

Supporting Students with Long COVID In Higher Education



**A Workbook for
Disability Service Providers**

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INTRODUCTION

READ THIS FIRST! This introduction was created to provide users of the workbook with an understanding of how and why the resource was created, and by whom. There is also an explanation of how the workbook is organized.

As the start of the new school year approached and concerns about COVID-19 refused to recede, disability service providers began to consider how the past year of the pandemic would impact on the year to come for students at their institutions¹. An August 6th *Last Word* post (shown in the Appendix) sheds light on emerging concerns about students who would be coming back to school in the fall and would present with Long COVID.

Long COVID describes a wide range of new, returning, or ongoing health problems people can experience four or more weeks after first being infected with the virus that causes COVID-19². Even people who did not have COVID-19 symptoms in the days or weeks after they were infected can have post-COVID conditions³. These conditions can have different types and combinations of health problems for different lengths of time⁴.

Disability service providers have maintained throughout the past year that issues of mask mandates, or vaccine mandates, or assigning alternatives (including remote learning) were not the purview of the disability service unit, but rather had institution-wide implications and were more appropriately determined at a higher level⁵. Students with Long COVID, on the other hand, are clearly of central concern to disability services providers⁶. They may present with physical or mental impairments that may substantially limit one or more major life activities. It will be the job of the disability services unit to determine what, if any, accommodations are necessary in order to assure equal access to educational opportunities⁷.

While we acknowledge the responsibility, the difficulties in fulfilling that mandate also become evident. In mid August, a call went out to the professional community, soliciting volunteers for a Task Force that would pull together information to assist in supporting the students with Long COVID that we expect will find their way to the disability services offices in the weeks and months to come. This workbook is the “work product” of the Long COVID Task Force, a group of 33 individuals who volunteered their time, energies, and expertise over the last month to create a resource for practitioners.

Who We Are

The 32 members of the Task Force represented a wide range of higher education settings and perspectives on disability services. We come from large, 4-year schools, small, private liberal arts institutions, community colleges, and specialty institutions (for example, focusing on the arts, or on science, or entirely online). We have expertise in working with unique populations of students, from those at primarily minority-service institutions, to those in urban and rural institutions, to those with specific expertise in working with deaf students or those with mental health difficulties. The Task Force includes the voices of service providers who have been doing the work for a couple of decades, and some who have been involved for only a couple of years. There are a few consultants and faculty members. When we considered diversity within the Task Force, we focused on the student populations served, rather than on the personal status of Task Force members. A full listing of the Task Force members can be found in Appendix A.

How/Why This Workbook Was Created

The Task Force came together as a private online community, using a closed listserv to communicate. We engaged for two weeks wrestling through the issues before we considered the best format to convey the information. It took some time and some trial-and-error to determine a workable format. Our last challenge was to compile the information we thought most important for service providers working with students presenting with Long COVID.

Students presenting with Long COVID may face a myriad of symptomology, and may or may not be able to articulate what they are experiencing. Some will come with documentation from a medical provider who has been following their progress, while others may have little or no outside documentation of having had COVID-19, much less of the Long COVID symptoms. In some cases, their symptoms of Long COVID may have direct impact on their academic pursuits. These are the functional limitations that we have traditionally focused on as disability service providers. We have some working knowledge of how to provide appropriate accommodations to support equal access for students when it comes to their studies.

However, some of the symptoms of Long COVID reported in the literature regard the physical health and well-being of the student, from long-term medical complications (for example, damage to heart or lungs, or those now immuno-compromised and more vulnerable), to significant impact on energy levels, muscle weakness, and mental health difficulties. We recognize these are not issues that disability service providers can resolve through the accommodation process, yet they cannot be ignored when considering accommodations. The provision of support to this population of students who are realizing their new limitations, and who face an uncertain future in knowing whether those limitations are temporary or permanent, is new territory.

How the Workbook is Organized

The Task Force decided to share information from our discussions on how best to support students with Long COVID, as well as some practical information that may be immediately useful for service providers. The workbook is divided into the following sections:

Introduction

This opening presentation is to help the reader understand how the resource is intended to be used, and how it came to be.

Intake Interview

As neither the students nor the service providers have experience with the impact of Long COVID, we believe that much of the critical information needed to support this population of students will emerge from the intake interview. Some students will bring formal documentation that should be considered, while others will have little besides their own self-report. The Task Force felt that the first step for service providers preparing for an intake is to decide on the scope and depth of the interview they would conduct. In other words, determine the purpose.

Question to Explore

The questions you will ask will be dependent on what information you seek and your determined purpose. The Task Force speculated on various ways to group and present questions in an intake interview. Rather than suggest a standard template, this chapter presents the individual perspectives of a number of Task Force members, explaining how and why they would structure their information gathering.

Facilitating Accommodations

Once you have gathered information about the difficulties faced and concerns of students with Long COVID, what will you do with that information? Just as members of the Task Force had different ideas about how to structure an interview, so there were different ideas of how best to tie the information gathered to the necessary and appropriate accommodations and support. Those varied approaches are presented in this section.

Tips/Strategies/Resources

As the conversation progressed within the Task Force, members often offered strategies that they have found useful in working with students with disabilities in the past and that may be useful for students with Long COVID. We also discovered a number of useful online references and articles that might be of use.

Conclusion

Our hope is that the summary information provided will remind readers of content and give structure to their “next steps.” There is also discussion of how readers may continue their exploration of these issues through ongoing interaction with, and access to, members of the Task Force.

How The Workbook Is Intended to Be Used

The Task Force determined, from the outset, that there would be no suggestion of a template for service providers to pick up and follow in responding to the needs of students with Long COVID. The workbook provides various ideas and options, but the decision as to which options to choose must rest with you. To support that decision-making, scattered throughout the various chapters, the reader will find boxed sections titled “Things to Consider.” The questions suggested and information provided within those boxes are aimed to assist in reflecting on the material.

Throughout the workbook, you will find information presented in different “voices.” In other words, we chose to maintain the individual voice and perspective of the Task Force, rather than reformulating their words/views into a single style. This was a conscious decision to remind the reader that our field is populated by individuals with a broad range of expertise who do not necessarily think alike, but who are all very good at their job – your job! Those individual contributions will be presented with the abbreviation “PP” after the title of the section. That will be your indication that you are reading the **P**ersonal **P**erspective of some member of the Task Force.

We hope you will find the information we have collected to be helpful when students with Long COVID come looking for your support!

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THE INTAKE INTERVIEW



GATHERING INFORMATION THROUGH INTAKE INTERVIEW

Task Force members agreed that much of the information service providers would need in order to determine the impact of the student's Long COVID symptoms must come from the student during the intake interview. We questioned, however, how in depth such an interview might be. Some favored asking only the questions that would help determine necessary academic accommodations and support, while others felt that getting a more complete picture of the student's current status would help put their academic functioning in perspective.

PURPOSE OF THE INTAKE INTERVIEW (PP)

Two Different Interviews Serving Two Different Purposes

There are two types of intakes: the “just the facts” interviews and intakes that are deep dives. Depending on your environment, your resources, the culture of your organization and your own philosophy, you will determine which kind of interview works best for you.

Just the facts Approach

The purpose of this intake is to learn what the student is looking for from the disability services office. Why have they come? What is their documentation? Do they an idea of what support they need? In this interview, we deal with what is known by the student, known from the documentation, and perhaps by the guidance that has been given by the institution via the mission statement or policies and procedures. The “just the facts” approach allows you to establish supports that are requested if the student is eligible and meets the guidance of the ADA in Section 504 the Rehabilitation Act.

A Strategic Deep Dive

The purpose of this intake is to learn about *why* a student is meeting with you (they ultimately decide what supports they establish, in what classes or if to use supports at all). Have they come because they wanted to? Do they have concerns? Did a parent insist or has an instructor or clinician told them to? Knowing *why* is important for disability services providers because it's our first clue into the motivation of a student. It can also indicate the student's level of awareness and understanding of their diagnosis or condition(s) and how the impact. In casting a wide net during the intake, we often discover more than their eligibility status. We may learn how to tailor academic and non-academic supports to fit the unique expression of long COVID in this particular student. We may also discover other disabling conditions that are creating barriers for that student. While we know that there can be a compounding effect of multiple conditions, we are yet to know the full impact that Long COVID could have. One plus one can sometimes equal five!

A strategic comprehensive intake can help tease out the negative synergistic impacts and allows you to tailor the support to the diagnosis and the symptoms that a student has, unique to their major, the technology utilized in a particular class, and the teaching modalities of a particular instructor. This approach allows you to establish supports, as may be requested by the student, and to offer other appropriate supports based on their diagnosis, symptoms, major, and useful technology that is available. In other words, tailored to the individual situation means actively listening and offering ideas, but it does not imply that you should “give away the store”. Understand a strategic deep dive takes time (30 – 60 minutes) but can make a world of difference in understanding the need of a student and establishing appropriate access for the student.

THOUGHTS ABOUT INTAKE INTERVIEWS IN GENERAL (PP)

Professional Judgment Will Influence Your Interview Process

As disability service providers in higher education, we are tasked with three primary responsibilities: to establish whether a student has a disability, to understand how a disability may impact a student with respect to the academic, residential, and other programs/activities offered by the institution, and to make informed decisions about what, if any, reasonable accommodations are necessary to afford a student with a disability equal or equitable access to the opportunities available to all other students. We receive documentation in all forms, shapes and sizes, that helps in varying degrees with answering some of these questions, and we may also have a general understanding about some of the potential impacts a student could be experiencing due to specific diagnoses. That said, we will not know a student's experience until we actually speak to them.

Professional judgment is an essential component in establishing whether a student has a disability and what if any accommodations are necessary for access. Each situation must be considered individually to understand if and how the student is impacted by their condition. The intake interview provides us with an opportunity to get this individualized perspective. We can ask important questions, but mostly, we can listen and observe.

How we choose to engage in the interview process with a student may be dictated by several factors. For instance, those of us at larger institutions or with smaller staff sizes may not have the time or capacity to engage students in discussions that dive deep into the student's experience with their condition/disability, and may need to focus on the facts in order to make sure the necessary information is obtained to make immediate decisions. In addition, the documentation we receive (or don't receive) may dictate how deep we need to go during our intakes. For example, if the documentation submitted by the student is fairly comprehensive, the student intake can be used primarily to fill in any missing pieces. In many cases, though, the time/capacity and documentation available may not be good indicators of need. Rather, the student will dictate how deep you can and/or need to dig. Some DS providers, for instance, choose to begin all intake interviews using the same standard questions to determine their line of questioning based on information shared by the student via observations, including what the student says or doesn't say. This works when the student is able and willing to articulate the necessary information. But what happens when they don't want or know how to respond?

THE "HOW TO'S" OF INTERVIEWING (PP)

Pre-Intake Homework

Prior to a *scheduled* intake, I look up the student's major, year, schedule. I am interested in the number of credits, type of classes, their instructors, and when their classes meet. I also check their University placement scores, SAT & ACT scores, do they play a sport, live on campus or commute and then I review any documentation that has been submitted. This information becomes background for the interview. In light of COVID and Long COVID this information can be very important because of the breadth of symptoms and its varied impacts.

This homework allows me to do two things:

1. Tailor the intake to known activities and expectations of their program or major. Again, think **strategic deep dive**.
2. Engage more informally. This is often our first meeting and it's an opportunity to build rapport and demonstrate that I am not just another person asking personal questions. I can share helpful tidbits about a major or their advisor. I hope my office might be an ally, and can offer strategies targeted to their skills, gifts, interests and their disability(s).

The best way to do an intake is to make it conversational. I don't want the student to feel they are being interrogated.

Examples:

Oh, I see you are an art major. What's your preferred medium? "Paint" That's great. I see you are taking two back-to-back studio classes (3 hours each). Do you like the classes? How are you feeling after the first and second class? Are you able to focus by the second class? Are you feeling like you are equally engaged in both? If not, why?

For an early morning intake:

Nice to meet with you this morning. I am a morning person. Are you? "no". Did you wake up in time for breakfast before our meeting? "No". I see you have several classes in the AM. How does your (insert disability) impact how you feel/focus/participate in class? Will missing breakfast add to the difficulties you already experience in the morning?

The use of humor can be helpful but risky. I always direct the humor at myself to see if I can get a smile or a chuckle. A comment about pets or how long I have been at the school (no I did not lay the cornerstone) and usually an ending comment that if they need anything, a paper clip or rubber band, that they can always stop by. Students who found themselves in a pickle (problem) have come back and said "You said I could always stop by...." They were/are listening and I think they remembered because it stood out to them.

KEY POINTS:

- On the two ends of the continuum there are intakes based on "just the facts" and intakes that are deep dives. Depending on your environment, your resources, the culture of your organization and your own philosophy, you will determine which kind of interview works best for you.
- The purpose of the "just the facts" interview is to learn what the student is looking for from the disability services office. The "just the facts" approach allows you to establish supports that are requested if the student is eligible and meets the guidance of the ADA in section 504 the rehabilitation act.
- The purpose of the "deep dive" intake is to learn about *why* a student is meeting with you (they ultimately decide what supports they establish, in what classes or if to use supports at all). It can also indicate the student's level of awareness and understanding of their diagnosis or condition(s) and how it's impacting them.
- We know that professional judgment is an essential component when it comes to establishing whether a student has a disability and what if any accommodations are necessary for access. We also know that each situation must be considered individually to understand if and how the student is impacted by their condition. The intake interview provides us with an opportunity to get this individualized perspective. How we choose to engage in the interview process with a student may be dictated by a variety of factors.
- Doing pre-interview preparation can help to provide context to the interview and allow the interviewer to gather targeted, relevant information regarding the student's needs.

Things to Consider...

- 1. What kind of interview will you do? Do you have the staffing, time, and general capacity to do an in-depth and comprehensive intake with the student?**
- 2. How much of the decision as to the depth of your interview will be determined by the documentation you receive (or don't receive)?**
- 3. How much of the decision as to the depth of your interview will be determined by the nature of the accommodation requests the student is making?**
- 4. How will you prepare for your intake interview?**

THE DOCUMENTATION DILEMMA

Service providers with different philosophies or in different settings do not necessarily look for the same kind of documentation in support of students with any kind of disability; thus, they will not all be looking for the same kind of information to document that the students who present with Long COVID are substantially limited by their symptoms and need accommodation for equal access. This will be compounded by the fact that not all students who present with Long COVID will have formal or comparable documentation available. Still, service providers will need to consider what documentation they want/need to see, as it will guide the kind of interview they do and the questions they ask. The Task Force recognized that there are parallels between the situation we face in looking for students in this new and unique situation with challenges we have faced in the past with other populations.

Service Providers Look for Different Types/Scope of Documentation for Other Disabilities

We Cannot Dictate Guidelines for Documentation of Long COVID

After some discussion, the Task Force members agreed that we would not attempt to develop a protocol for what is or is not acceptable medical documentation of Long COVID. In part, that was because we could not agree on what should be accepted/required. How formal or informal you want documentation to be is going to be mirrored in how formal or informal you want documentation of ANY disability to be on your campus – and we acknowledge that different institutions are all over the map in terms of what they are willing to accept. Your approach to what documentation you look for will be influenced by your philosophical leanings when it comes to service and support to students with disabilities. That philosophy does not change depending on the population of students to be served – nor should it.

Social vs Medical Model of Service (and of Documentation) (PP)

I think about how often I see that third-party documentation, most commonly referenced as "medical documentation" referred to in questions posted to the listservs and I suspect this will be the main tripping point for a lot of folks. "There's no medical documentation...." or "The medical documentation doesn't seem to support this...." etc. And so I am wondering if Long COVID may prove to be the crisis point for the "medical/social divide", if I can call it that, in the profession.

I haven't been in this work all that long - a little over six years. And I started in a bit of an unusual circumstance, at a different community college - me, completely new, my colleague, barely six months in the field. In a lot of ways, we learned together, by sharing and reviewing each other's appointments on a daily basis, by asking questions of our colleagues and by using our sense of "what is right and fair? What would help the student but doesn't advantage our student over other students in the class and doesn't modify the instructor's methodologies or intended outcomes? Because the other thing we brought, both of us having backgrounds in TRiO (and other social justice initiatives) was a lack of the history of the development of disability or access services. Because we had no immediate mentors, we developed our approach from what we knew, which was a "social" model of disability. Folks new to the profession are, at the most basic, trained on process as defined by colleagues who have been in the field longer, and by campus philosophies and cultures. I know from experience working with folks around my state that some of those campus philosophies continue to give great weight to "medical documentation".

As we may see many students with Long COVID who have little formal documentation, I wonder if what we are embarking on is a new, perhaps stronger wave of decoupling a medical document with access needs.

Does Formal Documentation Exist? Will It Help Us? (PP)

It would be great if we could provide some tips on how to evaluate the documentation of Long COVID. However, I am not sure what we might get or what students might be able to provide. Is Long COVID going to be like the early years of students with Fibromyalgia? Which was only diagnosed by ruling out everything else under the sun? The CDC currently has language that states overall, it is important for healthcare professionals to listen to and validate patients' experiences, recognizing that *diagnostic testing results may be within normal ranges even for patients whose symptoms and conditions negatively impact their quality of life, functioning (e.g., with activities of daily living), and ability to return to school or work.*

The documentation we receive may be a note from a doctor who is sharing symptoms and states they are ruling "in or out" various diagnoses. They, too, seem to be, "landing the plane while building the runway".

What Will Students Bring? (PP)

Should you ask for documentation?

According to the Mayo Clinic, Long COVID can cause organ damage in the brain, lungs, and heart; blood clots and blood vessel problems; problems with mood and fatigue. Other long term symptoms can include: fatigue, shortness of breath or difficulty breathing, cough, joint pain, chest pain, memory (concentration or sleep problems), muscle pain, depression, anxiety, and dizziness when standing. Due to the novelty of the pandemic situation there will be a lot of grey areas in terms of documentation and the types of documentation.

The importance of self-disclosure will be the most pertinent during this time. It was reported throughout the pandemic, in my rural area, that individuals were being advised not to be tested for COVID regardless of the symptoms they were experiencing. These individuals were informed to stay home for 14 days; for these types of individuals there will be no formal documentation of that time. These individuals are living with the after effects of COVID without formally being diagnosed with COVID. Some individuals who are experiencing Long COVID symptoms did not have a preexisting condition or disability and are struggling with a whole new aspect of their everyday life. These individuals may need the most assistance to understand how and why accommodations are utilized in a post-secondary setting.

Individuals with a preexisting condition or disability may be able to provide documentation related to their preexisting condition but are still experiencing Long COVID symptoms. If these individuals regularly need to see a member of the medical community for regular treatment of their preexisting condition or disability; they may be able to present you with documentation. However, some of these individuals may fit into the above category of not being able to provide documentation in regards to Long COVID. For all individuals' self-disclosure of their experience will be the most helpful. For all individuals asking questions regarding to their treatment plan; if they have one, will help determine if documentation is necessary. Any individual experiencing an active treatment plan will be able to provide documentation giving a description of the symptoms, diagnosis(es), and whether the symptoms have increased or decreased since the diagnosis. Other individuals will not be treated regularly and will only have their experience to share.

Echoes of Other Populations with Limited Documentation

Hurricane Katrina (PP)

In the aftermath of Hurricane Katrina, in 2005, there were an estimated 175,000 college students displaced from their home campuses. Colleges and universities across the country opened their doors to those students and said, "Just come. You can continue your education here until they are ready to have you back at your home institution. We'll worry about the paperwork later." That included several thousand students with disabilities (at the time, the estimate was that students with disabilities were close to 10% of the college population).

That meant there were students with disabilities showing up on college campuses (potentially a few here, a few there) who had NO documentation of their disability, NO likelihood of being able to get documentation, and who brought only their own self-report of their disability and need for accommodation. That seems pretty close to what we are facing with students with Long COVID today -- bewildered students who may show up at the disability services office with no documentation of the impact of their Long COVID, and no clear understanding of what WE need to know so that we can help them.

Back in 2005, we quickly pulled together a set of interview questions that folks could consider using in gathering information from these students. We divided the interview into two parts – the part that focused on academics for the student, and the part that focused on the students' broader adjustment to being in an unfamiliar environment. Perhaps there are parallels between that work and what is needed now.

Concussion Syndrome (PP)

In 2010 we started to see a dramatic uptick in students with concussions. Our Disability Services staff sought training from Brainsteps PA, (created by the PA Department of Health, and implemented by the Brain Injury Association of PA) and then had them present to the faculty and staff. One piece of the education at that time was to share that concussions are a real and significant injury, and that although a student might look fine, they actually may be experiencing some significant symptoms as a result of this TBI. Trainings and materials that we were identifying were geared to the K-12 system and not a good fit for our institution. As our number of students with concussion increased, the hodgepodge of documentation that we were receiving offered little guidance. Whether from a PCP, Urgent Care, ER, Trainer, Chiropractor, or another, the information did not tell us much more than "Yes, they are Concussed". Recommended accommodations, if there were any, weren't a good fit for Higher Ed. What to do?

We started by researching the domains that are impacted by a concussion (Physical, Cognitive, Emotional and Sleep) and risk factors such as History of Concussions, Headache, developmental disability, Psychiatric History, etc. We quickly knew that this was information we needed to be able to provide appropriate supports and that students were not reporting accurately, either on purpose or because they were not able to decipher the questions. I began to conversationally interview the students to give context to the questions. Initially when asked about headaches on a scale of 1 to 10 I would often get 10s. Later when I would give context of "on a scale of 1-10, 10 I am cutting your leg off with a chainsaw what number are your headaches" I would often get a different number and also a smile or chuckle. Another question that was significant was if a student was having difficulty with word finding. They would often say no but when I held my travel mug up and asked "what do you call the thing I am holding" you could see there was a lag, sometimes quite significant. We learned that it was not only the questions in the intake, but how we did the intake. These are only a few examples.

Back then we felt we were out there alone. There was no system in place, but we needed to find a way to figure out how to appropriately support these students. We knew they were eligible but not for what and for how long. We needed to know how it was impacting them and later we needed to re-interview them to see what continued to be appropriate as they were healing.

The parallels to the situation we face with student who present with Long COVID seem hard to miss. Students are presenting with Long COVID. We may even have clear documentation of it. Now what? What does that mean? What does that mean for the student, in HE? In a certain major? A student that also has other risk factors involved? How do we get a handle on it? It seems we have our work cut out for us!

KEY POINTS:

- How formal or informal you want documentation to be is going to be mirrored in how formal or informal you want documentation of ANY disability to be on your campus – and we acknowledge that different institutions are all over the map in terms of what they are willing to accept.
- Your approach to what documentation you look for will be influenced by your philosophical leanings when it comes to service and support to students with disabilities. That philosophy does not change depending on the population of students to be served – nor should it.
- The importance of self-disclosure will be the most pertinent during this time. Some individuals are living with the residual effects of COVID without formally being diagnosed with COVID. Some individuals who are experiencing Long COVID symptoms did not have a preexisting condition or disability and are struggling with a whole new aspect of their everyday life. These individuals may need the most assistance to understand how and why accommodations are utilized in a post-secondary setting.
- Individuals with a preexisting condition or disability may be able to provide documentation related to their preexisting condition but are still experiencing Long COVID symptoms.
- In the aftermath of Hurricane Katrina, students with disabilities were shifted to college campuses across the country with NO documentation of their disability, NO likelihood of being able to get documentation, and who brought only their own self-report of their disability and their need for accommodation. That experience seems to mirror what we are facing today with Long COVID – bewildered students who may show up at the disability services office with no documentation of the impact of their Long COVID, and no clear understanding of what WE need to know so that we can help them.
- The same was true in determining how best to support students with concussions when there was little support to suggest what they needed. The parallels to the situation faced with students who present with Long COVID are evident.

Things to Consider...

1. What kind of information will you look for in order to determine a student's legitimate need for specific accommodations? Will you want third party documentation, or do you think you will rely heavily on student self-report through the intake interview?
2. Looking at your answer to (1), consider the demographics of the student population at your institution. Will all students have equal access to the level of documentation you are seeking?
3. How will you handle requests from students who have either no documentation, or documentation that is inconclusive?

QUESTIONS TO EXPLORE



QUESTIONS TO EXPLORE

The questions you will ask will be highly dependent on your purpose in asking them. The Task Force speculated on various ways to group and present questions in an intake interview. Below you will find a bank of questions generated by Task Force members that may provide some ideas of things you choose to ask, followed by the individual perspectives of Task Force members, explaining how and why they would structure their information gathering. There is a great deal of overlap among these individual offerings (that is, questions that appear in more than one suggested list of questions). In the boxed "Things to Consider," this lengthy listing of possible questions to ask is summarized and grouped to allow the reader a quick reference to options in creating their own question bank.

Question Bank

The Task Force generated a Question Bank that readers may find useful. In some cases, the same question is asked in several different ways as you move through this listing. The hope is that the you will find something on the list that you might not have thought to ask that you drop into your own chosen interview format.

How Has COVID Impacted the Student's Life?

Experience with COVID

Have you had COVID-19? Were you formally diagnosed through testing, or was it based on the symptoms you experienced without formal testing.

What might be harder for you on campus now that isn't purely academic? For example, with your current situation, do you think it will impact your normal routine in the Dining Hall, or at the University Gym? Is there something we can do to make sure those services still work for you-

What were your daily routines like before having long-COVID and how have they changed? For example, sleeping routines, wake times, the need for rest during the day, meals, and other aspects of self-care?

What in life and/or school is harder to do now?

What is different for you now? Has there been a change in your ability to focus and retain information? Can you describe how that impacts on your classroom experience? What have you been doing to support the changes in your daily life?

- How has their daily routine/life changed?
- How did COVID impact them (hospitalization, ventilator, other)?

Are you now using medical devices or medications, and how time-consuming are these routines?

What in life and/or school is harder to do now?

Based on what you know about starting or continuing in your degree program, what tasks do you think will be difficult for you that would not have been as difficult before?

What frustrates you nowadays?

What about your life/things you're able to do is the same as before?

What kind of trajectory have you experienced thus far with your illness? Do you feel you're slowly improving, it's up and down, there are new surprise symptoms popping up...?

What kind of support do you have from friends and family?

How has your mental health been impacted (anxiety, depression, general outlook on the situation)? Do you feel hopeful? If experiencing challenges in this area, how have they impacted you and are you seeking therapy?

What are the top things you want to tell me/that you want people to understand about you and your life right now?

Are you working in addition to going to school? How many hours? When? How is that going—are you consistently working, have you had to take time off/reduce hours—what's your experience been like with maintaining your job since having COVID?

Have you felt that focusing on one task or finishing the task in a normal timeframe has been negatively affected since you had COVID?

Would you be able to explain how this 'brain fog' plays out in your day? What is different for you from pre-COVID?

What strategies or tools have you discovered that you're trying to utilize in your day-to-day life to try to adjust to (name a particular barrier/limitation)?

- What is your stamina like? Are there times of day that are better for you? Does your stamina fade gradually so that you are not aware of the change, or suddenly with little warning?
- In your daily life, what sorts of things are you doing differently?
 - Sleeping
 - Eating
 - Walking
 - School work
 - Work (if student is employed)
 - Interacting with friends/family
- Is there pain associated with your symptoms? In what part of your body are you feeling discomfort? Is the pain consistent, or does it vary across the day? Has the pain gotten better or worse since you first became aware of it? (A lot of the damage from virus initiated conditions like long COVID, comes with a pretty significant amount of peripheral nerve damage and there can be pretty intense pain that goes along with that. I don't have to tell you that pain is exhausting.)
- How does all of this make you feel? (This would be my way of getting at any mental health concerns... I am not a licensed therapist, but I am a super good listener and very good at referring when this sort of question gets a response outside my wheelhouse)
- Who are the people in your support network? Are they near or far? How often are you in contact?

It might be helpful to have a brief of what happened during COVID for the student. Were they hospitalized? On a ventilator? Did they recover at home? At what point did they realize they were

experiencing long haul?

When do you suspect that you contracted COVID? When did you first notice symptoms?

Have your symptoms changed at all from ____ to now?

Do you notice any changes in the severity of your symptoms...

- when you're managing a flare-up of your other disability(ies)? - For students who already have coexisting diagnoses besides long COVID
- when you're stressed?
- at certain times of day?

- What brought you here today?
- When were you diagnosed with COVID?

- Have your moods changed? In what ways?
- Do people comment on your moods more than they used to?

- When do you suspect that you contracted COVID? When did you first notice symptoms? *(I like this since many were told to stay home if they didn't need medical treatment, so many were not formally diagnosed)*
- Have your symptoms changed at all from ____ to now?
- Do you notice any changes in the severity of your symptoms with *changes in activity*?

Academic Questions

- On an average day, how long are you able to work on school work? How does this compare to before you had COVID?
- Are there times of day that are easier/harder for you to concentrate/do academic tasks?
- What have been the major academic impacts since your diagnosis and ongoing long-haul status?
- Are there certain accommodations you were wondering about before coming to the office that you think may make sense for you?

- What kind of classes are you taking this semester? What are the things that you anticipate needing to do in those classes for activities and assessments?
 - Take lots of notes?
 - Write lots of papers?
 - Lots of reading?
 - Lots of computer work?
 - Things that require lots of fine motor coordination?
 - Activities that require Physical strength?
 - Things that require a lot of cognitive effort?
 - Group projects?
 - Performances?
- How are you impacted in your classes?
 - Writing
 - Listening
 - Sitting
 - Attendance
- What about when you're working on assignments/projects?
 - Reading
 - Computer use
 - Writing
 - Research

- How comfortable are you with technology in general? What kinds of technology do you currently use on a regular basis? Are there specific symptoms related to screen use?

The following examples provide four very different formats for conducting interviews. These four Task Force members approach intake interviews with different goals and resources to intervene in a variety of ways.

Interviewing Students New to COVID... and Disability (PP)

For individuals who have not gone through an accommodation process before either in K-12 setting or post-secondary, building rapport and making sure the individual fully understands the process will be the most important. Start with broad questions about who they are, what major, and what made them seek out accommodations. After establishing the broad questions, you may want to ask more in-depth questions to help establish the necessity of accommodations. Some question samples are below:

- What did your day-to-day life look like before COVID?
 - Perhaps a walkthrough of a school day and a leisure day
- Activities enjoyed
- Symptoms still experiencing due to COVID
 - Have any symptoms lessened or disappeared since having COVID
 - Have any symptoms stayed the same or worsened since having COVID
 - Have any other diagnoses occurred due to COVID
 - What type of barriers are you facing in your classes with these symptoms
 - What type of barriers are you facing in your leisure activities
 - What modifications have you needed in these activities to make them enjoyable
 - Walkthrough a typical school day and leisure day
- Self-assessment piece
 - Students are given a sheet with “typical” areas of struggles (eg. Short-term memory, “brain fog”, note-taking, etc.)
 - Students circle/choose their areas of struggle
 - The intake can be guided by what the student has indicated is currently a struggle
 - Things that have worked so far
 - Things that have not worked
 - How is it different than before COVID diagnosis

In-Depth (Branching) Interview (PP)

General/Background Information

I would start with general information to get an understanding of the student’s concerns and needs. Since many students experiencing Long-COVID may not have supporting documentation (or those that do may have very vague documentation), I would ask questions that compare pre- and post-COVID to get an understanding of how Long-COVID is impacting them currently and how its impact has changed over time.

- Overview
 - What brought you here today?
 - What piqued your interest in exploring potential accommodations? (*This question may*

prompt them to share specific examples of things that have changes or activities that have been impacted recently.)

- Who referred you to the DSS office (physician, professor, other)? *(I'd be interested to know what happened and/or what the student disclosed to encourage the referral.)*
 - Are there certain accommodations you were wondering about before coming to the office that you think may make sense for you? *(If the student has thoughts, branch to specific accommodations questions.)*
 - History of COVID
 - When do you suspect that you contracted COVID? When did you first notice symptoms? *(Many were told to stay home if they didn't need medical treatment, so many were not formally diagnosed.)*
 - Were you formally diagnosed? Did you have a positive test?
 - Did you have any symptoms?
 - Did you receive any formal treatment from a healthcare provider? (hospitalizations, ventilator, other)
 - Have your symptoms changed at all from ___ to now? (Improved? Gotten worse? Varies?)
 - Do you notice any changes in the severity of your symptoms
 - when you're managing a flare-up of your other disability(ies)? - For students who already have coexisting diagnoses besides long COVID
 - when you're stressed?
 - at certain times of day?
 - when you're doing certain activities?
 - Have you been working with a healthcare provider to manage symptoms? Have they made any recommendations?
 - Physical Health
 - Any other relevant diagnoses? *(e.g. Students with well-controlled ADHD may notice more significant symptoms post-COVID.)*
 - What do you need to do now to take care of yourself in terms of doctor appointments (whether virtual or in-person), using medical devices and medications, etc. and how time-consuming are these routines?
 - Have you noticed any difference in your class attendance? Have there been any academic consequences for your attendance?
 - What is your stamina like? Are there times of day that are better for you? Does your stamina fade gradually so that you are not aware of the change, or suddenly with little warning? *(If concerns, branch to "Academic" and "Labs, Clinicals, Experiential Learning.")*
 - Is there pain associated with your symptoms? In what part of your body are you feeling discomfort? Is the pain consistent, or does it vary across the day? Has the pain gotten better or worse since you first became aware of it? *(If concerns, branch to "Academic" and "Labs, Clinicals, Experiential Learning.")*
 - Mental Health
 - Have you noticed any changes to your mental health recently (e.g. depression, anxiety, etc.)?
 - Do you have access to mental healthcare (e.g. therapist)? Do you have a support system in place (e.g. family, friends, etc.)?
- * Refer to campus Counseling Center, if needed.

- Routines
 - What were your daily routines for self-care like before having long-COVID? (e.g. dietary, sleep schedule, relaxation, etc.)? Have any of your routines changed? If so, how? *(If residential student, branch to “Residential”.)*
 - What were your daily routines for academics like before having long-COVID? (e.g. homework, studying, etc.)? Have any of your routines changed? If so, how?
 - Are you working in addition to going to school? How many hours? When? How is that going—are you consistently working, have you had to take time off/reduce hours—what’s your experience been like with maintaining your job since having COVID? *(If concerns, branch to “Labs, Clinicals, Experiential Learning.”)*
- * Refer to campus resources (Counseling Center, Tutoring Center) and assistive technology (e.g. timer, scheduler), if needed.
- Activities
 - What in life and/or school is harder to do now? What have you been doing to support the changes in your daily life?
 - What about your life/things you’re able to do is the same as before?
 - What might be harder for you on campus now that isn't purely academic? For example, with your current situation, do you think it will impact your normal routine in the Dining Hall, or at the University Gym? (and what can we do to make sure those services still work for you...)
 - What strategies or tools have you discovered that you're trying to utilize in your day-to-day life to try to adjust to (name a particular barrier/limitation)?

Based on the information gathered from the previous questions, I may (or may not) ask specific questions about the University activities/programs that may be impacted:

Academics

- Have you noticed any changes in your academics/grades recently?
- What areas of academics have historically been your areas of strength? Have any of these activities changed post-Long-COVID? What areas of academics have historically been your areas of weakness? Have any of these activities changed post-Long-COVID? *(Ask specific questions about challenges.)*
 - Can you please share more about the challenges of (activity) ? Do you have any examples of how this activity has been impacted recently?
 - Reading *(Do you read at a slower pace than usual? Do you need to reread more often?)*
 - Memorizing *(What sorts of things have you forgotten recently? Any non-academic examples, such as meetings or chores?)*
 - Processing speed *(How long does it take you to complete a reading assignment (5-10 pgs.) for a course? Does it vary based on the content/subject?)*
 - Writing
 - Sitting/standing
 - Oral expression
 - Attention/Distractibility *(What sorts of things tend to be the most distracting for you?)*
 - Mental stamina
 - Listening in class

- Note-Taking (*Are you taking too many notes? Too little? Are you getting distracted and missing things? Are you having trouble distinguishing what's important?*)
 - Testing (Have you completed your tests on time? If not, what percentage is remaining? Are you able to check your work?)
 - Completing homework
 - Managing stress/anxiety
 - Computer work (*What computer-based activities are particularly challenging/limited – for example, prolonged screen use?*)
 - Working in groups
 - Speaking in front of people
 - Attendance
- If the student talks about attention, focus, fatigue, pain, brain-fog, and/or lack of stamina, you may want more specific examples of the severity of these symptoms. You may want to ask:
 - On an average day, how long are you able to work on assignments/school work? How does this compare to before you had COVID?
 - Have you felt that focusing on one task or finishing the task in a normal timeframe has been negatively affected since you had COVID?
 - Would you be able to explain how this 'brain fog' plays out in your day? What is different for you from pre-COVID?
 - Are there times of day that are easier/harder for you to concentrate/do academic tasks?
 - What kind of classes are you taking this semester? What are the things that you anticipate needing to do in those classes for activities and assessments?
 - Have you utilized any non-accommodations resources to manage your symptoms? (e.g. Writing Center, Tutoring Center, assistive technology, etc.)
 - Based on what you know about starting or continuing in your degree program, what tasks do you think will be difficult for you that would not have been as difficult before?

Labs, Clinicals, and Experiential Learning (*for example, student teaching, medical rotations, and so on*)

- What does your (clinical rotation, field placement, etc.) schedule look like this year?
 - Do you have any concerns about maintaining stamina throughout the scheduled time period? (*Some clinical rotations are 8+ hours and students may need to consider having a modified schedule*)
 - Do you find yourself needing to take breaks throughout the day? Do you expect that you may need breaks during your clinical placement?
 - Do you have any concerns about your symptoms being more pronounced during this time of day? (*Many labs are conducted in the evening; a student may have significant fatigue after a whole day of classes and/or after medication wears off. It may also be an issue if they have new issues with their sleep schedule/routine.*)
- What does the day-to-day activities consist of? Do you have any physical limitations that we would need to be aware of? (*If the student is unsure, I would recommend looping in the clinical education coordinator. Some clinical rotations may involve physical activity, like lifting patients, which could be a barrier for those with fatigue and/or chronic pain.*)

Residential

- Where have you been living since you started experiencing symptoms? (At home or in residence hall?)

- Have you noticed any challenges/barriers to daily-living?
- Do you anticipate having any physical limitations to access in the residence hall? (climbing stairs, walking to the restroom, other)
- Do you anticipate having any social limitations to access in the residence hall? (for example, maintaining self-care while sharing a room)
- Have you noticed any challenges while living with others post-COVID (roommate conflicts, challenges with routine, and more)? Do you have any new routines that may need to be discussed with a roommate beforehand (sensitivity to light, need for mid-day breaks/naps)?
For those who lived at home, they may have examples from living with parents, siblings, etc.

Other Considerations for Certain Populations

- Be mindful that some students who come from low-income families or live in medically underserved areas may have less access to medical care and may not have received any treatment for Long-COVID and may lack supporting documentation.
- Be mindful that some cultures emphasize high-expectations and working hard; some students may feel like they are failing by asking for help/accommodations.
- This process may be unfamiliar for students who do not have a history of a disability and/or may not identify as being disabled. It's important to encourage them to advocate for themselves and not be hesitant to share if they have concerns, if their needs change, or if something isn't working.
- Be mindful that any questions surrounding the history of COVID are framed in an informative sense, rather than a judgmental sense. For example: We want to know when they first noticed symptoms to compare their symptoms from the beginning until now. We don't necessarily need to know *how* they got COVID. For our purposes, it doesn't matter if they got COVID safe at home or at a crowded concert.
- For professional/graduate students or students who plan to take national exams (GRE, MCAT) – it will be important to be transparent about the process for obtaining accommodations for national boards/exams. It's not clear at the moment whether these agencies will be as flexible with documentation requirements for students with Long-COVID. These students may need notice to pursue additional testing and/or obtain documentation, if needed.

Follow-Up (Annually?)

Since Long-COVID may affect students differently, I think it would be important to follow-up regularly. Some symptoms may subside and not require accommodations. Other symptoms may change or arise over time.

- When we spoke last on (date) , you reported some challenges with (activities: sleeping, reading) , Can you share some updated information about how you are doing currently?
- Have you taken any steps or utilized any strategies to manage Long-COVID, aside from utilizing accommodations (speaking to their clinician, utilizing AT, using campus academic resources, changing routines)?
- What accommodations have you used this year?
- Are there any accommodations that you haven't used? If so, why?
- What challenges/barriers do you anticipate this upcoming year?
* Make a plan for your next check-in.

Active Listening Leads The Way (PP)

My intake appointments with students are generally about an hour in length... I do that because I firmly believe that it takes at least that much time for the student to tell me their story. I do not ever have a structured list of questions that I use, but I have been doing this for a long time. I always begin with something along the lines of “tell me why you’re here”. I find that as long as I am on my game with active listening, I find out a great deal more than if I have a list of 20 questions to run through.

I definitely see this as a branching interview process. If I find out that a student is experiencing a lot of fatigue pain and brain fog, I will go down one road. If, while I am on that road, I find out that this is a student who sees their computer as something to be terrified of then I will modify my approach. I think that’s why I have only two major categories. The if/then possibilities are gigantic and probably worthy of a section all their own! With that in mind:

Introductory Questions

- What brought you here today?
- What were your daily routines like before having long-COVID and how have they changed? For example, sleeping routines, wake times, the need for rest during the day, meals, and other aspects of self-care?
- What is your academic story?
 - In what areas did the student excel/do well?
 - What have been consistent challenges?
 - What resources have been [consistently] available to the student?
 - What has been helpful/what has not?
- What is different for you now? Has there been a change in your ability to focus and retain information? What have you been doing to support the changes in your daily life?
- When did you notice the changes?
- What in life and/or school is harder to do now?
- What do you need to do now to take care of yourself in terms of doctor appointments (whether virtual or in-person), using medical devices and medications, etc. and how time-consuming are these routines?
- Based on what you know about starting or continuing in your degree program, what tasks do you think will be difficult for you that would not have been as difficult before?
- What frustrates you nowadays?
- What about your life/things you’re able to do is the same as before?
- What kind of trajectory have you experienced thus far with your illness? Do you feel you’re slowly improving, it’s up and down, there are new surprise symptoms popping up...?
- What kind of support do you have from friends and family?
- How has your mental health been impacted (anxiety, depression, general outlook on the situation)? Do you feel hopeful? If experiencing challenges in this area, how have they impacted you and are you seeking therapy?
- Are you working in addition to going to school? How many hours? When? How is that going—are you consistently working, have you had to take time off/reduce hours—what’s your experience been like with maintaining your job since having COVID?
- What are the top things you want to tell me/that you want people to understand about you and your life right now?

- What might be harder for you on campus now that isn't purely academic? For example, with your current situation, do you think it will impact your normal routine in the Dining Hall, or at the University Gym?

Drilling Deeper

Once I had gathered enough information to get me a sense of the barriers that the student was experiencing (both the ones that they were able to articulate and some others that I might notice without being explicitly told) along with the ones they had been able to manage themselves, I would move into the second part of the interview, where we would talk about ways to mitigate those barriers. Sometimes this means learning how to use a calendar effectively, or use software to assist with notetaking, or books in a format that would allow the student to listen to them instead of just reading them or making modifications to the testing environment. At a different institution from mine, it might be priority scheduling... That is not an option for us because we are small enough that our course offerings are pretty tightly structured, but I can see it being a possibility somewhere else. We might talk about a single room for medical reasons. The student is always the baseline for this conversation. My suggestions have to be rooted in who they are as a whole person. Technology solutions might work really well for someone who saw technology as an opportunity to make themselves more efficient, but I would be more cautious with someone who saw technology as an additional barrier.

- What is your stamina like? Are there times of day that are better for you? Does your stamina fade gradually so that you are not aware of the change, or suddenly with little warning?
- In your daily life, what sorts of things are you doing differently?
 - Sleeping
 - Eating
 - Walking
 - School work
 - Work (if student is employed)
 - Interacting with friends/family
- Is there pain associated with your symptoms? In what part of your body are you feeling discomfort? Is the pain consistent, or does it vary across the day? Has the pain gotten better or worse since you first became aware of it? (A lot of the damage from virus initiated conditions like long Covid, comes with a pretty significant amount of peripheral nerve damage and there can be pretty intense pain that goes along with that. I don't Have to tell you that pain is exhausting.)
- How does all of this make you feel? (This would be my way of getting at any mental health concerns... I am not a licensed therapist, but I am a super good listener and very good at referring when this sort of question gets a response outside my wheelhouse)
- How comfortable are you with technology in your daily life? What sorts of technology do you use on a regular basis?
- On an average day, how long are you able to work on school work? How does this compare to before you had COVID?
- Are there times of day that are easier/harder for you to concentrate/do academic tasks?
- What have been the major academic impacts since your diagnosis and ongoing long-haul status?
- Are there certain accommodations you were wondering about before coming to the office that you think may make sense for you?
- What kind of classes are you taking this semester? What are the things that you anticipate needing to do in those classes for activities and assessments?

Exploring Symptomology (PP)

I use a list of topics that I skim through when doing my concussion intakes that I feel may be useful for students with Long COVID, as well. They fall under different domains. I think breaking it into domains allows for skimming when *strategically diving deep*. That way, if I hear something that gets my Spidey sense tingling, then I will go deeper in that area. I also ask about their diet and substance intake. That may seem intrusive to some, but I find it useful. As a former prevention specialist, I have seen how substances, legal or not, impact a student's cognition. If you are drinking 5 pots of coffee and taking 5-hour energy drinks this may be impacting your anxiety?

Somatic/Physical symptoms

Headaches

Light Sensitivity

Nausea

Noise Sensitivity

Fatigue

Numbness/Tingling

Visual Problems (focusing, blurry vision...)

Vomiting

Balance Problems

Dizziness

Tinnitus

(COVID)

Sense of taste

Sense of smell

Both could be important for students in dietetics, food science, maybe chemistry

Hearing

Voice (where they intubated and has it affected their voice? Music majors)

Cognition

Feeling mentally foggy

Problems Concentrating

Problems Remembering

Thinking Slowly

Word Finding ("this thing I am holding in my hand is a.....Mug")

Emotional/Behavioral

Irritability

Sadness

Feeling more Emotional

Nervousness (do not use the word Anxiety in intakes. *Everyone* has anxiety. It has become a persona so I ask, are you feeling nervous or jumpy?)

Sleep

Drowsiness (If you closed your eyes and I stopped talking would you fall asleep on me?)

Sleeping more than usual

Sleeping less than usual

Trouble falling asleep

Multiple awakenings

Substance intake

Caffeine

Alcohol

Marijuana

Other Drugs

Supplements

Rx's

KEY POINTS:

- There is no single template of questions to suggest for an interview with a student presenting with Long COVID. Service providers should decide what questions to ask based on their own style, circumstances, and purpose in asking.
- Don't ask questions if you have no reason to know the answer. If the information would not change what you can/will do for the student, there is no reason to ask it.
- Some service providers choose to explore non-academic areas of functioning, while others may focus solely on how COVID-related symptoms impact on academics and on requested accommodations and support.
- The evidence suggests that the impact of Long COVID symptoms is likely to change over time (sometimes dissipating, sometimes getting worse), and there is insufficient data to know what the timeframe should be for re-evaluation. We do know it is likely to be less than a full academic year. In other words, while you normally assign accommodations at the beginning of the school year and leave those in place for that academic year, the status and needs of students with Long COVID should probably be reassessed more frequently.

Things to Consider...

The following topic and question list highlights some of the broad themes across the different PP that were shared by the task force. While this list can be a good starting point guide conversations with students, readers are encouraged to review the various PP for more in-depth insight on the respective topics.

1. Details on COVID Diagnosis and history, such as...
 - a. When diagnosed?
 - b. Symptoms still experiencing due to COVID?
 - c. Have any symptoms lessened or disappeared since having COVID?
 - d. Have any symptoms stayed the same or worsened since having COVID?
 - e. Have any other diagnoses occurred due to COVID?
2. Other health matters relevant to this discussion, such as...
 - a. Other diagnoses?
 - b. Changes in mental health?
3. Why seeking accommodations now, such as...
 - a. What brought you here today?
 - b. What peaked your interest in exploring potential accommodations?

Things to Consider...(Cont.)

4. Classroom Impact, such as...
 - a. What type of barriers are you facing in your classes with these symptoms?
 - b. What is your most pressing academic concern right now given your schedule this semester?
 - c. What course activities (lectures, tests, assignments, notes, reading, etc.) are harder now or more frustrating to do/experience?
 - d. What course activities have not been impacted in anyway?
 - e. Have you tried any new strategies to address your concerns?

5. Life Impact, such as...
 - a. What type of barriers are you facing in your leisure activities?
 - b. What life activities are harder now or more frustrating to do/experience?
 - c. What course activities have not been impacted in anyway?
 - d. Have you tried any new strategies to address your concerns?

6. Work impact, such as...
 - a. What type of barriers are you facing in your work environment?
 - b. What work activities are harder now or more frustrating to do/experience?
 - c. What course activities have not been impacted in anyway?
 - d. Have you tried any new strategies to address your concerns?

7. Community support, such as...
 - a. In what ways are you connected on campus?
 - b. What campus resources do you routinely utilize?
 - c. What kind of support do you have from friends and family?

FACILITATING ACCOMMODATIONS



FACILITATING ACCOMMODATIONS

Once you have gathered information about the student with Long COVID, it is time to consider what, if any, support or assistance can be given to the student. Accommodations are provided to students who have substantial limitations, in order to assure that they have full access. Is the student substantially limited by the lingering symptoms? How will you determine appropriate accommodations? Some favor going from symptoms, to functional limitations, to accommodations. Some favor looking at what accommodations are available and matching them with the information gathered in the intake interview. Are there limits to what can be provided in the name of access? In the pages that follow, all of those questions are explored.

Access vs Success

The purpose of accommodations is to ensure that students with disabilities have access to the educational experiences and opportunities that are available to all other students in attendance at a college or university. As such, we (DSS providers) have an obligation to consider each student on a case-by-case basis, to engage in an interactive process with that student, and to determine what, if any, reasonable accommodations are necessary to provide access, and thus, prevent discrimination.

While we want all students to be successful, and while accommodations may increase the chances of success for a student with a disability by providing access to certain opportunities, this is not the purpose of accommodations. Nevertheless, Section 504 and the ADA provide a floor, not a ceiling with respect to what we can do to ensure access for students; therefore, post-secondary institutions often vary in terms of the types and degree of accommodations and support they are willing to provide in order to enhance the chance of success for their students.

Difference Between “Accommodations” and “Supports”

Colleges and universities have a legal and ethical responsibility to ensure that qualified students with disabilities have access to the same opportunities available to all other students at the institution. While accommodations are provided to help the institution meet these mandates for access, many colleges and universities offer other student support options to enhance the chance of success for all students. Some examples of these success-based options include, content tutoring, academic coaching, and peer advising. In addition, many DS offices have started offering additional supports for students with certain types of disabilities. For example, mentoring support for students on the autism spectrum has become a popular option of late to increase retention for this population. These support options are not legally or ethically required by the institution; however, if they are provided, they must also be accessible for students with disabilities.

Determining Accommodations for Long COVID

Is Long COVID Really So Different?

Yes, it's true, our offices may be faced with a growing wave of students who, through no fault of their own, will have ambiguous documentation, little sense even themselves of what symptoms and problems they have (which will change over time), and we will receive no authoritative understanding/guidelines from the medical community at all (because long-COVID is too new) to provide standards for us to work with.

It is also true that we do not have case law or a history of complaints and resolutions to guide us with respect to the outcomes for Long COVID. There is a broad array of symptomology for Long COVID students, which includes both things that could impact on academics and long-term health consequences. More, the symptomology could be intermittent and is likely evolving for many students (that is, what answers you get from the students today may be different six weeks from now – better or worse!!!). In addition, we can't be sure whether we are dealing with one population of students with Long COVID or two – or is it more? There are certainly going to be long haulers who have never had difficulties (disability-related symptoms) before, and are struggling both to manage and to acknowledge the problems they are dealing with now. But there are also going to be students with disabilities – students known to the DSS office and already working with us BEFORE we had ever heard of COVID – who are going to be experiencing different or exacerbated impact of their disability because of their Long COVID experience. What about students who are experiencing Long COVID symptoms and don't recognize it?

While there is a lot that we don't know, we do know that Long COVID can be a disability (i.e., results in a substantial limitation in a major life activity). And once we accept this notion, and recognize that the research regarding the long-term effects is ever-evolving, then we need to focus on what we can do to assist all of us with "landing the plane while building the runway."

If Long COVID is a disability, then why wouldn't we approach the question of accommodations and support options in a manner consistent with what we have always done – look at how and to what degree the student is impacted in a major life activity, identify reasonable accommodations for access purposes, and refer students to other student support services as needed?

One way to approach this is to start with the symptoms experienced by the student:

Common Symptoms of Long COVID:

- Tiredness or fatigue
- Difficulty thinking or concentrating (sometimes called "brain fog")
- Shortness of breath
- Headaches
- Dizziness on standing
- Fast-beating or pounding heart (known as heart palpitations)
- Chest pain
- Cough
- Joint or muscle pain
- Depression and/or anxiety
- Fever
- Loss of taste or smell

Once you know what and how severe the symptoms are, the next question is how do these impact on the student's learning and/or other major life activities:

What Are the Potential Impacts on Learning/Major Life Activities?

- Caring for oneself
- Performing manual tasks
- Seeing
- Hearing
- Eating

- Sleeping
- Speaking/communicating
- Breathing
- Learning: reading, concentrating, thinking, writing, communicating
- Interacting with others
- Working

As Long COVID is the new kid in town, it could be helpful to think about this in terms of what we already know about certain disabilities and their impacts on students' educational experiences:

How is This Similar to Disabilities We Already Accommodate?

Examples:

Difficulty thinking or concentrating often impacts ability to focus on the task at hand as well as short term and working memory. These are common impacts for students with ADHD, Concussions and TBIs.

Shortness of breath or difficulty breathing can impact walking, physical activity in general, and concentration. These are common impacts for students with mobility impairments, Cystic Fibrosis (and other pulmonary-related health issues), and POTS.

Once you have established the functional impacts and barriers experienced by the student, this should allow you to determine potential options for reasonable accommodations and other supports:

What Are Some Possible Accommodations?

Examples:

- Extended time on tests
- Reduced distraction testing
- Audio recording for classes
- Note taking support
- Alternative text materials
- Priority scheduling
- Reduced course load

What Other Possible Supports Exist at Your Institution?

Acknowledging the Limits of What Can/Should be Done for Students with Long COVID

A reasonable accommodation is one that provides the student with an equal opportunity to participate, without discrimination, in a course, program, or service. The purpose of accommodations is to ensure equal opportunity to be successful, but accommodations DO NOT guarantee success.

When meeting with a student we need to determine if the student is a student with a disability. In this case, does long-haul COVID rise to the level of a disability in which the person is substantially limited in one or more major life activities? If so and as we gather information on the life activities in which the student is substantially limited, we then need to determine if the requested accommodations are

logical and reasonable relative to the disability. Eventually, we may have to determine if the accommodation is reasonable to certain courses. For long-haul COVID, consider facilitating accommodations in the same way as you do with other disabilities and accommodations. Apply accommodations that would address where the student does not have equal access due to an academic barrier in conjunction with the student's substantial limitation, such as more time for exams (perhaps due to brain fog and slower processing), a note-taker (perhaps due to difficulty concentrating on verbal information while writing simultaneously) or alternative text (perhaps due to slower reading or poor reading concentration).

We may see a wider range of long-haul COVID impacts compared to what we may see for other disabilities, such as ADHD. The impact may be highly unique to an individual. Applying accommodations may require some additional consideration in order to determine what is reasonable. However, determining reasonable accommodations will always go back to the goal of ensuring equal access. Given the uncharted territory here, our professional judgment and our professional assessment will be very important. Students and the campus community may be reliant on us to connect the dots in appropriate equal access ways.

Planning to Accommodate Students with Long COVID (PP)

Students need to have an understanding of the difference between access and success in terms of accommodations. A key point will be to make sure a definition and/or example of both and stress that accommodations are to remove the academic barrier. Even individuals who have a history of receiving accommodations may not fully understand the difference. This also leads to the opportunity to explain that accommodations may change depending on the class and academic barrier and how that process works.

Tutoring and office hours may be a valid support for students with or without accommodations but wouldn't be considered an accommodation. Having a list of available supports at the college but also in the community may be beneficial for students as they navigate through this process. I have a list of available community supports that range from food banks to mental health providers and more that are available to all students. Students are reminded of supports available on campus and shown how to access them from the website or connecting them directly with the person.

My approach for accommodating students with Long COVID will rely a lot on the experience of the student, their major, as well as continuation of care. With Long COVID being such a novelty, I think there will be a need to check in with these students a bit more often to begin with as symptoms can increase, decrease, or new ones appear. This will look like more contact with these students via text, email, or phone call as needed until symptoms are stabilized. To determine the types of accommodations; a list of symptoms they are experiencing along with frequency will be used to develop a flow chart. This flow chart coupled with what they are doing now to combat the symptoms, for example: wearing sunglasses for light sensitivity, and the academic barriers they are experiencing will help to determine accommodations.

KEY POINTS:

- The purpose of accommodations is to ensure that students with disabilities have access to the educational experiences and opportunities that are available to all other students in attendance at a college or university
- The purpose of accommodations is to ensure equal opportunity to be successful, but accommodations DO NOT guarantee success.

- Accommodations are provided to students who have substantial limitations, in order to assure that they have full access.
- While there is a lot that we don't know, we do know that Long COVID can be a disability (i.e., results in a substantial limitation in a major life activity).
- If Long COVID is a disability, then why wouldn't we approach the question of accommodations and support options in a manner consistent with what we have always done
- Apply accommodations that would address where the student does not have equal access due to an academic barrier in conjunction with the student's substantial limitation.

Things to Consider...

1. What are the student's Long COVID symptoms? What are the substantial limitations the student is reporting?
2. Do the symptoms and impacts seem similar to other accommodated disabilities? If so...
3. What types of accommodations are provided to create equal access for similar functional limitations?
4. What does the student need for equal access? Would the accommodations address equal access or rather promote student success?
5. What academic barriers does the student report?
6. What accommodations would reasonably address those academic barriers?

TIPS/TRICKS/STRATEGIES/RESOURCES



TIPS/TRICKS/STRATEGIES/RESOURCES

Throughout the course of our conversations, folks offered up ideas that had worked for them, and might work for others in reaching out to students. Some of these tips/tricks/strategies are specific to issues of Long COVID. Others are generic. They are about ideas that have been used successfully with students, not specifically about students with Long COVID. They are offered here in the hope that you may find something useful to incorporate into your interactions. The resources provided are divided into two sections. There is an annotated bibliography of some of the articles found online that seem particularly cogent to our discussion, and some additional resources that give a broader picture of the state-of-the-art for students experiencing symptoms of Long COVID.

Strategies That Address Inability to Focus, "Brain Fog" (PP)

- Students with this symptom are unable to stay focused on a long-term task or feel overwhelmed easily with a complex project. What would you consider could help them best in the classroom?
- Accommodations: extended time on a long exam or an exam with critical thinking questions, breaking up long projects into parts, one-on-one progress checks with the instructor
- Extended time on a long exam or an exam with critical thinking
Students can easily feel worn out quicker than they used to so the extended time will give them a chance to rest their eyes and regroup. If blank paper was allowed, it would give the student time to organize their ideas through mind mapping for drawing a chart
- Breaking up long projects into parts
Example of one of these projects: instructor assigns summaries of each chapter at the end of the semester
Instead of turning in these chapter summaries all at the end, the student could turn in a few at a time and receive a grade. This gives them a check on the progress so they can improve and allows them to not feel so overwhelmed if they had to do the chapter summaries all at once at the end of the semester along with everything else due for their other classes
- One-on-one progress checks with the instructor
This one is not as important as the other two but I feel in terms of focusing, receiving feedback helps a person focus better than if they are not receiving feedback on how to improve on their assignments or exams

I suggested these because I feel I had (and sometimes still have) brain fog after I had COVID. These are some things that if I was a student I think would help me most. In undergrad and even grad school, I did so well at focusing and managing my time. When I got this job in 2017, I prided myself for how well I could multitask. This year and last year, though, I'm very forgetful, it's hard for me to focus for a long period of time, and I'm very easily distracted. I know age and burnout can cause this, but I fully believe my issues are also Long COVID

Is Long COVID a Temporary or Permanent Disability? (PP)

I agree that the impact of Long COVID may change over time, but I don't necessarily think that leads to a distinction between a temporarily disabling condition and a permanently disabling condition. For what it's worth, I feel roughly the same way about head injuries. You can get better, but it doesn't mean that the damage is all gone and that the symptoms won't recur. I am way more inclined to deal with the now. If the symptoms abate sufficiently that the student no longer requires accommodations,

or requires fewer accommodations, that would be something that would be uncovered as time passed. One of the reasons that I like to check in with students at least every semester is for this very reason. Things change. Different faculty organize their classes differently, students mature in their ability to manage themselves... And symptoms improve or deteriorate.

Recognizing the Transient Nature of Symptoms (PP)

Can we ever really determine long-term accommodations for COVID, or do we need to go semester-by-semester for now? I believe that anyone with what can be a transient condition have to be reevaluated each semester. While they may still be eligible, they may be eligible for different things. Will someone with Long COVID who needs extra time for exams today due to brain fog really need it in 2 years? How will we know? How will doctors know? Unfortunately, it is likely that they won't know on an individual level. It is much like students that have Post concussive syndrome or Fibromyalgia. There will have to be a certain amount of trust in the self-report.

Pacing Is Important (PP)

The concept of pacing and managing for an even, predictable output of energy seems to be surfacing as a way to improve engagement in life activities. For students with Long COVID, service providers may want to consider offering some "disability" specific coaching, when possible. This might include strategizing with the students on how to pace themselves to maximize their energy. It could include executive functioning strategies that would help minimize the impact of the brain fog. Sometimes we can look at a student's class or personal schedule and can "see" the train wreck about to happen but they cannot (especially if they have never had to consider any of these things before). I think it is also important to be sensitive that they may be scared by these changes and perhaps grieving the losses (perceived or anticipated) of their function or ability.

We may also be able to strategize with coaches about the participation of student athletes in non-mandatory practice and conditioning.

Strategies for Self-Management (PP)

Here are some ideas that might be useful to students with Long COVID in managing their time and energy.

- Listen to music while working independently
 - When doing homework and having difficulty staying on task: Set a timer to go off every X number of minutes. When it does, check to see if you are paying attention to what you're doing and working effectively. If you find that you keep drifting and just can't get into it, step away and take a break before trying again.
 - If doing art or writing, step away from your work periodically. When you come back to it, you see new things, or you might find that you're done, which can be a hard place in your work to identify.
 - Find a place on campus to store materials that you don't need to take home every night so that you have less to carry
- * Students with concussions who are photosensitive sometimes wear sunglasses or a baseball cap to class

Strategies for Students Experiencing Executive Functioning Difficulties

A lot of these symptoms can fall under the umbrella of executive functioning (e.g. brain fog, concentration, fatigue). We often have students come to the office with ADHD, concussions, etc., and

they'll report academic challenges that wouldn't necessarily fall under accommodations. The most common one we hear is "I have trouble with procrastinating. I can't prioritize my assignments and I get distracted while working at home." We've seen this even more frequently during the remote learning period. I've gotten in the habit of providing a list of free or low cost AT that students can use on their personal devices to address these challenges. A while back, I was at an AHEAD conference and someone from Augsburg shared an [AT resource](#) on their website; I am a big fan of it because it's very extensive and categorized based on the need to be addressed. I think a lot of these executive functioning tools would be relevant for long haulers:

- audiorecording or notetaking supports (if they have issues remaining focused for longer classes)
- to-do lists (for managing all of their assignments)
- mindfulness/anxiety-management apps (e.g. Calm)
- distraction-reduced browser tool for homework

Accommodations we've used before for brain injuries:

- Extended time on tests
- Breaks during tests (in-room)
- Getting PPTs 24 hrs in advance for advanced review and to print (if needed in paper form)
- Use of assistive technology (e.g. read aloud, speech to text, etc.)
- Alternate materials (e.g. digital or large print)

This isn't an accommodation, but I would also encourage students to use campus-wide supports (Tutoring, Writing Center, Counseling, Health Center, etc.), as some of them may have heard of them, but never used them or needed them pre-COVID.

<https://www.augsburg.edu/class/groves/assistive-technology/everyone/>

Short (Stray!) Tips

In terms of long haulers and fatigue, if possible, having the student describe when (time(s) of day) and how the fatigue hits (is it a walking break, nap, etc.). Some accommodations for the low energy are food/drink in the classroom, breaks in the classroom, breaks out of the classroom not to exceed XX amount of time out of class, having student switch to a different class time when the student did not experience low energy, and taped lectures.

Accommodations for head injuries or concussions include extended time, breaks during exam (in room), assistive technology (text to speech, speech to text), enlarged font, scribe, and inverted colors (this can be done by anyone now on technology but not all students realize that it can be done or how to do it with LMS). All of these might be useful for long-haulers.

We talk with students who have fatigue and attention issues about using a modified pomodoro or chunking method for doing homework and staying current in class. The literature around Long COVID seems to parallel some of the work that has been done with Chronic Fatigue/ME and Fibromyalgia. The concept of pacing and managing for an even, predictable output of energy seems to be surfacing as a way to improve engagement in life activities.

<https://todoist.com/productivity-methods/pomodoro-technique>

Online Sources of Interest

RESOURCES From Federal Agencies

Guidance on "Long COVID" as a Disability Under the ADA, Section 504, and Section 1557 (Health and Human Services)

<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html>

Post-COVID Conditions (Center for Disease Control))
<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>

Guidance for Handlers of Service and Therapy Animals (Center for Disease Control)
<https://www.cdc.gov/healthypets/covid-19/service-therapy-animals.html>

How ACL's Disability and Aging Networks Can Help People with Long COVID (Administration for Community Living)
https://acl.gov/sites/default/files/COVID19/ACL_LongCOVID.pdf

Coronavirus Resources (U.S. Department of Labor)
<https://www.dol.gov/agencies/odep/topics/coronavirus-covid-19-long-covid>
<https://www.dol.gov/agencies/odep/topics/coronavirus-covid-19-long-covid?CFID=30507243&CFTOKEN=b92514cab0e85de2-3C316D23-050A-B58E-D9C088B27F5030E6>

JAN COVID-19/General ADA/Interactive Process (Job Accommodation Network – JAN)
<https://askjan.org/topics/COVID-19.cfm>

Supporting and Protecting the Rights of Students at Risk of Self-Harm in the Era of COVID
https://www.ada.gov/students_self-harm_fact_sheet.pdf

Higher Education Long COVID RESOURCES

The “Long Covid” of American Higher Education (Society for Advancement of Socio-Economics)
<https://sase.org/blog/the-long-covid-of-american-higher-education/>

Repository of Third Way's Higher Education Public Opinion Research (Third Way)
<https://www.thirdway.org/series/repository-of-third-ways-higher-education-public-opinion-research>

Telework during COVID-19: exposing ableism in U.S. higher education (Taylor and Francis Online)
<https://www.tandfonline.com/doi/full/10.1080/09687599.2021.1919505>

Mental Health, Higher Education, and COVID-19: Strategies for Leadership to Support Campus Well-Being (American Council on Education)
<https://www.acenet.edu/Documents/Mental-Health-Higher-Education-Covid-19.pdf>

Covid long-haulers face new challenges as they head to college. Universities are listening. (NBC News)
<https://www.nbcnews.com/news/us-news/covid-long-haulers-face-new-challenges-they-head-college-universities-n1278505>

“Is this my life now?”

https://www.espn.com/college-football/story/_/id/32127148/clemson-defensive-end-justin-foster-my-struggle-long-haul-covid

COVID-19 and Students with Disabilities in Higher Education

COVID-19's Impact on Learning Accommodations (Chronicle of Higher Education)

https://connect.chronicle.com/rs/931-EKA-218/images/LearningAccomodations_AWS_TrendsSnapshotv2.pdf

COVID-19 and Undergraduates with Disabilities: Challenges Resulting from the Rapid Transition to Online Course Delivery for Students with Disabilities in Undergraduate STEM at Large-Enrollment Institutions (CBE—Life Sciences Education)

<https://www.lifescied.org/doi/10.1187/cbe.21-02-0028>

COVID-19 Resources for Students During the 2020-2021 Academic Year (The NCCSD Clearinghouse and Resource Library)

<https://www.nccsdclearinghouse.org/covid-19-resources-for-students.html>

College Students with Disabilities, Reasonable Accommodations and COVID-19 Q&A (Disability Rights South Carolina)

<https://www.disabilityrightssc.org/college-students-with-disabilities-reasonable-accommodations-and-covid-19-qa/>

TRACKING MEDICAL SYMPTOMS/IMPACT

Seeking causes of post-Covid symptoms, researchers dust off data on college students with mononucleosis (STAT)

<https://www.statnews.com/2020/09/11/persistent-symptoms-after-covid19-hard-to-study/>

COVID-19 may affect “Flight or Fight” response in young adults (Medical News Today)

<https://www.medicalnewstoday.com/articles/covid-19-may-affect-long-term-flight-or-flight-response-in-young-adults>

Treating patients with long COVID (American Psychological Association)

<https://www.apa.org/monitor/2021/07/treating-long-covid>

More than 50 long-term effects of COVID-19: a systematic review and meta-analysis (Scientific Reports)

<https://www.nature.com/articles/s41598-021-95565-8>

More than HALF of Covid Survivors experience symptoms such as anxiety and fatigue six month after recovering from the virus, study finds

<https://www.dailymail.co.uk/health/article-10088131/More-HALF-Covid-survivors-experience-symptoms-six-months-recovering-virus.html?ITO=applenews>

KEY POINTS:

- “Brain Fog” is a common symptom for students with Long COVID who experience academic consequences. Many of the same strategies suggested for students with head injuries may be helpful to these students.
- Whether Long COVID is to be considered a disability or a temporary disability, it seems clear that the reported impact may shift over time and that there will need to be reevaluation to determine appropriate accommodations for current impact.
- Energy levels may be taxed for students with Long COVID, and may impact on their ability to focus on cognitive tasks just as much as it interferes with their physical stamina.
- There are strategies that the student can employ to help manage their own attention and focus that are not formal accommodations but may be suggested in response to self-report of the student’s struggle.
- Many of the strategies and accommodations we have used to support students with other disabilities that result in similar functional limitations may be of use for students with Long COVID.

Things to Consider...

1. While Long COVID is a newly recognized disability, the functional limitations created by some of the reported symptoms are not new to us. They are also reported for students with other disabilities, and we have developed strategies and accommodations to support students that can be used now.
2. Determining appropriate accommodations and support for students with Long COVID will be a very individualized process because the reported symptoms vary in nature and severity across the population.
3. It will be important to review current impact and reassess need for support much more frequently for students with Long COVID than we typically do for students with disabilities. Evidence suggests that symptoms may fluctuate significantly in the short run, and there is too little history to determine how long the impact will continue.

CONCLUSION



CONCLUSION

This workbook was created by a group of professionals in disability services *for* professionals in disability services. We believe that this information included here may be helpful, while we recognize both the limitations and the potential for its use.

A Resource, Not a Reference Guide

We chose to call this a workbook because it will require *work* on the part of the user. This is not a reference guide that you can pick up and follow when the student with Long COVID walks through your door. There are no checklists here that will make it easy for you to conduct an intake interview or assign accommodations. Rather, we have shared our conversations and experience in a way that we hope will provide direction for the reader in creating an interview format appropriate to your circumstances and assigning accommodations that effectively address the student's functional limitations.

Connecting With Others on Campus

Many students may be experiencing disability for the first time, and may not know our offices exist. Moreover, they may not understand that what they have is actually a disability (or have trouble seeing themselves as disabled). Many may not realize that what they are struggling with now qualifies them to get support under the ADA. Without some form of active outreach to explain the connection, what we do may seem foreign to them. There is a bridge to be made for the students between calling something Long COVID and calling it a disability/something that limits their access/something that makes them eligible for accommodations.

This workbook does not discuss coordinating services and support institution-wide because we recognized the existing lines of communication and administrative structure will vary significantly across campuses. But we urge the user of this workshop to seek out other units on campus that may have contact with students experiencing Long COVID (for example, Residence Life or Counseling). They need to know what services/support you are in a position to provide so that they can make appropriate referrals. At the same time, you need to know what services/support they are providing. Remember, too, that outside the day-to-day functions of student life units on campus, the institution may be creating additional resources to support students as part of the larger response to the pandemic. Those efforts may include active outreach to students experiencing Long COVID symptoms (that is, they may be seeking out students rather than waiting for them to come looking for services). Make sure that they are aware of the services/support your office can provide so that they can direct students to you as appropriate.

Next Steps for the Task Force

We hope to disseminate this workbook widely and we encourage readers to share it with anyone and everyone for whom you feel it may be useful. This document represents a first offering of this information in the most expedient (text-based) format we were able to create in a timely manner. We are making plans to create a virtual version of the workbook, complete with hyperlinks, that will make the workbook easier to navigate.

We are also establishing a moderated listserv to answer questions and make suggestions about this workbook. The listserv is not intended to provide advice on what to do in support of students with Long COVID. Our existing professional listservs already provide ample opportunity to reach out to the broader disability services community or such advice and counsel. Rather, our dedicated listserv will focus solely on the utility of this resource and proposed additions, over time, to the information provided.

Members of the Task Force are planning to submit a proposal on the AHEAD 2022 conference that details both the process we followed in creating this workbook and what we have learned, in a year's time, about providing support to students with Long COVID.

Next Steps For the User

We hope you will make the time to read through the entire workbook so that you will know what this resource encompasses. After the initial reading, you may find the Key Points listing and the boxed *Thing To Consider* at the end of each section will serve to remind you of the information shared that might be useful for you to review in detail and form your own plan of action.

If you would like to join the dedicated listserv tracking the use of this workbook and highlighting additions/corrections to the information presented, please contact JaneJarrow@aol.com.

When we first came together, members of the Task Force acknowledged that we were looking forward to the professional exchange as much as we were to creating the resource. It was our hope that joining a dialogue with colleagues on the topic of working with students who have Long COVID would give guidance, clarity, and energy to do a better job working with such students on our own campuses, as well as what it might provide for others. As we approached 18 months since the start of the pandemic, everyone was feeling more than a little tired and stale and this was a way to restore some excitement in the work. It has had that impact for many of us. We hope you will be equally enthusiastic about what you find here!

Respectfully,
The Long COVID Task Force
October, 2021

APPENDIX A

LASTWORD_LONGCOVID

LONG COVID TASK FORCE

August 6, 2021

We Are In It For the Long Haul

By Jane E. Jarrow, Ph.D

Earlier this week, colleague Scott Lissner posted some resources for folks to check out regarding the issues that will surround the “long haulers” – students who had COVID at some point in time over the last 18 months and are now experiencing post-COVID complications. I spent some time reviewing those resources (and others). We have our work cut out for us, folks.

(Just for expediency, I am going to choose terminology to identify the problem we are discussing here. The literature recognizes and uses various terms to identify these concerns, but most of the references from the Feds use the term “Long COVID,” so that is what we will use here.)

We have spent a great deal of time, thus far in the pandemic, trying to make a clear distinction between issues of COVID and issues of disability. A lot more students reporting mental health issues? That is a COVID issue, not a disability issue, since not all of those issues rise to the level of disability. Students requesting to be remote rather than coming to campus? That’s a COVID issue. They may request it because of their disability, but the response to that request is the same (given from the institution) no matter what the reason or need for the request. Students who cannot wear masks when there is a mask mandate on campus? The decision as to how to respond is an institutional (COVID) decision, not a DSS decision.

Guess what? The issue of support for students with Long COVID IS our issue, because it IS about disability. All of the resources I reviewed this week (including information from HHS, the Department of Justice, the Department of Education and the Job Accommodation Network) make it clear that Long COVID is to be considered a disability under federal law and students experiencing symptomology from Long COVID are entitled to protection under 504 and the ADA (to include accommodations, as necessary).

I found an interesting quote in the footnotes of the guidance from DeptEd:

IDEA does not require children to be identified with a particular disability category for purposes of the delivery of special education and related services, since a child’s entitlement under IDEA is to FAPE and not to a particular disability label. (FAPE is “free, appropriate public education” – JEJ)

What does that translate to for those of use working in postsecondary settings? It may be the first departure from our typical thinking when it comes to students with disabilities. This time, the reason behind the substantial limitations the student is experiencing doesn’t matter (that is, it doesn’t matter whether it is ADHD, or PTSD, or COVID, or ???). The issue is what we can/should do to support students with disabilities who are presenting with substantial limitations... and for the foreseeable future, that is going to include students with Long COVID.

The resources I reviewed suggest that we could (should?) expect serious problems in the near future for “long-haulers” –

It’s still too early to say for sure. Our experience shows most long-haulers tend to fall into the high-risk category, but there’s also a growing percentage of people who were otherwise healthy before they became infected. From what we know so far, it still seems random as to who experiences these long-lasting symptoms and who doesn’t.

This group, which many refer to as “long-haulers,” is mixed with those who experienced both mild and severe cases. And this condition can affect anyone – young, old, those who were healthy, those who had a chronic condition, those who were hospitalized and those who weren’t.

Even people who did not have symptoms when they were infected can have post-COVID conditions. These conditions can have different types and combinations of health problems for different lengths of time.

If those quotes aren’t disquieting enough, here is a quote taken directly from the CDC website (<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html>):

Long COVID is a range of symptoms that can last weeks or months after first being infected with the virus that causes COVID-19 or can appear weeks after infection. Long COVID can happen to anyone who has had COVID-19, even if the illness was mild, or they had no symptoms. People with Long COVID report experiencing different combinations of the following symptoms:

Tiredness or fatigue

Difficulty thinking or concentrating (sometimes referred to as “brain fog”)

Headache

Loss of smell or taste

Dizziness on standing

Fast-beating or pounding heart (also known as heart palpitations)

Chest pain

Difficulty breathing or shortness of breath

Cough

Joint or muscle pain

Depression or anxiety

Fever

Symptoms that get worse after physical or mental activities

(NOTE: I added the emphasis of italics or bolding to this list – JEJ)

The kicker here is the last thing on the list – symptoms that get worse after physical or mental activities. Not only are we going to start seeing students come forward asking for support for their COVID-related limitations, but the more they try and the more they work at things, the more their symptoms may be exacerbated!

One other interesting note from the DeptEd guidance:

Some children or students who were already identified as having a disability under IDEA and/or Section 504 and who have contracted COVID-19 may experience new or worsened symptoms related to their pre-existing disability, to COVID-19, or to both. If these symptoms persist in the form of Long COVID, these children or students may need new or different related aids and services...

That suggests that part of the process in determining appropriate accommodations for students who present with Long COVID may be to review existing accommodations (for continuing students with disabilities) to see how these new limitations may impact on their old support system.

So what can we do, as disability service providers, to support students who are experiencing

symptoms of Long COVID? Look at the list, above, and think in terms of what functional limitations those symptoms may create for students. While we are not used to seeing those things as potentially overlapping to this degree, we have seen most of the things on the list with other students with disabilities over the years. We have some idea of how to support students with disability-related tiredness or fatigue, what kind of accommodations to explore for students with difficulty thinking or concentrating, for those with depression and anxiety, as well as for some of the miscellaneous medical issues listed there. If you don't get hung up on the label (or cause), and focus on the functional limitations, the task of identifying appropriate accommodations and support seems a little less daunting.

It seems to me that the key to successfully providing support for students with Long COVID is going to be getting these students to come forward in a timely manner. Students who are experiencing symptoms of Long COVID are going to be in one of two groups – either they will be students with disabilities, already known to our offices, who contracted COVID, are now facing new struggles, and who reach out to us for help. OR... they will be students who know nothing of disability services, have never been to our offices, and don't think of themselves as disabled. This is the group I worry about most. They are the ones who will come back to school in the fall, assuming that COVID is behind them, find themselves struggling in unexpected ways, and take too long to put the pieces together, figure out it may be a result of their COVID infection and that they COULD ask for help, and make their way to our offices. What do I mean by it taking "too long?" I mean that by the time they show up in the DSS office, their difficulties may have significantly impacted on their current courses, and even with the best of intentions, we don't do retroactive accommodations.

So – how to we get the word out more quickly to encourage students to come forward? While supporting students with Long COVID academically may be the charge of the disability service office, it is likely that the institution will be providing information, campus-wide, for students who are experiencing Long COVID symptoms. (Remember, there are a lot of individuals whose Long COVID includes anxiety, depression, PTSD, and more. We know that campuses ARE attuned to the rise in mental health problems.) My guess is that there will be programming developed on a campus-wide basis to support students returning to campus and academic life in the Fall. Find out what those plans are and find a way to get them to include reference to unexpected academic struggles, with reference to getting in touch with your office ASAP.

That covers the issue for everything EXCEPT the one thing that most DSS providers get most hung up on – documentation! I scoured all those resources this week. There is no mention of how to confirm (verify) that someone is struggling with Long COVID. The literature talks about "patients report..." or "patients experience..." But no one talks about how we might document that these students had COVID and are now experiencing Long COVID complications.

I spoke to several DSS "old-timers" whose counsel I respect, and asked them what they would be looking for as documentation when it comes to confirming the student's status as a "long-hauler." They all began with wanting verification from a medical source that the student had been diagnosed with COVID-19 at an earlier point, and then some indication that the Long COVID symptoms were being (at least) monitored by their physician. When I pushed back, there was some tacit agreement that when it came to describing Long COVID's impact on student functioning, the student *might* be able to share that directly, as the physician would only know what the student told them anyhow – why not cut out the middleman? But all agreed that you would want to begin with medical documentation of the student's positive COVID status that could be the trigger for the Long COVID symptoms.

I disagree. I think we may see a lot of students with Long COVID who have no medical documentation of having had COVID in the last year. Think back to the guidance being given, for months, regarding what to do if you experienced the symptoms of COVID – fever, cough, loss of taste/smell, exhaustion. Folks were told that if they had such symptoms, they were to self-isolate and take it easy as much as possible, and to contact their physician if they were having significant difficulty breathing. I think there are a lot of folks out there who never saw a physician to confirm the diagnosis. Even now, the CDC site includes information for individuals who are doing COVID self-testing at home (with the handy-dandy kit available from your local pharmacy). If you get a positive test result, the CDC says you should REPORT the positive test result to your physician and then stay home and stay away from everyone until it passes. They only want you to go see the doctor if the symptoms worsen sharply. I think we are going to see students who had relatively mild cases of COVID who never saw a physician (and thus don't have any medical documentation of a positive COVID test) because they knew they had been exposed, recognized the symptoms, and just waited it out.

In the end, though, it doesn't matter whether you ask for formal documentation or not. Either way, it may not help you in determining how best to support the student. My guess is that many of these students who are newly experiencing this symptomology may not know what to report to you. They may know that they are struggling, but not necessarily understand which symptoms are creating the struggle. You need to develop an in-depth interview format to use in drawing out information about the impact of Long COVID on students who don't know what to tell you. I am guessing this might make a great topic for some of those statewide weekly and bi-weekly chats that various state groups have been holding this year. This would make a great "group project" with everyone suggesting questions and wording. Make it happen!

If "forewarned is forearmed," then you have been warned. The only positive note I can offer is to remind you that we are all in this together... for the long haul. I would much rather read multiple listserv threads about how to support those with Long COVID than yet-another set of questions about those @\$%^ ESAs!

Let's focus on what's important, folks!
Janie

We do not have a fear of the unknown. What we fear is giving up the known.

It isn't enough to think outside the box. Thinking is passive. Get used to acting outside the box.

(and one more – your COVID-19 funny for the day)

On average, a panda feeds for approximate 12 hours per day. This is the same as an adult at home under quarantine, which is why they call it a "pandemic."

LONG COVID TASK FORCE

FACILITATOR: Jane Jarrow, Disability Access Information & Support

Bonni Alpert, Alpert Consulting

Katherine C. Aquino, St. John's University

Kimberley Bassi-Cook, Seton Hill University

Terri Bassi-Cook, Seton Hill University

Stephanie Batchelder, Rhodes State College

Margaret Camp, Clemson University

Glennis Daniels-Bacchus

Kyle Droz, Northeastern University

Daphne Gilles, Borough of Manhattan Community College

Robin Goodall, Vermont Technical College

Lucheia Graves, Bennett College

Sandra Harrison, Pepperdine University

Sara Henry, University of Maine

Rebecca Johnson, Troy University

Amy King, University of New Orleans

Andrea Keklikian, Academy of Art University

Matthew Lowe, University of Central Florida

Kaitlyn Martin, University of the Sciences

Adam Meyer, University of Central Florida

Joanna Morey, Lawrence University

Stephanie Nance, University of Kentucky

Lindsay Northrup-Moore, American University

Maria Pena

Kathy Shearer, Spokane Falls Community College

Jacqueline Smith, Carlow University

Teague Stanley, University of Nebraska, Omaha

Cassie Kilroy Thompson, University of Maryland, Baltimore Campus

Eric Trekell, Everett Community College

Lisa Vance, North Iowa Area Community College

Jim Walterhouse, Howard College

Steve Zani

APPENDIX B

KEY POINTS & THINGS TO CONSIDER

GATHERING INFORMATION THROUGH THE INTAKE INTERVIEW

KEY POINTS:

- On the two ends of the continuum there are intakes based on “just the facts” and intakes that are deep dives. Depending on your environment, your resources, the culture of your organization and your own philosophy, you will determine which kind of interview works best for you.
- The purpose of the “just the facts” interview is to learn what the student is looking for from the disability services office. The “just the facts” approach allows you to establish supports that are requested if the student is eligible and meets the guidance of the ADA in section 504 the rehabilitation act.
- The purpose of the “deep dive” intake is to learn about *why* a student is meeting with you (they ultimately decide what supports they establish, in what classes or if to use supports at all). It can also indicate the student’s level of awareness and understanding of their diagnosis or condition(s) and how it’s impacting them.
- We know that professional judgment is an essential component when it comes to establishing whether a student has a disability and what if any accommodations are necessary for access. We also know that each situation must be considered individually to understand if and how the student is impacted by their condition. The intake interview provides us with an opportunity to get this individualized perspective. How we choose to engage in the interview process with a student may be dictated by a variety of factors.
- Doing pre-interview preparation can help to provide context to the interview and allow the interviewer to gather targeted, relevant information regarding the student’s needs.

Things to Consider...

1. What kind of interview will you do? Do you have the staffing, time, and general capacity to do an in-depth and comprehensive intake with the student?
2. How much of the decision as to the depth of your interview will be determined by the documentation you receive (or don’t receive)?
3. How much of the decision as to the depth of your interview will be determined by the nature of the accommodation requests the student is making?
4. How will you prepare for your intake interview?

THE DOCUMENTATION DILEMMA

KEY POINTS:

- How formal or informal you want documentation to be is going to be mirrored in how formal or informal you want documentation of ANY disability to be on your campus – and we acknowledge that different institutions are all over the map in terms of what they are willing to accept.
- Your approach to what documentation you look for will be influenced by your philosophical leanings when it comes to service and support to students with disabilities. That philosophy does not change depending on the population of students to be served – nor should it.
- The importance of self-disclosure will be the most pertinent during this time. Some individuals are living with the residual effects of COVID without formally being diagnosed with COVID. Some individuals who are experiencing Long COVID symptoms did not have a preexisting condition or disability and are struggling with a whole new aspect of their everyday life. These individuals may need the most assistance to understand how and why accommodations are utilized in a post-secondary setting.
- Individuals with a preexisting condition or disability may be able to provide documentation related to their preexisting condition but are still experiencing Long COVID symptoms.
- In the aftermath of Hurricane Katrina, students with disabilities were shifted to college campuses across the country with NO documentation of their disability, NO likelihood of being able to get documentation, and who brought only their own self-report of their disability and their need for accommodation. That experience seems to mirror what we are facing today with Long COVID – bewildered students who may show up at the disability services office with no documentation of the impact of their Long COVID, and no clear understanding of what WE need to know so that we can help them.
- The same was true in determining how best to support students with concussions when there was little support to suggest what they needed. The parallels to the situation faced with students who present with Long COVID are evident.

Things to Consider...

1. What kind of information will you look for in order to determine a student's legitimate need for specific accommodations? Will you want third party documentation, or do you think you will rely heavily on student self-report through the intake interview?
2. Looking at your answer to (1), consider the demographics of the student population at your institution. Will all students have equal access to the level of documentation you are seeking?
3. How will you handle requests from students who have either no documentation, or documentation that is inconclusive?

QUESTIONS TO EXPLORE

KEY POINTS:

- There is no single template of questions to suggest for an interview with a student presenting with Long COVID. Service providers should decide what questions to ask based on their own style, circumstances, and purpose in asking.
- Don't ask questions if you have no reason to know the answer. If the information would not change what you can/will do for the student, there is no reason to ask it.
- Some service providers choose to explore non-academic areas of functioning, while others may focus solely on how COVID-related symptoms impact on academics and on requested accommodations and support.
- The evidence suggests that the impact of Long COVID symptoms is likely to change over time (sometimes dissipating, sometimes getting worse), and there is insufficient data to know what the timeframe should be for re-evaluation. We do know it is likely to be less than a full academic year. In other words, while you normally assign accommodations at the beginning of the school year and leave those in place for that academic year, the status and needs of students with Long COVID should probably be reassessed more frequently.

Things to Consider...

The following topic and question list highlights some of the broad themes across the different PP that were shared by the task force. While this list can be a good starting point guide conversations with students, readers are encouraged to review the various PP for more in-depth insight on the respective topics.

2. Details on COVID Diagnosis and history, such as...
 - e. When diagnosed?
 - f. Symptoms still experiencing due to COVID?
 - g. Have any symptoms lessened or disappeared since having COVID?
 - h. Have any symptoms stayed the same or worsened since having COVID?
 - i. Have any other diagnoses occurred due to COVID?
3. Other health matters relevant to this discussion, such as...
 - a. Other diagnoses?
 - b. Changes in mental health?
4. Why seeking accommodations now, such as...
 - a. What brought you here today?
 - b. What peaked your interest in exploring potential accommodations?
5. Classroom Impact, such as...
 - a. What type of barriers are you facing in your classes with these symptoms?
 - b. What is your most pressing academic concern right now given your schedule this semester?
 - c. What course activities (lectures, tests, assignments, notes, reading, etc.) are harder now or more frustrating to do/experience?
 - d. What course activities have not been impacted in anyway?
 - e. Have you tried any new strategies to address your concerns?

6. Life Impact, such as...
 - a. What type of barriers are you facing in your leisure activities?
 - b. What life activities are harder now or more frustrating to do/experience?
 - c. What course activities have not been impacted in anyway?
 - d. Have you tried any new strategies to address your concerns?

7. Work impact, such as...
 - a. What type of barriers are you facing in your work environment?
 - b. What work activities are harder now or more frustrating to do/experience?
 - c. What course activities have not been impacted in anyway?
 - d. Have you tried any new strategies to address your concerns?

8. Community support, such as...
 - a. In what ways are you connected on campus?
 - b. What campus resources do you routinely utilize?
 - c. What kind of support do you have from friends and family?

FACILITATING ACOMMODATIONS

KEY POINTS:

- The purpose of accommodations is to ensure that students with disabilities have access to the educational experiences and opportunities that are available to all other students in attendance at a college or university
- The purpose of accommodations is to ensure equal opportunity to be successful, but accommodations DO NOT guarantee success.
- Accommodations are provided to students who have substantial limitations, in order to assure that they have full access.
- While there is a lot that we don't know, we do know that Long COVID can be a disability (i.e., results in a substantial limitation in a major life activity).
- If Long COVID is a disability, then why wouldn't we approach the question of accommodations and support options in a manner consistent with what we have always done
- Apply accommodations that would address where the student does not have equal access due to an academic barrier in conjunction with the student's substantial limitation.

Things to Consider...

7. What are the student's Long COVID symptoms? What are the substantial limitations the student is reporting?
8. Do the symptoms and impacts seem similar to other accommodated disabilities? If so...
9. What types of accommodations are provided to create equal access for similar functional limitations?
10. What does the student need for equal access? Would the accommodations address equal access or rather promote student success?
11. What academic barriers does the student report?
12. What accommodations would reasonably address those academic barriers?

TIPS/TRICKS/STRATEGIES/RESOURCES

KEY POINTS:

- “Brain Fog” is a common symptom for students with Long COVID who experience academic consequences. Many of the same strategies suggested for students with head injuries may be helpful to these students.
- Whether Long COVID is to be considered a disability or a temporary disability, it seems clear that the reported impact may shift over time and that there will need to be reevaluation to determine appropriate accommodations for current impact.
- Energy levels may be taxed for students with Long COVID, and may impact on their ability to focus on cognitive tasks just as much as it interferes with their physical stamina.
- There are strategies that the student can employ to help manage their own attention and focus that are not formal accommodations but may be suggested in response to self-report of the student’s struggle.
- Many of the strategies and accommodations we have used to support students with other disabilities that result in similar functional limitations may be of use for students with Long COVID.

Things to Consider...

4. While Long COVID is a newly recognized disability, the functional limitations created by some of the reported symptoms are not new to us. They are also reported for students with other disabilities, and we have developed strategies and accommodations to support students that can be used now.
5. Determining appropriate accommodations and support for students with Long COVID will be a very individualized process because the reported symptoms vary in nature and severity across the population.
6. It will be important to review current impact and reassess need for support much more frequently for students with Long COVID than we typically do for students with disabilities. Evidence suggests that symptoms may fluctuate significantly in the short run, and there is too little history to determine how long the impact will continue.