



Report on Students with Chronic Health Conditions

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Section 1: Introduction and Background

JCR Request: Report on Students with Chronic Health Conditions: The budget committees request that the Maryland Higher Education Commission (MHEC) and the Maryland Department of Health (MDH) establish a workgroup to examine the data available on students with chronic health conditions attending institutions of higher education in the State. The data examined should include demographics of students with chronic health conditions and the type of conditions, challenges faced by these students, existing policies at higher education institutions regarding the rights and needs of these students, and resources and programs available to these students. The report should include recommendations on enhancing and continuing data collection on students with chronic health conditions; eliminating challenges faced by these students; and accommodating needs of these students, including resources and programs. The report should be submitted by September 30, 2021.¹

Workgroup Membership

The Joint Chairmen’s Report (JCR) asked the Maryland Higher Education Commission (MHEC) and the Maryland Department of Health (MDH) to establish a workgroup. MHEC circulated a call to the MHEC Segmental Advisory Council to identify 2-3 individuals from each segment to participate in the workgroup (see appendix). MDH identified agency representatives. A membership list is provided in the appendix of this report. Dr. Emily A. A. Dow, Assistant Secretary for Academic Affairs, and Kristi Pier, Director, Center for Chronic Disease Prevention and Control, Prevention and Health Promotion Administration, MDH, were the staff liaisons to the workgroup. The workgroup met four times between July and August 2021.² The report provided here is a summary of the workgroup discussions and is intended to fulfill the JCR request.

Definitions

For the purposes of this report, the workgroup agreed to define the terms “chronic health” broadly using the Centers for Disease Control and Prevention (CDC) definition of chronic diseases. The CDC defines “chronic diseases” as “conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both.”³

The workgroup also discussed the definition of “student,” particularly as it relates to age. While the traditional undergraduate college student population ranges between 18 and 24 years old, Maryland colleges serve a growing population of adult students (both at the undergraduate and graduate level). Again, for the purposes of this report and when appropriate, the workgroup made an effort not to limit discussions to the traditional, undergraduate, 18 to 24 year old college-going population.

¹ Link to JCR request (page 197): <http://mgaleg.maryland.gov/Pubs/BudgetFiscal/2021rs-budget-docs-jcr.pdf>

² The workgroup met on July 13, July 26, August 23, and August 31, 2021. At the recommendation of Delegate Peña-Melnyk, the third meeting included a presentation from the Physician-Parent Caregivers, Inc. and students invited by Dr. Santi Bhagat, President and Founder of Physician-Parent Caregivers, Inc.

³ <https://www.cdc.gov/chronicdisease/about/index.htm>

For the purposes of this report, the definition of “disability” is from the Americans with Disabilities Act of 1990, as Amended (ADAAA). The ADAAA clarified the scope of the definition of disability because it was being narrowly interpreted by the Supreme Court. The term "disability" means, with respect to an individual (A) a physical or mental impairment that substantially limits one or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.

2021 Legislative Session: HB59/SB147

Before addressing the specific elements in the JCR request, it is important to note a bill filed in 2021 to establish a Task Force on Higher Education Students with Chronic Health Conditions (HB59⁴, cross-filed with SB147⁵). While HB59/SB147 did not move forward, the workgroup did review several legislative materials related to the bill, including recorded testimony, written testimony, and the related fiscal and policy notes.

Olivia’s Law

The workgroup also recognizes Olivia Paregol, a University of Maryland freshman who died after an outbreak of adenovirus on the College Park campus in 2018. This led to the Maryland General Assembly passing SB329 (HB187) during the 2020 legislative session, known as Olivia’s Law. The legislation requires public institutions of higher education in Maryland to submit an outbreak response plan to MDH annually. What is relevant to this report is that Olivia Paregol had an underlying health condition that weakened her immune system.

⁴ <http://mgaleg.maryland.gov/mgawebsite/Legislation/Details/HB0059>

⁵ <http://mgaleg.maryland.gov/mgawebsite/Legislation/Details/SB0147?ys=2021RS>

Section 2: Existing Data

The JCR asks the workgroup to examine the data available on students with chronic health conditions attending institutions of higher education in the State. More specifically, the JCR request that the examined data should include:

- demographics of students with chronic health conditions and the type of conditions;
- challenges faced by these students;
- existing policies at higher education institutions regarding the rights and needs of these students; and
- resources and programs available to these students.

There is limited data currently available on students in higher education with chronic health conditions. The workgroup focused discussions on two statewide surveys coordinated by either MDH or MHEC. When possible, demographic breakouts are provided. Limitations regarding current statewide data collection and demographics of students with chronic health conditions (including the type of condition) are discussed in the following sections.

Existing Data: Maryland Behavioral Risk Factor Surveillance System (BRFSS)

MDH manages an annual telephone survey related to disease, risk factors, behaviors, and demographics. The survey utilizes a random sampling method based on telephone numbers for both landlines and cell phones for non-institutionalized adults ages 18 years old and older living in Maryland (the target sample size is 15,000 completed surveys per year). The protocol is derived from the CDC and is standardized across all US states and territories. The survey includes about 150 questions and takes about 20 minutes to complete. A sample question is, “have you ever been told by a doctor, nurse or health care professional that you have a chronic health condition (such as diabetes)?” The survey does not collect information that would indicate if a participant was a student at a Maryland college or university.

On July 13, representatives from MDH presented comparative information between two age groups: 18-25 years-old and 25 years-old and over. Making this age break assumes that a majority of the 18-25 year olds attend college in some capacity (this is a limitation of this analysis). Additionally, the analysis combined data for all available years (2011-2019). Only 13.9% of the sample are 18-25 years old.⁶

For many chronic health conditions, the prevalence of conditions are significantly lower among those in the 18-25 years old sample compared to the 25 years old and over sample; arthritis (3.2% vs 27.8%), COPD (1.9% vs. 6.2%), and cardiovascular disease. Note, while the prevalence rates for diabetes, skin cancer, other cancer, and kidney disease are unreliable due to small sample sizes, the prevalence of these diseases is significantly lower among the 18-25 years old sample. However, the prevalence for asthma (19.5% vs 12.4%) and depressive disorder (17.1% and 15.5%) are higher for the 18-25 years old sample compared to the 25 years old and over sample. Based on this analysis, not many traditional college-aged students are dealing with traditional chronic health conditions.

⁶ MDH implements a suppression methodology to protect privacy. For the purposes of this report, data are suppressed if the sample size is less than 50.

The workgroup recognizes there are several limitations to the BRFSS and its subsequent analyses. Again, this survey does not specifically target college and university students and not all students at Maryland colleges and universities fall into this traditional age group. Secondly, college students are often transient and may be hard to capture with this particular survey. For example, cell phones may not have a Maryland area code making it more difficult to capture Maryland students in the Maryland survey (and pay-as-you go cell phones are not included in the sample). Third, this survey does not capture if someone is currently attending any type of postsecondary education, only the participant's highest level of education attainment. Fourth, while oversampling is undertaken, the younger population is still underrepresented.

Existing Data: American College Health Association Fall 2020 National College Health Assessment

The ACHA-National College Health Assessment (ACHA-NCHA) is a national research survey organized by the American College Health Association (ACHA). The survey began in 2000 and has since been revised four times. The current iteration (ACHA-NCHA III) began in Fall 2019 and data is collected every semester; reports and executive summaries are provided on the ACHA website.⁷ 137 institutions nationwide participated in the Spring 2021 survey, with 96,489 student respondents. At least one college or university campus from Maryland participated (the report does not identify specific campuses). The survey includes a number of health questions, such as questions related to nutrition, sexual behavior, sleep, mental health and well-being. Pertinent to this report, the Spring 2021 Executive Summary report provides the following table relevant to "Ongoing or Chronic Conditions." Note, chronic conditions listed in the ACHA-NCHA primarily include mental health conditions (i.e., anxiety, depression, panic disorders, Obsessive Compulsive Disorder) and substance abuse. Factors such as asthma, diabetes, and heart disease are not included in these analyses.

⁷ https://www.acha.org/NCHA/ACHA-NCHA_Data/Publications_and_Reports/NCHA/Data/Reports_ACHA-NCHAIII.aspx

J. Ongoing or Chronic Conditions									
<div style="float: right; border: 1px solid black; padding: 2px;"> Cis Men n = 27822 Cis Women n = 63416 Trans/GNC n = 3994 </div> <p>The questions for the <i>ongoing or chronic conditions</i> are presented differently in this report than the order they appear in the survey. In the survey, all items appear in a single list, ordered alphabetically. In this report, the conditions are presented in groups to ease burden on the reader. The findings are divided into mental health conditions, STIs and other chronic infections, and other ongoing or chronic conditions in this report.</p>									
Mental Health	College students reported ever being diagnosed with the following:				*Of those ever diagnosed, those reporting contact with healthcare or MH professional within last 12 months				
	Percent (%)	Cis Men	Cis Women	Trans/ Gender Non-conforming	Total	Cis Men	Cis Women	Trans/ Gender Non-conforming	Total
ADD/ADHD - Attention Deficit/Hyperactivity Disorder		9.2	7.8	21.9	8.9	55.0	70.5	72.3	66.1
Alcohol or Other Drug-Related Abuse or Addiction		1.8	1.2	3.4	1.5	40.0	36.3	40.8	38.2
Anxiety (for example: Generalized Anxiety, Social Anxiety, Panic Disorder, Specific Phobia)		15.9	33.2	54.8	29.1	66.7	73.8	77.0	73.0
Autism Spectrum		1.7	0.7	6.7	1.2	27.6	44.3	51.7	39.8
Bipolar and Related Conditions (for example: Bipolar I, II, Hypomanic Episode)		1.4	2.2	7.2	2.2	62.0	74.5	73.0	71.6
Borderline Personality Disorder (BPD), Avoidant Personality, Dependent Personality, or another personality disorder		0.5	1.1	4.5	1.0	55.9	64.1	64.4	63.4
Depression (for example: Major depression, persistent depressive disorder, disruptive mood disorder)		14.4	25.7	51.1	23.6	63.7	73.1	76.4	71.7
Eating Disorders (for example: Anorexia Nervosa, Bulimia Nervosa, Binge-Eating)		1.1	6.2	11.8	5.0	47.8	49.5	49.5	49.5
Gambling Disorder		0.1	0.0	0.4	0.1	12.5	11.1	46.2	21.5
Insomnia		3.8	6.4	15.1	6.0	53.1	58.6	54.4	57.2
Obsessive-Compulsive and Related Conditions (for example: OCD, Body Dysmorphia, Hoarding, Trichotillomania and other body-focused repetitive behavior disorders)		2.2	5.1	11.9	4.6	52.3	62.4	65.2	61.4
PTSD (Posttraumatic Stress Disorder), Acute Stress Disorder, Adjustment Disorder, or another trauma- or stressor- related condition		3.0	7.6	20.0	6.8	62.8	68.8	72.6	68.5
Schizophrenia and Other Psychotic Conditions (for example: Schizophrenia, Schizoaffective Disorder, Schizophreniform Disorder, Delusional Disorder)		0.3	0.2	1.3	0.3	56.3	56.3	55.1	56.6
Tourette's or other neurodevelopmental condition not already listed		0.3	0.3	1.4	0.3	21.5	44.9	50.0	39.7
Traumatic brain injury (TBI)		1.0	1.1	2.1	1.1	37.1	37.1	43.8	37.9
<i>*Only students who reported ever being diagnosed were asked about contact with a healthcare or mental health professional within the last 12 months.</i>									
	Percent (%)	Cis Men	Cis Women	Trans/ Gender Non-conforming	Total				
<i>Students reporting none of the above</i>		72.6	58.0	33.1	61.1				
<i>Students reporting only one of the above</i>		12.1	14.0	12.0	13.4				
<i>Students reporting both Depression and Anxiety</i>		10.1	21.6	44.4	19.3				
<i>Students reporting any two or more of the above (excluding the combination of Depression and Anxiety)</i>		5.2	6.4	10.6	6.2				

Existing Data: Maryland Colleges and Universities

In addition to national and statewide surveys, college campuses may know about a student's chronic health condition through two primary channels: (1) When a student requests educational accommodations (and residential/housing accommodations) due to a documented disability and/or (2) when a student visits a campus-run health center and/or counseling center.

Academic or Residential Accommodations

When a student requests an academic or residential accommodation⁸, the campus must comply with federal laws, specifically the Americans with Disabilities Act of 1990, amended in 2008, Section 504 of the Rehabilitation Act of 1973 (Section 504), the Fair Housing Act, Health Insurance Portability and Accountability Act, and Family Educational Rights and Privacy Act. In order to obtain accommodations, a student must self-disclose and work with the appropriate organization on campus (typically, the Department of Disability Services or Department of Student Services). The differences between how students are accommodated in high school and college impact identifying students with disabilities. For example, disclosure of disability is voluntary in higher education, whereas the Individuals with Disabilities Education Act (IDEA) mandates public schools identify students with disabilities. Also, colleges and universities may require documentation from a medical provider at the student's expense and often public schools provide a full and individual assessment (FIA) at no cost to the student or family. Any student level data maintained by the campus must adhere to privacy and confidentiality rules as required by federal and state law.

Annually, MHEC produces a report on students who registered with disability services at Maryland colleges and universities and provides analysis on graduation, transfer, and retention outcomes for those students. To better understand higher education outcomes for students with disabilities in Maryland, MHEC, in collaboration with the Maryland Department of Disabilities and in partnership with the state's higher education institutions, created a survey administered to colleges and universities to collect retention and completion data on these students. The 2021 report can be found on the MHEC website.⁹

As the 2021 MHEC report notes, "In fiscal year 2019, 15,814 undergraduate students and 1,417 graduate students were registered with their institutions' disability services office as students with disabilities, which represents 3.8% of all students enrolled in fiscal year 2019 (a 0.2% increase from fiscal year 2018). Specifically, this represents 4.3% of undergraduate students and 1.6% of graduate students enrolled." The report represents both temporary and permanent accommodations. Due to privacy concerns, data from the Maryland campuses are submitted in the aggregate and are not broken out by specific demographic categories, type of disability, or type of accommodation.

The workgroup recognizes that some chronic health conditions do not merit an educational or residential accommodation (e.g. cardiovascular disease). Therefore, it is assumed there are postsecondary students with chronic health conditions who never request accommodations.

Campus-run Health Centers or Counseling Centers

The second pathway through which a campus may know about a student's chronic health condition is when a student visits a campus-run health center and/or counseling center. Campus-run health/counseling centers function like an independent clinic and, again, must follow federal

⁸ Requests for accommodations may go beyond the classroom or housing (e.g., parking, dietary, assistance animals)

⁹ <https://mhec.maryland.gov/publications/Documents/Research/AnnualReports/2021ReportonStudentswithDisabilities.pdf>

and state privacy laws. Health/Counseling centers collect data for student-patients and data may be tracked when there is a campus-sponsored health plan.

There are several limitations regarding data collections a campus-based health/counseling center may have. First, many campus-run health/counseling centers may only be treating conditions as needed on an acute care, episodic basis as opposed to providing ongoing primary care services, and may not have resources to serve students with chronic health conditions. Secondly, students may have established support through existing medical providers and specialists for their chronic health condition in the community and may never find a need to visit a campus-based health and/or counseling center. Third, data collection, to the level that such data exist, may not be standardized and may differ greatly between data collected through campus-run health centers and campus-run counseling centers, both within and across institutions, making it difficult to make comparisons within campuses and between campuses. And, fourth, not all campuses have health centers and/or counseling centers.

Some college campuses have administered a “Health Entrance Form” for incoming or new students which is generally a self-report form regarding a variety of health conditions and is usually collected at the time of initial enrollment. Campuses often follow-up and inform the student about campus resources. However, not all Maryland campuses utilize or require health entrance forms, and some campuses have since moved away from using a health entrance form as it may become a health record for which the college is liable. Collecting health information on students implies the health center (or the campus at large) is expected to manage the student and their health condition; there is potentially medical or legal risk in such an expectation.

Section 3: Recommendations on Enhancing and Continuing Data Collections on Students with Chronic Health Conditions

Challenges in Collecting Data on Students with Chronic Health Conditions

The workgroup notes there are some general challenges with data collection and statewide comparisons, such as:

- Campuses must maintain privacy and confidentiality according to federal law (FERPA-disability services; HIPAA-counseling/health centers; Americans with Disabilities Act; Section 504 of Rehabilitation Act). Additional detail on these laws are outlined in Section 4 below.
- Students may not realize they are entitled to accommodation for their chronic health conditions because they do not consider it a disability. Therefore, they often do not seek services from the office or person on campus who could assist by arranging modifications or accommodation.
- Students may have been bullied, stigmatized, or stereotyped by experiences in high school. They may actively choose to not disclose because of these past experiences.
- A stand-alone specific medical diagnosis should not be included in an educational record; therefore, medical data should be kept separate from educational records (see existing policies for more about federal laws and guidance from the U.S. Department of Education on this issue).
- Campuses must balance serving the health needs of different age groups (e.g., returning adults is a growing college population) and student populations with different needs where the provision of one size services does not fit all.
- Maryland is home to a diverse array of campuses with varying resources (e.g., community colleges v. 4-year institutions, residential campuses v. non-residential campuses, campuses with medical school affiliations or other allied health professions, size of campus).
- Students often feel over-surveyed.
- Students may not wish to disclose their private health information to their college or university, especially when there may be stigma attached (e.g., mental health, substance use, sexual health, etc.).
- A student may never seek or wish to seek campus-based resources if they have an established provider that manages their chronic condition (accessing extended resources that the campus may not have the capacity to provide or because the student prefers to continue to work with their own provider).
- A student may not see the campus-based health services as a permanent ongoing resource, only as a one-time stop; similarly, a campus-based health/counseling center may only be designed to provide more acute care, episodic services and not long-term, ongoing primary care or specialty care.
- Once a student is referred to a specialist, the campus may not have the clinical resources to follow-up on the outcome of the referral and provide ongoing care.
- The acuity and/or complexity of a student's case may be such that the campus health center or counseling center may not be the appropriate place for these patients to receive care. This would be the case especially in colleges and universities that do not have a

medical school or hospital affiliation.

- Like any medical office, student-patients may never show up to an initial or follow-up appointment.
- If data are collected (without healthcare services provided at the same time), does that mean the college/health center providers are responsible for the care of that student? Why would campuses collect data in the absence of a specific use or purpose? In the practice of medicine, there is typically a duty to follow up if healthcare data are collected by the campus healthcare provider, with potential medical-legal risk and liability.

Recommendations on Collecting Data on Students with Chronic Health Conditions

The workgroup offers the following recommendations for consideration to enhance and continue data collections on students with chronic health conditions:

- Define the purpose and use of data collected;
- Define the attributes or variables of the survey;
- Consider privacy and implement appropriate safeguards; and
- Identify appropriate state agencies that should be involved in a statewide collection, such as the Maryland Department of Disabilities.

Section 4: Existing Policies at Higher Education Institutions Regarding the Rights and Needs of Students with Chronic Health Conditions

The workgroup recognizes there are a number of federal laws which dictate and mandate how campuses interact and provide services to students with chronic health conditions. Institutions may have additional policies on how students may navigate receiving support due to a disability, but all of these policies must adhere to the following federal laws.

The American Disabilities Act (ADA)

The ADA National Network website¹⁰ provides the following summary regarding a college or university's responsibility to students with disabilities:

“Both public and private colleges and universities must provide equal access to postsecondary education for students with disabilities. Title II of the ADA covers publicly-funded universities, community colleges and vocational schools. Title III of the ADA covers privately-funded schools. All public or private schools that receive federal funding are required under Section 504 of the Rehabilitation Act to make their programs accessible to students with disabilities.

All the programs of postsecondary institutions, including extracurricular activities, must be accessible to students with disabilities. The schools can do this in several ways: by providing architectural access to buildings, including residential facilities; by providing aids and services necessary for effective communication, like sign language interpreters, Braille or electronic formats and assistive listening devices; and by modifying policies, practices and procedures, such as testing accommodations and access to school facilities for service animals. Accommodations and program modifications should be individually designed to meet the needs of the student with a disability.

Accommodations and modifications of policies and practices are not required when it would fundamentally alter the nature of the service, program, or activity or give rise to an undue financial or administrative burden.

Postsecondary institutions often have an office that coordinates accommodations for students with disabilities. The student should notify the appropriate person or institutional office well in advance of the needed modification or accommodation.”

The Americans with Disabilities Act (as Amended in 2008)

In the document “Questions and Answers about the Department of Justice’s Final Rule Implementing the ADA Amendments Act of 2008,” on ADA.gov¹¹, an explanation on why Congress amended the 1990 bill is provided:

¹⁰ <https://adata.org/faq/what-are-public-or-private-college-universitys-responsibilities-students-disabilities>

¹¹ https://www.ada.gov/regs2016/adaaa_qa.html

“[a] response to several Supreme Court decisions that had narrowly interpreted the Americans with Disabilities Act’s (ADA) definition of disability. This narrow interpretation resulted in the denial of the law’s protection for many individuals with impairments such as cancer, diabetes, and epilepsy who had been the subject of adverse actions due to their disabilities. The law made a number of significant changes to the ADA definition of “disability” to ensure that it would be easier for individuals seeking the protection of the ADA to establish that they have a disability that falls within the meaning of the statute.”

Because of the ADA, a person with an impairment in major body functions could be considered a person with a disability. Additionally, mitigating measures (such as medications or hearing aids) and if a condition is episodic cannot be used to determine if the impairment substantially limits a major life activity.

Section 504 of the Rehabilitation Act of 1973

Section 504 is the law that protects the rights of students with disabilities attending colleges and universities. Chronic illnesses are named in the U.S. Department of Education’s handout, “the Civil Rights of Students with Hidden Disabilities Under Section 504 of the Rehabilitation Act of 1973”¹² and provides the following information:

"Hidden disabilities are physical or mental impairments that are not readily apparent to others. They include such conditions and diseases as specific learning disabilities, diabetes, epilepsy, and allergy. A disability such as a limp, paralysis, total blindness or deafness is usually obvious to others.... A chronic illness involves a recurring and long-term disability such as diabetes, heart disease, kidney and liver disease, high blood pressure, or ulcers."

Health Insurance Portability and Accountability Act (HIPAA)

HIPAA generally applies to colleges and universities that have health centers or counseling centers, particularly if a medical provider is billing to insurance companies (including Medicaid).

Family Educational Rights and Privacy Act (FERPA)

As noted on the U.S. Department of Education’s website, “the Family Educational Rights and Privacy Act (FERPA)... is a Federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education.” FERPA dictates how a college or university collects specific data on students and how that data can be used or shared.

Depending on the nature of a chronic health condition, collecting health information may be considered an educational record for colleges and universities. The U.S. Department of

¹² <https://www2.ed.gov/about/offices/list/ocr/docs/hq5269.html>

Education provided guidance on the interaction between HIPAA and FERPA, which can be found on their website.¹³

The Fair Housing Act

The Fair Housing Act protects people from discrimination when they are renting or buying a home, getting a mortgage, seeking housing assistance, or engaging in other housing-related activities. College students who live in dormitories and residence halls owned or operated by the institution are protected under the Fair Housing Act. For students with chronic illnesses who require an assistance animal, the Fair Housing Act is the law that applies.

¹³ <https://studentprivacy.ed.gov/resources/joint-guidance-application-ferpa-and-hipaa-student-health-records>

Section 5: Campus-based Resources Available

There are a number of resources campuses in Maryland may provide to students with chronic health conditions. Depending on the size of the institution and resource availability, some campuses may only be able to provide some of these resources to students. Below is a summary of campus-based resources available to students with chronic health conditions.

Disability Services

Every college or university in Maryland has a person or office devoted to serving students with disabilities. These offices work to provide appropriate educational accommodations to students. Additionally, if the campus has housing, these offices review and recommend housing accommodations. Most recently, accommodations in the virtual or remote format have increased in number. Sometimes disability services operate within a campus health or counseling center, if there is one, or they may operate independently in the Division of Student Affairs.

Health Centers and Counseling Centers

Some campuses in Maryland are able to provide a health center and/or a counseling center for students. However, not all colleges in Maryland have either a health center or counseling center. Depending on resources, these centers may only provide acute care and may not be intended for long-term care or services; however, these centers may also operate more like a stand-alone healthcare facility with expanded services and even access to medical specialists (this is particularly true in larger campuses and/or when a medical school is affiliated with the campus). Services provided may also include laboratory, radiology and pharmacy, as well as wellness services and other services specific to campus needs, such as services related to behavioral health, substance use and sexual assault. The types of services that are offered and provided depend greatly on the staffing and resources available and may be unique to each campus. Cost to a student may vary from one campus to another.

Additionally, some campuses may employ a behavioral response team for students in a mental health crisis. The team may conduct an initial evaluation and then create a response plan (which may include a referral to outside resources if campus resources are not available).

Student Organizations and Support Groups

Many campuses in Maryland have student organizations and/or student-led support groups specific to chronic health conditions. Often, these student organizations are coordinated with a campus staff member, faculty member, or campus office/department. For example, Active Minds¹⁴ is a national organization with local campus chapters to engage students in conversations about mental health. There are student organizations for specific health conditions, and there has been a recent increase in neuro-diversity support groups. Some of these student organizations are for educational or awareness purposes, while others are created

¹⁴ https://www.activeminds.org/blog/new-fall-gear-from-the-active-minds-shop/?gclid=Cj0KCQjwkIGKBhCxAARIsAINMioJAsLznw_fIVeU47k13a0GgBqddY6n4ihXW4AXqxTfxnqSFgWR4hw8aAhP6EALw_wcB

for the sole purpose of being a support group. Campuses encourage students to create these organizations as it allows students to create a community of their own.

Other Resources

Campuses also provide a number of other resources to students with chronic health conditions, such as:

- Tutoring, academic coaching, and other non-classroom based educational supports;
- A campus wellness center;
- An office regarding students' rights and responsibility (which is not just for student discipline);
- Nutritionist in dining services; and
- Specialized resources for athletes.

Additionally, campuses often work collaboratively in an effort to share best practices or successful innovative ideas. This is particularly true with regard to standardized protocols, where campuses may work together to share policies and procedures. There are regular meetings with Student Health and Counseling Center Directors as well as regional and national meetings where best practices are shared among institutions. Specifically, the Maryland Association of Higher Education and Disability has bi-weekly meetings.¹⁵

Last, campuses will regularly provide orientation and training for both faculty/staff and student leaders (e.g., first aid training for Residential Assistants), campus safety/campus police departments, and other campus-affiliated individuals to support students with specific needs.

The workgroup felt the importance to note that the COVID-19 pandemic has really challenged campuses to ensure a student's health and safety, even from a remote location. Campuses continue to respond to the needs of students and are constantly working to ensure that students have access to all available resources (e.g., telehealth appointments vs. in-person visits).

¹⁵ <https://www.ahead.org/about-ahead/about-overview/affiliates/maryland>

Section 6: Challenges Faced by Students with Chronic Health Conditions

Workgroup members heard directly from students at the August 23, 2021 meeting. Dr. Santi Bhagat, President and Founder of Physician-Parent Caregivers, Inc. (a voluntary non-profit organization), provided a presentation to the workgroup. Dr. Bhagat invited four students to speak with workgroup members.

In preparing for the meeting, the workgroup also reviewed the testimony (written and recorded) provided during the 2021 legislative session regarding HB59/SB147. The workgroup and students engaged in an informative dialogue. A summary of challenges shared by the students with the workgroup is provided below.

“Young Invisibles”

The students invited by Dr. Bhagat identified themselves as “young invisibles.” They noted they regularly feel unseen, as many chronic conditions are not visible. There is a recent effort called the “invisible wave” as a national discussion to advocate for civil rights. With medical improvements, many youth with chronic health conditions are living longer and transitioning into adulthood.

Education on Disability Services and Accessing Accommodations

The students invited by Dr. Bhagat expressed concerns they did not know about accessing accommodations on campuses or that the accommodation approval process was challenging. For example, one student noted the campus required medical documentation from a medical professional which would include a “recommendation on specific accommodations.” The student noted they struggled to get the right documentation due to lack of proximity to the primary care physician or specialist. Other students communicated limitations in insurance coverage for specific exams or assessments.

Similarly, the same students communicated they feel as though the administrators they interacted with did not value the accommodation requested. Some students communicated they were told to work directly with a faculty member and negotiate on a case-by-case basis. Students communicated they felt some faculty did not understand the specific needs of their chronic health condition or appeared to doubt the need for a specific accommodation.

Last, students noted that creating accommodations when a chronic health condition is unpredictable is challenging. Students are unable to predict “flare-ups.” Again, students were encouraged to work with the professor in hopes they would be accommodated.

It is important to note that frustrations from these students were apparent. However, the workgroup did not look at information, policies and procedures from the colleges and universities where they attended. Also, the workgroup does not know if their experiences were typical of other students with chronic illnesses attending the same college or university.

Health Transition from K-12 to Postsecondary Education

Some students noted they did not receive much, if any, guidance upon transitioning from high school on how to manage their chronic disease or to navigate accommodations while on campus. Some students in secondary school might be provided with services, accommodations and supports, which colleges and universities do not provide. It is important to note that college students with chronic illness may require residential accommodations or modifications that they did not need in secondary school, which can cause difficulty with the transition. Over the past 10 years, there has been increased energy and efforts regarding the health care transition from pediatric to adult care. The pediatric community is trying to launch people into adult medicine, which requires additional guidance to young adults on what that means for the medical care they need and how to seek that out.

Health and Counseling Centers

Students communicated that some campuses do not have an infrastructure for providing ongoing primary care to help prevent students from going to the emergency room. For example, students struggle to obtain renewal prescriptions, particularly when their primary care provider is located away from the campus.

Section 7: Recommendations for Eliminating Challenges Faced by Students with Chronic Health Conditions and Accommodating the Needs of Students with Chronic Health Conditions

The workgroup provides the following recommendations (in no particular order) to eliminate challenges and accommodate the needs of students with chronic health conditions:

- Collaborate with secondary education to provide greater support to students with disabilities who are transitioning out from K-12. These students should receive counseling on how to navigate requesting accommodations in higher education.
- Provide support (i.e., education on how to access services) to students who may receive a relevant health diagnosis while enrolled at a college or university.
- Ensure students with chronic conditions and other disabilities are viewed as part of the campus diversity effort.
- Promote equity and inclusion, and a welcoming environment for all students.
- Make sure all events on campus consider the needs of students and others who have various needs or limitations.
- Review policies (such as class attendance) that might disproportionately impact students with chronic conditions, and modify if needed.
- Educate faculty about Universal Design for Learning, which benefits many students, including those with chronic conditions.
- Educate students that all campuses follow applicable federal and state laws; the nature of services provided may vary from one campus to another depending on the students a campus serves and the resources available to a campus.
- Understand the balancing act campuses must enact with what is feasible with the resources available.
- Recognize insurance coverage may be limited (e.g., psycho-educational assessments are often not covered by insurance) and many campuses do not cover these costs.
- Encourage students to purchase the campus Student Health Insurance Plan (SHIP) when available (or at a minimum, a similar ACA-approved plan) or to ensure that they are enrolled in their parent's insurance when they enroll in college.
- Ensure students are educated about insurance options including out-of-pocket expenses, such as deductibles, copays and co-insurance when accessing care.
- Assure that campuses have an established written referral procedure for support resources or medical providers specialists that accept the students' insurance.
- Support campuses to employ resources that will assist students with insurance concerns and assist with resolution of such issues. Medical debt on top of student debt can have serious ramifications on student well-being and can accumulate and affect credit scores with long-lasting impact.
- Support campuses to employ centralized "case managers" for students to coordinate services among different departments (e.g., faculty, health centers, medical professionals, etc.). Larger campuses may need more than one case manager; currently, some campuses do not have any.
- Recognize that the current model of health care at colleges and universities often depends on self-report. Support campuses in identifying ways to connect with students not

reporting or seeking services but who may need services. This may include establishing campus-based “health case managers.”

- Provide general health education to the student body at-large, even in the absence of a chronic health condition. Such programs can help with identifying symptoms, creating proactive and health-aware citizens, and increase stigma awareness.
- Support efforts around stigma reduction among students (e.g., use of the word “disability” vs. chronic health condition; invisible vs. visible disability; stigma around mental health, addiction, HIV, sexual health/activity; concerns around confidentiality and discrimination; cultural stigma, particularly with international students; academic expectations).
- Recognize that some students may not seek help because they are utilizing parent insurance and educate students about health privacy.
- Recognize that specific student populations with specific chronic health conditions may be more vulnerable (particularly in completing their program of study). Support campuses in educating faculty and staff to best support vulnerable populations.

Additional Resources

- ADA.gov: Questions and Answers about the Department of Justice’s Final Rule Implementing the ADA Amendments Act of 2008 (https://www.ada.gov/regs2016/adaaa_qa.html)
- American College Health Association (ACHA) (<https://www.acha.org/>)
- CAST: Universal Design for Learning (<https://udlguidelines.cast.org/>)
- Department of Education: The Civil Rights of Students with Hidden Disabilities Under Section 504 of the Rehabilitation Act of 1973 (<https://www2.ed.gov/about/offices/list/ocr/docs/hq5269.html>)
- Department of Education: Transition Guide: (<https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-may-2017.pdf>)
- Invisible Illnesses: The challenge of caring for students living with chronic illness (<https://depauliaonline.com/35318/news/invisible-illnesses-the-challenge-of-caring-for-students-living-with-chronic-illness/>)
- Maryland Association on Higher Education and Disability (MD-AHEAD) (<https://www.ahead.org/about-ahead/about-overview/affiliates/maryland>)

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