibly address those issues, so that potentially more students can receive support from the centre.

Additionally, my interviews with staff at the centre taught me that these professionals truly want to provide the best support they possibly can to every one of their students and not just those who have IPCCs. This shows that the staff want to understand how they and the entire University system can improve the lives of undergraduate students who live with IPCCs. It is important to recognize that there are many more students within the University community who likely would benefit from centre support, but either are not made aware of its services, are concerned about their identity, possible labelling, and stigma, or do not have access to a physician to get medical documentation.

## **5.4 Limitations of the Research**

It is critical to recognize the limitations of this research. First, the research had a small sample size of five undergraduates and four disability coordinators. This is limiting as I would not have been able to capture all perspectives. Out of all nine participants, the research only drew the attention of one male student. This is also limiting given there may be a bias from the point of view of females who participated in this research. Further, while all of the student participants discussed their experiences specifically with their IPCCs, the disability coordinators no doubt were reflecting on their work supporting students with other “disabilities”, not solely their work supporting students who have IPCCs. This research also did not include interviews with faculty about their experiences having students with IPCCs in their courses.

This research is a case study of what occurs at one university. We must recognize that it is not suitable to generalize that all universities have the same structures and outcomes for accommodating students who have IPCCs.

## **5.5 Future Research Inquiry**

Academic accommodation centres are not the solution to helping students with IPCCs succeed in the University; they are merely a “band-aid solution.” If universities have such a centre, this indicates that the broader institution is not fully accessible to students who have IPCCs. If the need for academic accommodation centres is present, then this indicates the university is trying to remedy for the fact that some or all of their courses, environmental settings, or faculty and staff are not always accommodating of all students. As the disability coordinators have indicated, they want to eventually rid themselves of their job. If the University wants to eliminate the academic accommodation centre, then the University will need to change many current practices and deans, professors and staff will have to embed the

principles of inclusivity in all classes for all students. Future study or pilot programs exploring this universal inclusivity would advance our knowledge.

Where do we go from here? The need for future research about the success of other universities who have adopted a continuous assessment model is required before implementing this practice at the University where I completed my research. The continuous assessment model is one that has been implemented with some success at European universities. Research uncovering how the continuous assessment model has benefitted students who have IPCCs is also needed. Some future research questions to consider are: do universities with a continuous assessment model have fewer students with IPCCs accessing academic accommodations? Are academic accommodations necessary within such a model? What are the benefits and weaknesses of adopting the continuous assessment model for students, staff and professors?

Learning more details about the strengths and weaknesses of this model would be valuable because it would help the University know what to anticipate if the approach were implemented. Further research and learning from other European universities who have instituted this continuous assessment model would allow us to determine if it would be feasible in Canada.

Finally, because of the limitations of my sample size and focus of inquiry, I did not fully explore a number of themes that the student participants touched on. Although we were able to unpack the barriers for some international students, we were not able to comprehensively examine issues and barriers related to disability and masculinity. Furthermore, additional research about masculinity and disability would help us understand if there are differences between male and female undergraduate students seeking academic accommodations for their IPCC(s).

University learning and experiences are important opportunities, which should be available to all. While strides have been taken to make a university education accessible, there remain barriers. A little known and understood set of barriers are those that exist for a group of students—those living with IPCCs who need accommodations to fully succeed at university. However well intentioned the university, the accommodation centre, and the staff who work there, this research has shown that there are real and significant barriers for students with IPCCs. Some of these barriers prevent them from even asking for help. The student participants have also revealed their lived experiences with academic accommodations. There are policies and practices that challenge a student’s identity and can result in an unwanted categorization and label for some. There are consequences of stigma and burden.

This research also presents recommendations from several students and staff with first-hand experience of dealing with IPCCs in a university setting. This is a challenge for both future academic research and for university administrators: to make the University truly accessible and inclusive for all students, including those with invisible physical chronic conditions.

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## **Appendix A:**

### **Questions for Students who Previously or are Currently Registered with the Academic Accommodation Centre**

- 1) Could you tell me a little bit about yourself? What year are you currently in? What program are you taking?
- 2) Why did you decide to volunteer to participate in this interview? What type of chronic invisible physical condition do you identify as having?
- 3a) Why or why not have you been registered with the academic accommodation centre?
- 3b) Why or why not have you chosen to seek academic accommodation? Have you been registered each year you have attended the University?
- 3c) Has providing medical documentation prevented or delayed you from receiving academic accommodation?
- 3d) What kinds of academic support have you benefitted from?
4. Would you change anything about the current academic accommodations system?
5. In your opinion, do you find the staff at the academic accommodation centre supportive?
- 6a) Do you worry about what your friends, family and/or professors think because you receive help from the academic accommodation centre? If so, what strategies do you have to handle this issue?
- 6b) Do you ever try to “hide” your condition or “hide” the fact that you receive support from the academic accommodation centre so that others do not know you are registered at the academic accommodation centre?
- 7a) Do you identify as disabled?
- 7b) Are you comfortable with your disabled identity? Is it (partially) how you would define yourself?
- 8a) Given that you don’t consider yourself disabled, but you do identify as having an invisible physical chronic condition; how do you think that affects your university education and university experience? Has it affected your classes, meal hall dining, dorms, and social societies?

OR

8b) Given that you do consider yourself disabled. How do you think that affects your university education? How do you think that affects your university education/university experience? Has it affected your classes, meal hall dining, dorms, and social societies?

9) Can you provide an example of a situation where your fellow students made you feel that you were taking advantage of the system? For example, perhaps your fellow students might know that you require double time on an exam.

10) Can you provide an example of a situation where a professor made you feel that you were taking advantage of the system? For example, has a professor ever said that you should have used the “extra time” to write the exam longer in page length?

11a) Do you ever think that after you have disclosed that you are registered with the academic accommodation centre that professors treat you differently than other students in the class? Can you give an example of an experience where you felt the professor was treating you differently from others in the class?

11b) Overall, has that different treatment been a good experience for you or a bad experience for you?

12) Do you ever feel “troubled” that you consistently have to identify your “disabled” identity at the academic accommodation centre and not be treated just like any other university student?

13) When you have registered with the academic accommodation centre, have you ever found the amount of time that you are required to commit with the centre staff and professors and others very straining on top of managing courses and your medical condition?

14) Not negotiating accommodations with professors, or a staff member at the academic accommodation centre, on an average day, how much time out of the day do you yourself spend on managing your condition? For example, do you spend an hour doing stretches to manage your condition?

15) In your opinion, do you feel that academic accommodations “levels the playing field”?

16) When you think about the issues associated with having these chronic invisible physical conditions, is there anything that I should have asked you, that I did not ask?

17) Would you like to add anything?

## **Appendix B:**

### **Questions for Students who have not Previously Registered with the Academic Accommodation Centre**

- 1) Could you tell me a little bit about yourself? What year are you currently in? What program are you taking?
- 2) Why did you decide to volunteer to participate in this interview? What type of chronic invisible physical condition do you identify as having?
- 3) Why or why not have you been registered with the academic accommodation centre?
- 4) Would you change anything about the current academic accommodations system? Would those changes make you reconsider receiving academic accommodation?
- 5) If you weren't required to have proof from a medical professional to validate your condition, would you be more likely to utilize the services at the academic accommodation centre to accommodate your particular condition?
- 6) Do you ever feel "troubled" that you can't access the support of the academic accommodation centre because your medical condition is perhaps not on the list of recognized conditions that can be accommodated by the academic accommodation centre?
- 7) If you have not been able to or chosen not to be a registered student at the academic accommodation centre, has that decision ever affected your academic experience? How? Do you think not registering with the academic accommodation centre or not being permitted to register with the academic accommodation centre has affected your grades?
- 8) Not negotiating accommodations with professors, or a staff member at the academic accommodation centre, on an average day, how much time out of the day do you yourself spend on managing your condition? For example, do you spend an hour doing stretches to manage your condition?
- 9) In your opinion, do you feel that academic accommodations "levels the playing field"?
- 10) When you think about the issues associated with having these chronic invisible physical disabilities, is there anything that I should have asked you, that I did not ask?
- 11) Would you like to add anything?

## Appendix C:

### Questions for Staff at the Academic Accommodation Centre

1. What is it like to work at the academic accommodation centre?
2. On a daily basis, what tasks do you typically perform?
3. If a student needs academic accommodation, what are the steps they need to take to receive an accommodation?
4. Have you ever experienced a positive situation (or a positive story) with a student that you would like to share?
5. Do you face any bureaucratic challenges in your work? If so, what are some of those challenges?
6. How many undergraduates are registered at the academic accommodation centre?
7. What is the student (registered at the academic accommodation centre) to staff (at the academic accommodation centre) ratio?
8. If you could estimate, how many students are in their undergrad and also registered at the academic accommodation centre have an invisible physical chronic condition(s) (IPCCs)?
9. Have you ever noticed any “push back” from students because of the required documentation of students’ “disability(ies)” from medical professionals?
10. Do students ever vocalize concerns for how much additional time is required of them to receive accommodation? Such as; negotiating accommodations with professors, or a staff member at the academic accommodation centre, on top of managing their condition?
11. Have you ever had a situation where students decide not to receive academic accommodation because they do not want to be labelled as “disabled”?
12. What is the process of determining if a student is eligible to receive accommodation?
13. What happens if a student is not eligible to receive academic accommodation?
14. What are the most common types of invisible physical chronic conditions that students have who come to the academic accommodation centre for support? What type of accommodation do those students receive?
15. Because IPCCs are largely invisible, do you ever receive concerns from students that professors question the validity of the students’ “disability”?

16. Do you ever receive concerns from professors about the validity of a students' "disability"?
17. Do students worry about what their friends, family and/or professors think if they receive help from the academic accommodation centre? If so, how do you help students cope with this issue?
18. In your opinion, do you think that academic accommodations "levels the playing field"?
19. Is there anything you wish you could change about the current system in place for accommodating students?
20. Are there typical types of issues in your work that are repeatedly recurring?
21. Is there anything that I should have asked, that I did not ask?
22. Would you like to add anything?